

Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children in Neonatal and Pediatric Intensive Care Units

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Abstract

Over the past several years, pediatric critical care units increasingly count on the expert advisement of palliative care specialists. Given the limited availability of pediatric palliative care specialists, all palliative care clinicians may be required to care for pediatric patients and their families. Special considerations in caring for these patients include the relative importance of prognosis, involvement of child life, music and pet therapy, incorporation of parents in end-of-life rituals, care for siblings, use of medical technology, and prolonged duration of stay. The following top 10 tips provide recommendations for caring for seriously ill infants, children, adolescents, and the families of these critically ill pediatric patients. They are written by pediatric intensive care providers to address common issues around palliative care in intensive care units.

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SPECIALTY PALLIATIVE CARE is increasingly integrated into pediatric critical care. For example, as recently as five years ago, young patients were admitted to a pediatric intensive care unit (PICU) after years of cancer treatment, after a third bone marrow transplant, or in late stages of muscular dystrophy, without specialty palliative care involvement or advance directives. Palliative care was synonymous with end-of-life care for patients and providers alike and often unwelcome in the pediatric realm. With education and time, pediatric intensive care providers have increasingly partnered with specialty palliative care clinicians and often consult them on admission to the unit.

PICUs include neonatal intensive care units (NICUs), PICUs, and various pediatric specialty ICUs such as cardiac intensive care or neurointensive care. Patients in these units are often the sickest, most medically complex, and fragile children in the hospital. Many of these patients live in the hospital for the first six months of their lives—some “graduate” from the NICU to the PICU without ever going home. They suffer diseases and complications unique to the pediatric population—congenital heart disease, laryngomalacia,

intraventricular hemorrhage—and respond differently to illness. Neurologists counsel parents of children with neonatal strokes with much more optimism than many adult patients, owing to pediatric neuroplasticity and better outcomes. As such, caring for seriously ill infants and children and their families is a unique experience.

The following top 10 tips provide recommendations for caring for seriously ill infants, children, adolescents, and the families of these critically ill pediatric patients. They are written by pediatric intensive care providers to address common issues around palliative care in ICUs.

Tip 1: Check in on How Important Knowing Prognosis Is to a Family—Many Children Have Far Exceeded Their Predicted Survival

Worldwide, child mortality has decreased significantly, with >50% decrease in mortality across 0–18 age groups.¹ However, studies consistently demonstrate provider inability to accurately prognosticate, with one large study showing 50% of patients predicted to die surviving to discharge.² As

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these medically complex children are living longer, with continued inaccurate prognostication, many families have already been told their child is dying, some several times over. The majority of chronic patients in the PICUs have already exceeded their predicted survival. As such, their parents, and sometimes the patients themselves, are not always interested in prognosis, and sometimes react negatively to discussions of prognosis or declarations of impending death.

In discussing prognosis with families and patients, we recommend asking families how important prognosis is to them, and how it may or may not impact their decision making. Many times, parents have told us they are not interested in hearing negative thoughts or updates, and most assuredly do not want any negative commentary in the presence of their children. Different from adults, ask parents if they prefer to speak outside the room, and ensure they feel comfortable leaving their child's bedside, or find someone they trust to sit with their child. To start conversations, we often find it helpful to ask parents what their child is like at their happiest and healthiest, and sometimes ask to see pictures of their child outside the hospital.

Tip 2: Symptom Management in Pediatrics Draws upon a Variety of Resources, Including Life Specialists, Pet Therapy, and Distraction Techniques

Alleviation of pain and symptom management is critically important to most children and their parents. Yet 20 years ago, neonatologists debated if premature infants could even experience pain, and how best to handle painful interventions in the neonatal and pediatric population.³ Studies show that when using scoring tools to document patient pain, clinicians generate lower pain scores than parents or patients, and may underestimate patients' pain.⁴ Parents understanding of subtle pain cues offers a better understanding of the patient's comfort than clinicians are able to determine using objective scoring tools. Listening to patient and parent opinions on pain is of significant benefit, as a child's pain causes significant parental distress, lasting long after their hospital stay.⁵

Relief of pain, however, eases parental distress.⁶ Different than adults, consider nonopioid analgesics and nonpharmacological adjuvants for pain control. Pet therapy, child life specialists, and other creative pain management must be considered in a comprehensive symptom management plan. Child life specialists help prepare patients for upcoming procedures and alleviate anxiety. Distraction techniques including music and videos are proven to decrease pain and distress.⁷ Ask families what kind of music their children like, if there are any special videos or shows they like, if they want to make a recording of their voices or videos of siblings to share with the patient.

Tip 3: Ask Parents How They Want to Be Involved in End-of-Life Care

Death of a child often looks very different than death of an older adult. Parents are often intimately involved with withdrawal of life-sustaining support, participating in creation of hand and foot molds, lying in bed with their children at the time of death, and bathing and dressing their children after death.⁸ Parents often have specific music in mind, and specific people they may want in the room with them, beyond

immediate family. Child life specialists are very frequently involved in peri- and postmortem memory making.

