



Pediatric Palliative Care and the Pediatric Intensive Care Unit

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Published online: 28 April 2018

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Abstract

Purpose of Review The role of palliative care in pediatric critical care medicine is described, with a focus on communication practices, complex chronic medical disease, end-of-life care, and moral resiliency.

Recent Findings Palliative care medicine has an increasing presence in pediatric critical care medicine. The model for delivering quality palliative care from a primary to consultative role is evolving, as increasing numbers of patients and families benefit from this additional layer of care and advocacy. Palliative care medicine is complementary care at all levels and focuses on collaborating with families and patients by understanding values, contextualizing the traumatic nature of their experiences, and communication through shared decision-making. Enhancing and strengthening palliative care skills of pediatric intensive care unit (PICU) clinicians will provide one possible mechanism for addressing moral distress.

Summary Palliative care is an essential component of comprehensive care for our patients and families facing critical and life-threatening illness of any severity or prognosis. It augments and complements intensive care treatments, and it is based on need, not prognosis or outcome.

Keywords Pediatric palliative care · Pediatric critical care medicine · Hospice and palliative medicine · End-of-life care · Moral resiliency

Introduction

Mortality in the pediatric intensive care unit (PICU) in highly resourced countries remains low due to the incredible progress achieved in advanced medical and surgical therapies as well as utilization of life-sustaining technological supports. While the high survival in our PICU patients is remarkable, it has also transformed the growing population of children with complex and chronic medical care needs, whose hospitalizations are

often associated with prolonged PICU stays, additive co-morbidities, and increased hospitalization time overall [1•, 2]. Given the diversity of the patient population and the severity of illness of patients in the PICU, clinicians inevitably are faced with precarious and high-stakes encounters that require a unique skillset to facilitate complex decision-making processes. Not only are we providing care to patients at the end-of-life, but we are also assisting patients and families with delicate decisions that will affect each patient's longevity and quality of life for the patient and family.

In the past decade, pediatric palliative care medicine has transformed, as well. Far from being the care only provided to children near the end-of-life (EOL), pediatric palliative care now encompasses a broad range of services for patients at any stage of their illness as these specialized teams help families and children make important decisions for managing life-threatening illness in order to strive for the best life possible for as long as possible. Notably, as a certain proportion of these children survive into adulthood, their care will eventually be transitioned into adult hospitals and critical care medicine as well as adult palliative care services.

In this review paper, we will summarize the recent and relevant literature from the past 15 years that describes the evolving role of palliative care medicine in the PICU. We will

This article is part of the Topical Collection on *Pediatric Palliative Care*

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focus on the role of palliative care from primary to consultative (specialist) levels of care, and we will review studies that examine survivorship in patients and families, as well as the role of promoting moral resilience in both health care professionals and the patients for whom we provide care.

Trends in the Pediatric Intensive Care Unit

The rate of childhood mortality worldwide has been increasing over the past decade. In 2016 alone, an estimated 10.8 million children died [3]. In well-resourced countries, most childhood deaths occur in hospital settings, and the majority of those deaths occur in the PICU [4–9]. In contrast to worldwide mortality trends, several multi-center cohort studies have shown that overall PICU mortality rates in these well-resourced countries have actually decreased over time and remain low at <3% [10, 11, 12•, 13]. However, hospitalization length of stay is generally increased, and a large proportion of the deaths that occur with these longer hospitalizations occur in children with complex chronic conditions and generally include withdrawal or limitation of life-sustaining therapies [10, 11, 12•, 13, 14].

Other substantial changes in the epidemiology of PICU admissions and mortality show that the rate of admissions has also increased over the same period of time. In one study, over a ten year time frame, there was a 15% rise in PICU admissions, while mortality rate declined over that same period [13]. The overall decrease in mortality is not just proportionally attributed to the increase in PICU admission rates, but also because survival is now longer and the actual number of deaths per year is lower [12•, 13].

With advances in medical and technological therapies, children with chronic diseases have become an important and larger population of the general community. Many of these children are living longer than they were two decades ago and often will have dependence on life-sustaining technologies [2, 15, 16]. They are, therefore, an increasing proportion of the PICU population overall. Because of their medical complexity and technological dependence, they tend to have recurrent PICU admissions when hospitalized and the majority of their deaths tend to occur in the PICU [2, 16–19, 20•].

Palliative Care in the PICU

The goals of palliative care aim to ensure the best quality of life possible by minimizing suffering from physical, psychological, emotional or spiritual distress, optimizing functionality within those domains, and providing psychosocial, spiritual, and emotional support for the patient, family, and care providers through complex decision-making processes and communication [21]. Integrating general palliative care practices into daily PICU management is essential for establishing

trusting relationships with patients and families and advancing medical care that aligns appropriately with patient and family values. Several national advisory boards support these aims for delivering high-quality medical care for children with advanced illness [22–24].

