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## **Integrating Palliative Care into the Pediatric Intensive Care Unit A Report from the IPAL-ICU (Improving Palliative Care in the ICU) Advisory Board**

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## Abstract

**Objective**—This review highlights the benefits that patients, families and clinicians can expect to realize when palliative care service is intentionally incorporated into the PICU, focusing on pain and symptom management, enhancing quality of life, communication and decision-making, length of stay and sites of care, and grief and bereavement.

**Data Sources**—MEDLINE

**Data Synthesis and Conclusions**—The American Academy of Pediatrics suggests that palliative care should begin at the time of a potentially life-limiting diagnosis and continue throughout the disease trajectory, regardless of the expected outcome. Although the PICU is often used for short term postoperative stabilization, PICU clinicians also care for many chronically ill children with complex underlying conditions and others receiving intensive care for prolonged periods. Integrating palliative care delivery into the PICU is rapidly becoming the standard for high quality care of critically ill children. Interdisciplinary ICU staff can take advantage of the growing resources for continuing education in pediatric palliative care principles and interventions.

## Keywords

Palliative care; Pain management; Communication; Decision-Making; End of Life; Pediatric

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Every year at least 200 children per 100,000 require hospitalization in pediatric intensive care units (PICUs) to treat serious illness and trauma.(1) These settings are characterized by an intensive technological focus on life-saving procedures. Although the PICU is often used for short term postoperative stabilization, PICU clinicians also care for many chronically critically ill children with complex underlying conditions and others receiving intensive care for prolonged periods.(2) In one study, 1% of PICU patients accounted for 18% of PICU bed days. The median age of these patients was 4 months, and >70% of survivors had poor to very poor outcomes.(3) Approximately 90% of inpatient pediatric deaths occur in the ICU(2), often after withdrawal of life-prolonging medical therapy and accompanied by some degree of moral distress for caregivers and families.(1, 4)

Providing care for critically ill children, and children at the end of life, can be a valuable opportunity to establish close relationships with patients and families. Incorporating palliative care into medical management for these patients can benefit patients, families, and staff. Palliative care focuses on enhancing quality of life, minimizing suffering, optimizing function, and supporting families in complex decision-making and communication. Different approaches to incorporating palliative care services into the ICU can broadly be divided into “integrative,” “consultative,” and “mixed” models.(5) The integrative model focuses on maximizing and standardizing the palliative care principles and interventions that all ICU clinicians are trained to incorporate into usual patient care from the time of diagnosis. The consultative model incorporates subspecialty palliative care teams as needed for complex speciality level-problems.(6) Mixed models includes features of both integrative and consultative models. A 2013 national survey suggests that approximately 60% of children’s hospitals have pediatric palliative care programs.(7)

The purpose of this article is to highlight the benefits that patients, families and clinicians can expect to realize when palliative care service is intentionally incorporated into the PICU.

## Defining Quality Pediatric Palliative Care

Pediatric palliative care is both a medical/nursing specialty and an approach to care for delivering patient/family centered care to children with a serious illness and their families. The primary domains of ICU palliative care include optimizing pain and symptom management, communication and decision-making, continuity of care, and providing both emotional and logistical support for patients, families, and ICU staff.(8)

Palliative care has been more readily available for adults than for pediatric patients. The National Hospice and Palliative Care Organization highlights several fundamental differences between the experiences of life limiting illness for children compared to adults. (9) Intensive care is available in most communities for adults, but PICU care is often concentrated in larger metropolitan areas. Regionalized PICU care requires many children to be hospitalized far from home and their usual systems of support. PICU patients may have rare congenital conditions, with uncertain prognoses and continuously evolving treatment goals. The pediatric developmental spectrum from infancy to adolescence introduces additional complexity that affects diagnosis, clinical assessment, treatment, communication, and decision-making. Parents, who must speak for their children, often have limited experience with serious medical decision-making. Finally, the grief of a child's death has long-term implications for the entire family and extended community.(10)

Given these challenges, the American Academy of Pediatrics suggests that palliative care should begin at the time of a potentially life-limiting diagnosis and continue throughout the disease trajectory, regardless of the expected outcome.(11) One way to promote early integration of palliative care is to use a systems-based approach to patient identification.(12) PICU patients who meet consensus criteria for a high likelihood of unmet palliative care needs can trigger further evaluation by primary clinicians and, if necessary, palliative care consultants. Screening criteria used in adult ICUs are shown to promote palliative care integration with subsequent reduction in resource utilization yet without increasing mortality.(13–15) Screening criteria have not been well studied in the PICU, but they may be more likely to be implemented when related to high risk diagnoses or treatments (e.g. brainstem tumors, bone marrow transplant, extracorporeal life support).(16, 17)

The increasing proportion of children with complex chronic conditions in the PICU and the compelling need for family-centered care constitute a cogent argument for the mixed model with both integrative and consultative palliative care.(18) A 2007 survey of members of the Section on Critical Care of the American Academy of Pediatrics found that most respondents felt very confident managing pain, respiratory distress, seizures and other acute medical issues at the end-of-life. Confidence was lower around management of medical needs of children with complex chronic conditions. The areas where respondents were the most receptive to consultation were related to family needs, supporting the family at the end of life, managing transitions out of the PICU, and understanding hospice care. Respondents

found it most difficult to address family expectations about prognosis and to help families navigate uncertain futures.(19)