Sibling involvement is often critically important to parents, and an area of significant parental guilt, although sometimes forgotten in the trauma of the child's death. Studies demonstrate the profound impact a sibling's death may have on a child, and the importance of giving attention, information, and care to the ill child's sibling as possible.⁹ Parents may turn to you for advice on how to speak to their other children about the patient's illness, how to involve their children, and how to support their remaining children after death of their sibling. Consider referrals to counselors, school support, family bereavement groups, and even sibling bereavement camps.

Tip 4: Patient Families Often Form Close Bonds with Other Families in the ICU. A Significant Change in Patient Condition or Death of a Patient May Have a Profound Effect on Other Families in the ICU

Parents of critically ill children often experience social isolation, both by virtue of time spent in the hospital and feelings of lack of understanding from those outside the medical world.¹⁰ Subsequently, parents, and sometimes patients, often develop close relationships with their fellow ICU parents and their children. Through shared rooms, conversations in the Ronald McDonald parent room and house, and social media, parents of hospitalized children are interacting more and more.¹¹ As such, parents are intimately aware of other children's disease processes and progress. A significant loss or setback of one child may profoundly impacts another child or his family. Witnessing traumatic events has long-reaching, diverse consequences, including post-traumatic stress disorder, lower overall function, and increased health comorbidities.¹²

When one patient experiences a traumatic event, consider checking in with other patients and families in the unit as well. Often, parents' reactions to these events will come across as questions or fears about their child that seem incongruent. They will often ask about things like cardiac arrest, extracorporeal membrane oxygenation (ECMO), or mention other resuscitation measures or procedures that do not correlate with their child's current level of illness. Without violating Health Insurance Portability and Accountability Act (HIPAA) and patient privacy, you can ask parents "How are you feeling about some of the things that happened yesterday?" Without naming specific events or patients, you can probe their reaction, and most parents will be fairly open in discussing how they were affected.

Tip 5: Given the Inherent Caregiver Role of Parents and the Complete Loss of This Role in the Busy ICU Setting, Be Mindful of the Importance of Shared Decision Making

As medicine becomes less paternalistic, shared decision-making models have gained popularity. In pediatrics, the caregiver nature of parents makes engaging in shared decision making even more important. Meta-analyses demonstrate pediatric-shared decision making, improves patient and parental knowledge, and decreases decisional conflict.¹³ However, in the ICU setting, given the busy nature of the units and the minute-to-minute pace and complexity of life-sustaining technology, parents often feel sidelined or isolated from being able to make decisions about what is happening

to and for their child. Guiding clinicians toward a more open model of shared decision making will aid in provider–patient–family dynamics and improve relationships.

Furthermore, loss of the caregiver role—and feelings of inability to protect one’s child—results in significant loss of identity and guilt. Guilt plays a significant role in the parent experience, and fear of future guilt also plagues parents.^{14,15} Parental decision making is driven by multiple complex factors, and parents may need help parsing through their emotions and underlying factors to guide their child’s care.

Tip 6: In Framing Decisions Around Care, Most Parents Are Willing to Go Extreme Lengths to Get Their Child Home, Regardless of Personal, Professional, or Financial Hardship

The significant decrease in child mortality in developed countries has led to a significant increase in children dependent on medical technology, and an increase in the level of complexity of chronically ill pediatric patients.¹⁶ Children go home with destination ventricular assist devices (VADs), on continuous inotropy such as milrinone and dopamine infusions, on subcutaneous continuous prostacyclin infusions, with complicated home-feeding regimens, and even on mechanical ventilation. Parents are more than willing to accept aggressive levels of complexity of care and mechanical support to aid their children compared with the early 1990s.¹⁶

Parents stay home from work, risk job security, and take on professional losses, financial hardship, and negative social effects to prolong their child’s life.^{17,18} Parents and siblings are impacted, with healthy siblings demonstrating negative behaviors and processing upon return of their ill siblings.¹⁹ In discussions with parents, remember the multifaceted impact bringing home a technology-dependent child will have on the entire family unit. We can work to appropriately counsel families and provide necessary support resources. Ask families “Tell me what you imagine having your child at home with a VAD will look like...” “What kind of things does your family enjoy doing together, and how might your child’s home ventilator fit into that?” “What kind of accommodations might your home need to bring your child home?”

Tip 7: Formal Education on End-of-Life Care and Training in Communication Skills Are Not Routinely Included in the Education of Pediatric Providers

Bereaved parents have expressed both dissatisfaction with physician communication and the feeling their children experienced a significant amount of suffering at the end of life.^{20–22} Specific to communication near the time of a child’s death, parents express the desire for honesty, accessibility, clear language, and a caring affect.²³

Despite families emphasizing the importance of communication, pediatric trainees report feeling ill prepared to deliver bad news.^{24,25} Without clear and universal expectations for training in communication skills and end-of-life care, pediatric critical care medicine training programs rely on informal and passive learning methods such as journal clubs and lectures to learn these skills, more often than active, experiential methods such as simulation and role play.²⁶

As the expert in communication and end-of-life care, the palliative care provider can support the critical care team in several ways. Showing trainees one of several frameworks

for information sharing can be very valuable. In addition, the palliative care provider can offer examples for specific language, such as “I wonder...” and specific communication strategies such as the ASK–TELL–ASK method. Before family meetings, the palliative care team can offer to role play with trainees, allowing fellows the time to practice communication skills and receive feedback, or can assist with communication by attending or leading family meetings. Finally, when caring for a child at end of life in the critical care unit, the palliative care team should provide specific recommendations for both managing symptoms and providing anticipatory guidance to patients and families about the dying process.