While intensive care is available in most communities for adults, pediatric patients often depend on regionalized care for subspecialty or critical illness. This level of care often brings children and families far from their homes and usual systems of support. Coupled with this stressor are the added burdens unique to pediatric illness: congenital and rare acquired diagnoses, complex chronic conditions often with dependence on technological supports, and the changing developmental spectrum from infancy to young adulthood, all of which contribute to uncertain prognoses, continuously evolving treatment goals, and progressive changes in patient autonomy and decision-making capacity [21].

Because of these important differences, the American Academy of Pediatrics advocates that palliative care should begin at the time of diagnosis of a potentially life-threatening illness and continue throughout a disease trajectory, regardless of the expected outcome [22].

Models to Deliver Palliative Care in the PICU

Community pediatric palliative care is often limited, which means that children and families with palliative care needs also depend on regionalized palliative care. Given these important differences described for pediatric patients and the lack of sufficient general community resources, the argument for all pediatric intensivists to possess an armamentarium of primary palliative care skills is all the more cogent, as the PICU may often be the entry point into medical care for children with serious illness who access these regionalized systems [25–30]. Models that describe equitable delivery of palliative care are generally described as “integrative,” “consultative,” and “mixed” [31]. The integrative model maximizes and standardizes primary palliative care principles and interventions that all PICU clinicians should incorporate into their usual patient care from the time of diagnosis. The consultative model incorporates the specialist palliative care team when needed for complex and layered problems [32].

The mixed model of palliative care defines an approach that features both integrative and consultative approaches to ideal comprehensive palliative care, where specialists collaborate to distribute this limited resource of care as equitably as possible [31].

A 2007 survey of pediatric intensivists demonstrated that most respondents were confident in acute EOL management, but that greater confidence could be gained for managing family support and facilitating communication about prognosis at EOL or ongoing care outside of the PICU [33]. In an ideal situation, palliative care teams will have the opportunity

to develop a relationship with a patient and family over months to years due to the chronicity of the child's underlying illness and the utilization of supportive technologies. Yet, whether or not these relationships are in place at the time of presentation to the PICU, intensivists are compelled to provide certain core elements of palliative care as part of their routine care, such as aligning treatment with patient and family goals and basic symptom management [34].

In many institutions, a consulting pediatric palliative care team may not be available to the PICU. A 2013 national survey of over 200 children's hospitals (71% response rate) demonstrated that 69% of the institutions had an established pediatric palliative care program [25]. Actual service availability of the consulting team was variable, where 77% of programs offered on-site daytime coverage during weekdays, and only 4.5% offered availability on the weekends. About two thirds of the programs had a person available by telephone for night and weekend day coverage [25]. Thus, the vital importance for a PICU clinician and team to possess the capability to meet the primary palliative care needs for a patient and family is essential to quality and equitable care. Intensivists must hone their skillset to manage pain and symptom management both in acute illness and at the end-of-life—including pain, dyspnea, agitation, and delirium, as well as promote care that optimizes quality of life throughout the hospitalization, facilitate communication and decision-making conversations, and anticipate and support initial grief and bereavement.

Consultative palliative care utilizes a specialist team who consults on patients throughout the hospital both in the outpatient and inpatient settings. Many of these consultants follow patients throughout a continuum of care over months to years, sometimes from the time of diagnosis all the way to the end-of-life, and in any time frame in between. Importantly, palliative care specialists possess skills to address more complex palliative care needs, such as negotiating a difficult family meeting, addressing veiled existential distress, and managing refractory symptoms [34]. In addition to their specialized background, the consulting palliative care team is familiar with home supports and services, including hospice, from a clinical and regulatory standpoint, as well as complicated grief and bereavement, and different spiritual and burial practices. Like other subspecialty teams, the palliative care team will tend to have a distinct relationship with the patient and family. As the consulting team, they bring their complementary and deepened skillset to the frontline team while ensuring that the primary palliative care skills of the frontline team are sustained [34].

Special Considerations

The impact of critical illness on patients and their families is lasting. What has been described as “Post-Intensive Care

Syndrome” in adults [35], is also seen in children, as several studies have described decrements in physical, cognitive, and emotional functioning following PICU hospitalization [36–41].