## **PICU Opportunities: Existing Needs and Potential Solutions**

Caring for patients and families in the PICU presents several challenges that improved generalist and specialist level palliative care services can help to address. (Table 1)

### **Pain and Symptom Management**

The importance of assessing and managing pain and other symptoms is a *sine qua non* of intensive care. Pediatric intensivists report a high level of confidence in their ability to prevent and treat pain(19), yet successful symptom management may still be difficult to attain.(20, 21) Wolfe et al found that distressing symptoms before death were reported more frequently by parents of children with cancer than by physicians, and that parents felt the majority of children suffered “a lot” or “a great deal”.(21) Gaps in optimal pain and symptom management may result, in part, from the challenges in assessment. A child’s variable and evolving development necessitates targeted pain assessments and treatment tools.(22–24) In addition, if parents’ assessments of a child’s symptoms are systematically different than clinicians’ assessments, there can be an opportunity to explore and explain the differences. Tools to reliably assess pediatric symptoms such as fatigue, delirium, respiratory distress or nausea, are not as available as for adult patients. Whereas involvement of palliative care experts in pain and symptom management in the PICU may often be deferred until after a transition to end of life care(25), earlier engagement can be appropriate and could provide broader support for patients, families, and PICU clinicians. For example, a palliative care consultant might collaborate with the PICU team to include parent assessments of a child’s symptoms, or to more broadly address a child’s emotional and psychological distress related to these symptoms.

### **Quality of Life**

The stressful PICU environment can have far reaching ramifications for patients and families.(26–30) The provision of palliative care has the potential to improve quality of life, reduce pain and suffering and in some cases extend longevity.(31, 32) Children may be in the ICU for weeks, making it especially important to assess and optimize quality of life during a child’s hospitalization.(33) Children with chronic conditions are at risk of the longest ICU stays as well as repeat admissions.(34) Interdisciplinary palliative care services can help these patients maintain connections to school, friends, and activities to promote quality of life.(35)

The quality of life of the entire family is impacted by a child’s PICU hospitalization. Baluffi et al reported that over 20% of parents endorsed some aspect of post-traumatic stress disorder after PICU discharge, regardless of the child’s outcome.(26) Critical illness threatens the ability of parents to protect and provide for their children.(36) Parents must maintain a reserve of physical and mental health in order to manage the ongoing demands of parenting, including caring for other siblings, and preparing for an uncertain and potentially frightening future. Families can better cope with the acute stressors in the PICU given

adequate resources and support.(18) Meyer et al found that families' highest priorities for improving the PICU experience were: honest and complete information, ready access to staff, effective care coordination, emotional expression and support by clinicians, preservation of the parent-child relationship, and freedom to express their faith.(37) Overall, 73% of parents reported spiritual/religious themes including prayer, access to spiritual care, and belief that the parent-child relationship endures beyond death. Support for the family unit can be optimized by the collaboration of the PICU team with palliative care providers, who can help ascertain and address family needs throughout the PICU experience.

### Communication and Decision-Making

Parents of PICU patients often face difficult and value-laden decisions in the context of bewildering amounts of information and an "irreducible amount of uncertainty." (38) Families are guided in this process by a large number of clinicians, many of whom they do not know yet must entrust with the wellbeing of their children. Communication expertise around eliciting patient and family preferences and integrating them into serious decision-making is part of the core set of skills for PICU providers, but can also be supported by palliative care specialists.(39) The continuity that palliative care specialists may have across the different sites of care for a patient and family further strengthens the capacity of the healthcare team to communicate effectively in an ongoing process.

The PICU is a technologically-focused environment with constantly emerging, highly detailed patient information. Many parents prefer that this information be integrated into the larger context of the child's overall care, so that individual treatments, status changes and decisions are viewed within a "big picture" perspective.(37) These conversations should account for potential differences in cultural beliefs, education, values, and preferences that may exist between clinicians and families. Decisions are often needed quickly in the ICU, giving parents little time to absorb the complicated ramifications.(40) Conflicts between family members and medical teams regarding care decisions are common in ICU's.(41, 42) Studdert and colleagues documented conflict in over 50% of cases where children spent more than eight days in the PICU. Team-family conflicts were the most common and were more often associated with poor communication than other types of conflict.(43) Intra-team conflict may occur in over one-third of PICU cases,(43) and often centers on clinician disagreement about the continued use of aggressive interventions.(44) When conflicts arise, a palliative care specialist can serve a valuable role as a medical interpreter for both the family and staff, reducing the burden of stress and conflict, and promoting consensus for the benefit of the child.(45) Palliative care specialists can also help to clarify when conflicts warrant ethics consultation.(46)

