Implementing palliative care in the pediatric intensive care unit for pediatric hematology-oncology patients: a comprehensive narrative review

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Despite advancements in medical technology, pediatric hematology-oncology (PHO) patients continue to face significant challenges from life-limiting conditions. These patients often experience prolonged invasive treatments and admissions to the pediatric intensive care unit (PICU), leading to complex medical and psychosocial dynamics. This narrative review explores the need for and implementation of palliative care for PHO patients in the PICU. Palliative care aims to improve quality of life by addressing physical, psychological, social, and spiritual distress. Despite the World Health Organization's recommendations, the integration of palliative care into Korean pediatric care, particularly in PICU settings, remains nascent. The key aspects discussed include the importance of family-centered communication, active symptom management, and advance care planning. The unique needs of PHO patients in the PICU, including their frequent exposure to invasive procedures and the psychological burden on families, highlight the critical role of palliative care. Challenges such as PICU staff who are unfamiliar with palliative practices and the systemic barriers to effective communication are also examined. This review emphasizes the need for a structured approach to palliative care in the PICU, advocating for integrative models that combine primary, secondary, and tertiary palliative care interventions. The implementation of these models can potentially enhance the overall quality of care and the support provided to both patients and families. In conclusion, this review underscores the urgent need for comprehensive education and systemic support to facilitate the broad application of palliative care in PICU settings in Korea.

Keywords: Palliative care; Intensive care unit; Pediatric; Pediatric hematology; Cancer

INTRODUCTION

Life-threatening conditions (LTCs) are conditions for which curative treatment may be feasible but can fail [1]. The survival rate of pediatric and adolescent patients with LTCs has dramatically improved with the advancement of medical technology [2]. This has given hope and new life to many patients and their families. Nevertheless, many patients are not cured and eventually die. Advanced treatment technologies can be invasive, and aggressive treatments are often administered until the patient is near death,
or life-sustaining treatments are continued in intensive care units (ICUs) until death occurs [3]. Treatments can also result in acquired morbidities and chronic complex medical conditions in the survivors [4].

Although children with cancer are a major group that benefits from the latest treatments, they may also require ICU care due to the nature of their diseases and have the highest mortality rate across all pediatric age groups [5]. Therefore, palliative care, which evaluates the quality of life throughout the treatment process and sets and discusses treatment goals and directions, is essential for children with cancer [6,7].

Palliative care encompasses all treatments aimed at reducing or preventing the suffering experienced by patients with LTCs [8]. This includes the physical, psychological, social, and spiritual distress experienced by patients and their families. Thus, the goal of palliative care is to improve the quality of life by reducing the amount of suffering [9].

The World Health Organization states that appropriate palliative care should be provided to all patients with LTCs. Therefore, all patients treated in a pediatric ICU (PICU) should already be receiving palliative care, and children with cancer should certainly be included as candidates for palliative care. However, in Korea, palliative care has only recently begun to be applied in pediatric and adolescent care, and palliative care for ICU patients is still quite new. This narrative review explored the status of palliative care for patients admitted to the PICU, especially pediatric cancer patients.

CHARACTERISTICS OF CHILDREN WITH CANCER IN TERMS OF PALLIATIVE CARE

First, because children cannot be thought of apart from their families, pediatric and adolescent patients, particularly children with cancer, always require family-centered communication [6]. For children with cancer, the entire family is directly or indirectly involved in the child’s care, and their acceptance and thoughts about the possibility of death and the actual end of life vary. Second, active symptom control is necessary due to the diverse symptoms and pain caused by the disease. There are many factors that can cause pain, depending on the nature of the underlying disease (e.g., leukemia, solid tumors), and directly and significantly impact the quality of life [10]. Third, advance care planning (ACP) is crucial. ACP is an important aspect of palliative care, especially for children with cancer. It is vital throughout treatment to discuss the direction of treatment, quality of life, and decision-making during the end-of-life process [11,12].

CONSIDERATIONS FOR INTENSIVE CARE MANAGEMENT OF CHILDREN WITH CANCER

Children with cancer may be admitted to the PICU for transient events such as septic shock, tumor lysis syndrome, superior vena cava syndrome, or acute kidney injury. Up to 40% of patients need ICU care during their treatment period [13]. There is often a high chance of recovery, allowing for the safe continuation of treatment for the underlying disease. However, relapse or severe organ dysfunction sometimes causes the recovery to be prolonged or terminal. The patient’s underlying diagnosis may also be associated with a higher mortality risk, negatively impacting families [13]. Patients and families concurrently worry about the treatment of the underlying disease, the current PICU stay, and future treatments [14]. Over time, treatment of the underlying disease becomes increasingly difficult or the likelihood of relapse increases, gradually increasing the family’s anxiety and fear as well.