These deficits can only complicate or confound typical childhood developmental changes and patterns, and the consequences of these stressors can be multi-dimensional, as psychological and physical distress is experienced in approximately 25–50% in family members of critically ill children or adults [42, 43, 44••] (the growing body of literature on functional and psychosocial-emotional outcomes following critical illness has led to refinement of the unifying term to describe this phenomenon as Post-Intensive Care Syndrome-Family [35, 44••]).

The interventions to address these issues in patients and families are multi-layered. As just described above, this comprehensive care first necessitates that clinicians develop their core set of palliative care skills and utilize palliative care teams when indicated to understand where patients and families need us most. Furthermore, critical care and palliative care teams can aim to limit the potential negative sequelae of these stressors by incorporating key practices into their care, including family-centered care and shared decision-making (SDM), especially around limitations or withdrawals of life-sustaining medical treatment (LSMT). Importantly, self- and team-care is essential to prevent burnout in clinicians, who are at high risk of reaching this tipping point, because we are continually exposed to these critical situations that demand our immediate attention. We are compelled to maintain our own moral resiliency in order to provide appropriate and durable care [45]. If we do not understand the elements of our own distress or have the tools and skills to process these events, we will inevitably fail our patients and families who depend on our guidance through likely one of the worst and most terrifying experiences in their lives.

Family-Centered Care and Shared Decision-Making

Family-centered care focuses on the principle that the family is vital to a patient's recovery, as they are responsible for critical decision-making in life-threatening circumstances, and they will ultimately bear the burden of recovery for survivors that have post-discharge disability [46]. Strategies and recommendations focus on supporting family members in participating in the care of their child, supporting their bedside presence or absence (e.g., for family members who are financially stressed about income source), communicating effectively at the bedside or in inter-disciplinary conferences, specialist interventions and consultations including family navigators and spiritual/social support, and environmental concerns such as sleep promotion and noise reduction when possible.

One of the key elements of advanced communication is dialog that is inclusive and respectful of different patients and family values. Communication that is insensitive to

cultural, language, and spiritual differences will marginalize parents and family as they work tirelessly to protect their child.

Specific domains to inclusive and respectful communication incorporate support of the family unit, appropriate communication with the patient and family about treatment goals and plans, and SDM to promote high-quality family-centered care in the PICU [47•, 48].

At the time of presentation or diagnosis of a life-threatening condition that may or may not be reversible, families will understandably be overwhelmed and have difficulty considering long-term decision-making. The family will need time to absorb information in order to process how their life will change moving forward [49, 50]. Shared decision-making bridges the knowledge and experience of the physician and clinical team with the patient and family's background and values. Importantly, SDM is a continuum (Fig. 1) that ranges from purely patient-/family-driven decision-making to solely physician-driven decision-making and includes three main elements that encompass information exchange, deliberation, and treatment decisions [51•, 52]. Rarely, decisions are made from either end of the spectrum alone, and, in practice, almost every decision from seemingly value-neutral issues (e.g., peripheral IV placement) to critical “high-stakes” matters is a balance of the two parties. Studies that evaluate parental goals and influences support this communication practice of SDM [53–55]. For truly collaborative SDM, clinicians are responsible for ensuring that patient and family preferences guide the information delivery and decision-making process. While a long-term relationship certainly facilitates this complex engagement and may already be in place due to prior palliative care team involvement, many patients may be encountering medical care for the first time in the PICU. PICU and palliative care clinicians may foster alignment with patients and families within short time frames by utilizing active listening and

communication skills directed towards both informational and affective/emotional needs.

Communication at the End-of-Life

Between 30 and 60% of deaths in the PICU involve the withdrawal or limitation of LSMT, and in many of these situations, the death is unexpected as a child is usually admitted with the hope and goal of improvement and recovery to baseline, even if they also have a complex chronic condition [1•, 11, 12•, 13, 55, 56]. When the transition to EOL takes place, the decisional process is typically reached through negotiation and deliberation, often under an accelerated time frame with parents who are undoubtedly anxious, grieving, and traumatized [55].

EOL treatment and care is comprehensive and time-consuming. EOL care must address physical symptoms and distress, psychological and spiritual needs, cultural observances, family and team organization, and anticipatory grief and bereavement support [21, 47•, 56]. One survey reported that most PICU clinicians have confidence in their ability to manage and treat acute symptoms of dying patients, including pain, agitation, secretions, dyspnea, and seizures; however, they have less comfort with chronic issues such as skin breakdown and constipation and could use more confidence with managing communication at the EOL [33].