Discussions regarding preferences for life sustaining treatments near the end of life are particularly challenging, and clinicians may avoid or delay these important conversations. (47, 48) Children's physiological resilience and variability complicate predictions about their responses to ICU treatment. New surgical techniques and other treatments make it harder to define a therapeutic end-point. Many PICU clinicians and subspecialists are on a weekly or monthly rotation schedule, making continuity difficult for optimal care coordination and medical decision-making. Frank discussions about prognosis may only

occur after clinicians judge the child's future quality of life as unacceptable when they wish to recommend discontinuation of life-prolonging interventions.(37)

Data suggest that missed opportunities exist for engaging in family conferences with parents of PICU patients who face life-altering decisions.(49) Protocols for routine family conferences for adult ICU patients with a mortality risk greater than 25% have been shown to reduce ICU length of stay and resource utilization.(50) Randomized controlled trials in adult ICUs suggest that improving family-clinician communication in the ICU can dramatically reduce symptoms of anxiety, depression, and PTSD among family members. (51, 52) Palliative care consultants can support family conferences both through their presence at these conferences as well as supporting ICU clinician education regarding family conferences.

### **Length of Stay and Sites of Care**

Regardless of the child's condition and prognosis, integration of palliative care principles from the time of diagnosis can optimize continuity of care as the patient transitions across sites of care—including PICU, general pediatric wards, hospice, or home. In 2013, Keele et al reported on a cohort of over 24,000 hospitalized children, and found that palliative care consultation reduced the use of invasive interventions, decreased hospital lengths of stay (17 vs. 21 days), and reduced deaths in the PICU from 80% to 60%.(53) In academic pediatric hospitals with mature palliative care programs, most palliative care consultations are for children with potentially life limiting illnesses who are not at the end of life, as evidenced by the fact that over 70% of patients may still be alive after one year.(18) A palliative care consultant can assist in determining sites of care that can accommodate a patient's medical needs and maximize the family's quality of life. Parents become accustomed to constant monitoring of and attention to their child's needs by skilled professionals in the PICU, and fear of assuming responsibility for the child's care may make it difficult for them to absorb information and training for post-ICU care. Thus, parents may feel unprepared for their role in the next care setting after the ICU, may not understand essential management steps, and have difficulty accessing resources for guidance.

Together with the PICU team, the palliative care consultant can assist families in articulating goals of care across settings and anticipate challenges that arise during transitions. Direct involvement in care after the PICU affords the palliative care consultant opportunity to facilitate smoother transitions(53) and reduce PICU readmissions. Pierucci et al reported that patients in the PICU who received palliative care consultation and subsequently died had significantly shorter PICU stays and were more often transferred to less intensive care settings for the last days of their lives.(54)

### **Grief and Bereavement**

Bereavement encompasses the entire experience of anticipating death, death itself and subsequent adjustment to living.(55) Aspects of grief and bereavement are experienced by all families of PICU patients regardless of a child's outcome. Parental grief can be intense and prolonged, especially for parents whose children die acutely.(56) Multidisciplinary palliative care interventions, with an emphasis on psychological and spiritual care, can

provide anticipatory grief and bereavement supports throughout the PICU experience and potentially reduce the risk of pathological grief responses after ICU hospitalization and/ or death.(57) In 2012 Meert et al found that the Bereaved Parent Needs Assessment tool was a reliable and valid method to assess parent needs in the PICU.(58) Data suggest that grief experiences are affected by individual, familial and organizational cultures and by the methods of care delivery.(56) Interventions to reinforce caring staff attitudes can positively affect parental bereavement. Legacy activities, from handprints to organ donation, play a vital role because they support the family's ability to maintain a connection with their child before, during, and long after death. Recent data suggest that a substantial minority of parents value structured follow-up meetings with ICU clinicians after a child's death.(59)

## Conclusion

The evidence that integrating palliative care in pediatric intensive care settings improves care for patients and their families continues to increase.(60, 61) Pediatric intensive care units should adopt measures to assess their current palliative care practices and seeks ways to improve this care. Interdisciplinary ICU staff can take advantage of the growing resources for continuing education in pediatric palliative care principles and interventions(45, 62–65), and in methods for measuring and systematically improving the quality of palliative care. (66) Where available, they can involve palliative care specialists to assist in addressing complex and refractory issues. Current PICU fellows have had variable exposure to palliative care curricula during pediatric residency; in addition to above continuing education resources, collaborations with palliative care consultants are opportunities for fellows to build their capacity for providing integrative palliative care. Integrating palliative care delivery into the PICU is rapidly becoming the standard for high quality care of critically ill children.

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**Table 1**

## Domains of ICU Palliative Care

Source	Domains of Care
<i>Professional Consensus (Critical Care Peer Workgroup of Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care Program(67))</i>	Symptom Management and Comfort Care Patient- and family-centered decision making Communication with the team and with patients and families Emotional and practical support for patients and families Spiritual support for patients and families Continuity of care Emotional and organizational support for ICU clinicians
<i>ICU Patients and Families</i>	Timely, compassionate, clear communication by clinicians Patient- and family-focused decision making Patient care maintaining comfort, personhood Proximity of families to patients Interdisciplinary support of family including bereavement care

.Adapted from Nelson JE et al(68)