Children with cancer often undergo high levels of treatment. This means that clinical situations that can cause pain occur frequently, and their prolonged treatment increases the risk of sudden life-threatening crises [15]. From a psychosocial perspective, pediatric patients with cancer experience isolation from their peer group from the time of diagnosis and throughout the PICU treatment process. They may also experience isolation from their families, a situation that requires special attention and care [16].

PALLIATIVE CARE IN THE PICU: CHALLENGES

Healthcare providers in the PICU frequently lack familiarity with palliative care [17]. Most ICUs are designed for optimal efficiency in delivering intensive care rather than accommodating the presence of family, a challenge for family-centered communication. A prospective international multicenter study on PICU mortality showed that patients who died in the PICU were less likely to have a “do not resuscitate” (DNR) order or palliative care team consult than patients who died in other inpatient settings [18]. The absence of DNR directives and palliative care may exacerbate anxiety and stress for families, which in turn increases the difficulty of care for ICU healthcare providers [19].

Effective communication with the patient’s family is paramount in pediatric palliative care. The PICU is an inherently high-stress environment, where differences in opinion or conflicts can arise between healthcare providers and families, among the healthcare providers themselves, and among family members [20,21]. The most common source of conflict between healthcare
providers and families is disagreement regarding the treatment plan [22]. Differences in opinion may also arise among healthcare providers regarding pain management strategies and misunderstandings over roles within the team, all of which stem from communication issues [22]. In such situations, a palliative care specialist can mitigate tensions and guide discussions to determine the best course of action for the patient.

Discussing end-of-life care in the PICU is a delicate and challenging process, impacting all healthcare providers and family members. The burden associated with end-of-life discussions can lead to delays, often resulting in missed opportunities to address the emotional changes and negative perceptions that families may experience [23]. A study conducted in PICUs across the United States found that approximately 75% of conversations with guardians and 80% of discussions among healthcare providers focused solely on medical problems [24]. The study reported that when a higher proportion of the discussions centered on the patient, patient satisfaction increased. Family-centered communication significantly contributes to robust and stable relationships between healthcare providers and the patient’s family.

**PALLIATIVE CARE INTERVENTIONS**

**Advance Care Planning**

ACP involves discussions with the family to establish treatment goals and to collaboratively determine the direction of care [11]. This process encompasses end-of-life care. Discussing ACP with patients and families can be a formidable task for healthcare providers, yet it holds substantial significance for families [25,26]. In a study involving the families of deceased patients, the majority indicated that they perceived ACP as important and positive [26]. Through ACP, families can alleviate negative perceptions of both the treatment process and the dying process. Research indicates that parents who gain awareness that their child is nearing death within less than 24 hours are at higher risk of long-term pathological grief, such as the development of depression and early retirement from work [27].

ACP is challenging for both healthcare providers and families because it addresses emotionally distressing and uncomfortable topics. The primary reasons healthcare providers find ACP challenging include the unrealistic expectations of guardians, disparity between the actual clinical situation or prognosis and the parent's perceptions, and scenarios where parents are deemed unready to have the discussion [28]. Furthermore, difficulty in communicating with pediatric patients (as opposed to adult patients) significantly complicates ACP. In the context of the PICU, particularly when sedation is involved, communication can be nearly impossible, rendering appropriate ACP extremely challenging. Ideally, ACP is conducted before the end-of-life process commences, in accordance with the disease trajectory or ICU care. However, perspectives on this may vary based on the provider’s experience, education level, and specialty. In a study of pediatricians in Korea, the timing of ACP varied depending on their subspecialty [29]. For instance, when addressing a case of refractory leukemia, specialties other than pediatric hematology-oncology indicated they would conduct ACP only after ICU care and intubation had been initiated. The barriers to ACP identified by pediatricians in Korea included the lack of systemic support, concerns about accountability, difficulty in predicting prognosis, and uncertainty about timing. Unlike other international studies, the lack of systemic support was the most frequently cited barrier, reflecting the insufficient social support and awareness in Korea.

**Symptom Management**

Children with cancer and PICU patients frequently experience significant pain due to their underlying conditions as well as the treatment process [30]. Additional symptoms such as nausea, dyspnea, and delirium may occur, although it may be difficult to clearly assess these symptoms in the PICU for various reasons [31]. Preventing unnecessary pain is a crucial element in improving the quality of life, especially in end-of-life care. Research involving families who have lost a child has shown that parents who believed their child suffered from pain before death experienced prolonged pathological grief [32]. Therefore, it is essential to vigilantly observe for pain and discomfort in patients. The palliative care team should be involved early, when needed, to collaborate with the PICU team in actively managing pain.