Tip 8: More than Half of PICU Admissions Are Patients with Chronic, Preexisting Conditions, and as Such, Parents Are Intimately Familiar with Their Children’s Needs

More than half of all children admitted to the PICU have preexisting complex chronic conditions (CCC). CCC is defined by a condition that lasts more than one year unless death occurs, affects two or more organ systems, and requires care from specialty providers and likely hospitalization in a tertiary care center.²⁷ Children with CCC receive up to 90% of the most invasive therapies in the PICU, and have higher rates of repeat admissions and prolonged hospital stays.^{28,29}

Rather than experiencing respite, parents of children with CCC experience high amounts of stress and grief when their children are hospitalized. As the usual caretakers for their children, parents can feel a strong disconnect between their role of parent at home and their parent role in the PICU.³⁰ Parents of children with CCC report a desire for continuity of care and therefore, new providers create a sense of anxiety and frustration.³¹

Knowing a child’s unique history, special traits, and customized care regimen can support the values of care coordination, clear communication, and respect for shared decision making that parents of children with CCC report being most important to them. A new provider should ask the family what is important to know when caring for their child. A child with CCC may express pain with unique behaviors and providers can use individualized pain assessment tools to incorporate these behaviors. When considering changes in feeding regimen and other routine care, providers should ask how the change may impact the child and their schedule at home. Child life specialists, social workers, and case managers are uniquely positioned to support these families throughout their PICU stay and upon discharge.

Tip 9: As Death Is Rare in the PICU, Pediatric Teams Appreciate Recommendations on Management of End-of-Life Care, Postmortem Care, Family Grief, and Staff Emotions

The overall mortality rate for children admitted to the PICU is <5%. Pediatric trainees report on average caring for few children at the end of their life. The multidisciplinary palliative care team can provide consultation and support to families and staff when a child is facing end of life, with an emphasis on symptom control and psychological and spiritual care.

Encouraging palliative care consultation early when a child is facing the risk of death can help with anticipatory grief.³² The skills of a child life specialist, music therapist, and/or spiritual advisor can be particularly helpful for families facing the death of their child. The palliative care team can help create a supportive environment that promotes privacy and respect, allowing parents intimate access to their child by bringing in a big bed, decorating the room with mementos, and/or altering visitation rules.

Legacy activities and creating keepsakes such as the child's handprint, photographs or lock of hair, play a vital role as they allow the family to maintain a connection with their child long after their child's death. Inviting the family to participate in postmortem care and honoring cultural and family rituals can further honor the parent-child relationship. After a child's death, some PICU teams offer formal follow-up meetings and some palliative care teams can provide in home or follow-up bereavement support for parents and siblings.

Finally, the palliative care team can offer staff support during and after a child's death, helping staff to reframe the stress and burden of caring for a child at end of life, and find positive meaning in their experience. Systems of support may include regular debriefings after patient deaths, resources to address staff moral distress and burn out, and access to spiritual and psychosocial providers.

Tip 10: As Many Patients Spend Weeks to Months in the PICU, Ask Families About Their Support System, Their Other Children, Their Jobs, and How to Support Them Aside from Caring for Their Child

Many children are hospitalized in the PICU for weeks to months. In one study the median duration of mechanical ventilation for children before tracheostomy placement ranged from 22 to 64 days. Long PICU stays impact the quality of life of an entire family. Over 20% of families report symptoms of post-traumatic stress disorder after their PICU stay.³³

Families must manage the ongoing demands of parenting for their ill child, caring for siblings, jobs, and financial stress, while preparing for an uncertain future. Offering families resources and support can allow them to cope better. Ongoing access to and support from a social worker and a case manager can be critical to help parents navigate the financial and social stressors that accompany prolonged hospital stays. Although child life specialists, chaplains, and therapists are available to the child hospitalized in the PICU, their siblings may also benefit from specific attention by these psychosocial providers.

The palliative care team can collaborate with the PICU team to explore and address the family needs during their time in the PICU. Specifically, the palliative care team can offer assistance with coordination of care, communication, and ongoing psychosocial support.

Conclusion

Pediatric critical care teams increasingly rely on expert advisement from palliative care clinicians in caring for patients and families. Special considerations in caring for these patients include the relative importance of prognosis, involvement of child life, music, and pet therapy, incorporation of parents in end-of-life rituals, care for siblings, and use of

medical technology. Many pediatric intensive care patients are chronic patients, frequently readmitted throughout their lives, and familiar with the hospital setting. Furthermore, many pediatric intensive care stays are longer than average adult stays and significantly stress family structure, finances, and quality of life. Palliative care teams and critical care teams should continue to collaborate to best support patients and families in their palliative care needs.

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