By developing a core set of palliative care skills, critical care physicians may help to address the distress that patients and families experience in the transition to EOL care. Parents are most concerned about understanding their child's chance for survival, expected quality of life, and experience of pain and suffering as they move towards decision-making around the death of their child [57, 58]. In surveys of parents who experienced the death of a child in the PICU, parents reported varying levels of communication quality in the SDM processes surrounding their child's death [55, 58–60]. Strong communication

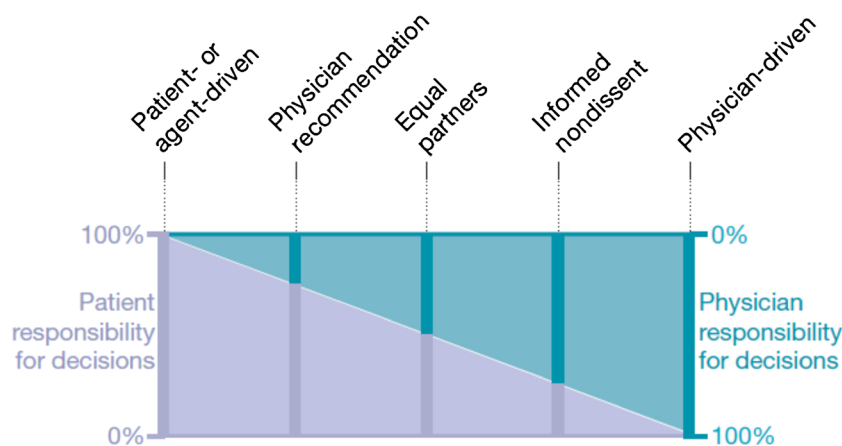


Fig. 1 Shared decision-making continuum. In shared decision-making (SDM), the continuum ranges from purely patient-/family-driven decision-making to solely physician-driven decision-making. Three main elements of SDM include information exchange, deliberation, and

treatment decisions. Rarely, decisions are made from either end of the spectrum alone (reprinted with permission from Kon AA. The Shared Decision-Making Continuum. JAMA 2010;305:903–4)

skills in EOL care are crucial to helping parents and families manage their grief, as bereaved parents have been shown to demonstrate intense grief after the death of their child [61, 62]. As intensivists, our inclination is to focus on data in the review of systems approach to address the function of individual organ systems and describe the interventions in place that are or are not working to treat the underlying medical problems. And while this informational review is important to provide throughout a child's hospitalization and generally *before* EOL discussions, it is not the level of information to provide when moving the conversation to the EOL transition—parents need to know that they have exhausted every avenue to give their child a chance for survival and they need to know that they are protecting their child from further suffering. It is essential to EOL communication that we comprehend the fact that educating families about their child's illness is an iterative process of both information delivery and affective and psychosocial communication that considers the patient's and family's personal and cultural understanding of the illness and treatment as well as the impact of this experience on their lives [47•, 49, 56].

Moral Distress and Resiliency

In cases where children are critically ill and dependent on multiple modes of LSMT, any member of the critical care team may demonstrate signs of distress. The behavior tends to be revealed in cases where care is perceived to be futile or cause undue suffering to the patient. Not all distress is moral distress, and, typically, moral distress is associated with anger, conflicts with personal integrity and colleagues, and work dissatisfaction, and ultimately contributes to compassion fatigue and burnout [63, 64•, 65, 66]. Perception of its presence in our work, conscious acknowledgement and acceptance of its existence, and endeavors to address it in ourselves and our colleagues are imperative in order to manage the negative consequences [63]. Moral distress can be interpreted as a sign that clinical teams are appropriately sensitive to the moral domain of their environment, which in the PICU is relevant given the fact that ethical dilemmas frequently emerge [63, 67].

The occurrence of these experiences of moral distress is an opportunity for dialog. Palliative care teams and clinical ethics consultants may be useful adjuncts in these situations. We would advocate that additional communication training can empower intensivists and the PICU team with tools to navigate through difficult situations directly with each other to foster moral resilience and promote self and patient/family integrity [45]. Enhancement of primary palliative care skills and utilization of our specialized teams to promote and facilitate open and respectful dialog are paramount to developing resiliency.

Conclusion

Palliative care is an essential component of comprehensive care for our patients and families facing critical and life-threatening illness of any severity or prognosis. It augments and complements intensive care treatments, and it is based on need, not prognosis or outcome. Although pediatric palliative care teams are available at many pediatric centers and new programs are increasing each year, workforce and time limitations preclude this care from reaching all patients and families who would benefit from this support. The importance of incorporating a core set of palliative care skills into our daily practice cannot be overstated—cultivating these skills will improve the quality of comprehensive care we provide to our patients and families and may eventually restore moral resilience in clinicians.

Compliance with Ethical Standards

Conflict of Interest Eileen Rhee and Wynne Morrison declare no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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