**Bereavement Care**

The death of a child can have long-term negative impacts on the psychological and mental health of the patient’s parents and siblings [33]. Studies have reported that the long-term mortality rate of parents who experienced the loss of a child is higher than similar parents whose child is alive [34]. Bereavement care involves assisting in the healing and recovery of parents and siblings who have experienced the death of a child, guiding them through a healthy grieving process and facilitating their return to everyday life. One study suggests five important elements in pediatric bereavement care: (1) acknowledging the parent’s role in the child’s life, (2) establishing keepsakes (3) follow-up contact, (4) education and information, and (5) remembrance activities [35].
However, contrary to the theory that bereavement care should facilitate the transition of parents towards a new reality, in practice only four out of twelve studies reported that interventions were initiated before the child’s death [35]. In addition, a study conducted in the United States found that five out of nine families who had lost a child felt abandoned by healthcare providers after the child’s death [24]. These findings highlight the need for standardized bereavement care.

**PALLIATIVE CARE MODEL IN THE PICU: CONSIDERATIONS IN KOREA**

The medical context in Korea is unique. Unlike countries with multiple healthcare providers rotating through PICU shifts, a limited number of fixed healthcare providers typically engage in restricted rotational duties due to staff shortages. This consistency allows families to interact with a stable group of healthcare providers, facilitating continuity of care. However, it can also result in high levels of fatigue among healthcare providers, potentially serving as a barrier to the provision of appropriate palliative care in the long term.

In Korea, it was only after a recent revision of the Hospice Palliative Care Act that aspects of palliative care, including the discontinuation of life-sustaining treatments, began to be actively applied throughout clinical practice [36]. Nonetheless, in actual clinical settings, futile life-sustaining treatments are often continued, and the cessation of life-sustaining treatments, such as mechanical ventilation, are rarely discussed before a patient’s condition deteriorates significantly.

In many countries, there is active research and social discourse on the withdrawal, withholding, or non-escalation of life-sustaining therapy [37]. These discussions typically occur under the following circumstances: (1) when life expectancy is limited, (2) when quality of life is limited, and (3) when the likelihood of benefit is low. However, for such discussions to take place, it is imperative to establish an environment conducive to comprehensive social dialogue, research, and thorough discussions among healthcare providers and families.

Compassionate extubation at home (CEAH) represents one aspect of PICU care that incorporates these discussions, enabling the patient to spend their end-of-life period in a comforting environment, which also enhances family satisfaction [38]. While coordinating and managing this process requires substantial effort, it has been reported that healthcare providers also find it worthwhile. However, updated palliative programs like CEAH require significant resources and manpower, making immediate implementation especially challenging in Korea, where the healthcare system must operate with limited resources and personnel. Therefore, the primary task in Korea should be to ensure that palliative care is broadly integrated into routine ICU care.

Recently, palliative care has been considered in models such as the tier approach model (Fig. 1), which is applicable in ICU settings [39]. Palliative care can be integrated into all areas of medical practice; thus, primary palliative care can be provided by all ICU team members. Primary palliative care involves evidence-based palliative care interventions delivered by ICU team members, including holistic care of the child, support of the family unit, involvement of the family and child in decision-making, communication and care planning, and support for grief and bereavement [40].

Secondary palliative care can be provided by specially trained ICU-based personnel. Depending on the staffing situation, secondary palliative care may be offered by the palliative care team or selected personnel trained through specific programs. Secondary palliative care aims to ensure that palliative care is provided and managed throughout the ICU care continuum, including the development of appropriate protocols and quality improvement [41].

Tertiary palliative care involves consultations by a separate subspecialty palliative care team when available. The palliative care team can handle complex cases, difficult decision-making situations, and special needs for communication and family care. Triggers for palliative care consultations in the PICU are based on the characteristics of the underlying disease, the treatment history, social risk factors, and family requests. This requires a tailored approach based on the healthcare institution, the pa-

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**Fig. 1.** A tiered approach for integrating palliative care into the pediatric intensive care unit. PC, palliative care. Adapted from Rothschild and Derrington [39].
CONCLUSIONS

Patients receiving PICU care and their families require access to palliative care throughout the treatment process, particularly those with underlying diseases like hematologic and oncologic disorders. The most crucial aspect of palliative care is family-centered communication, which lays the foundation for advanced care planning, pain control, and bereavement care.

In Korea, few hospitals have pediatric palliative care teams, and those that do often rely on national pilot projects for support. Thus, the immediate next step is to provide comprehensive education to ICU team members so that palliative care can be applied throughout the treatment process, ultimately improving the overall quality of PICU care.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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All the work was done by SHK.

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