

End-of-Life Care: in Pediatric Oncology

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OVERVIEW

- Despite remarkable progress in the treatment of pediatric malignancy, 30 percent of children with cancer still die.
- Cancer is the most common cause of nontraumatic death in children.
- 80 % of children dying with cancer are still suffering, and their symptoms are not being adequately palliated.

Why are children with terminal malignancy suffering?

- First and foremost, death in childhood is rare.
- Medical, psychological, social, spiritual, and other practitioners for children are not likely to have much experience in palliative and terminal care.
- Professionals are not likely to have sufficient training to handle the complex physical, emotional, and psychological care of dying children and their families.
- Heightened expectation of success leads to a reluctance of parents and health care providers to make a formal transition to non-cure-directed interventions.
- pediatric providers are more likely to suffer a sense of failure when children die.
- death of a child is one of the most significant psychological stressors a person may ever face.

Improving the quality of care and quality of life for dying children depends on improving the quality of education in pediatric palliative care.

RESULTS OF DELAYS IN THE INITIATION OF PALLIATIVE CARE FOR CHILDREN

1. losing the opportunity to promote palliative care principles to the patient and family;
2. being less able to tailor palliative care to the evolving needs of the patient;
3. crisis-oriented management, which exacerbates the sense of vulnerability and helplessness;
4. absence of a framework for preventive, proactive interventions or decision making;
5. difficulty in supporting the family's strengths and capacity to cope and in the maximizing quality of the remaining time.

TYPE OF DEATH

There are different types of paediatric death:

1. sudden unexpected death in a normal child;
2. a child with a life- limiting condition who dies unexpectedly;
3. a child with a life- limiting condition who has an expected death.

Predictors of death

- certain malignancies such as brain tumours;
- malignancies where all forms of treatment have failed, and disease progression is seen as rapid;
- when specific organ failure is occurring such as liver or renal failure
- a child starts to have increasingly prolonged periods of sleep apnoea;
- seizure frequency and intensity continue to increase to a level where the seizures and treatment for them begin to lead to secondary infection or respiratory suppression
- Cheyne–Stokes breathing occurs.

Laying the Groundwork for End-of-Life Management

Communication with patients and families about goals for end-of-life care

- **Communication Needs of Families of Children With Life-Threatening Conditions:**

1. **Straightforward information:** full disclosure allows families to better comprehend the issues and feel prepared.
2. **Coordinated and consistent communication:** families fear not knowing what is going on and want clinicians to help connect-the-dots using consistent and unambiguous language
3. Respecting the family-child relationship and families' unique knowledge of child
4. Faith, hope, and meaning-making

Communication with patients and families about goals for end-of-life care

5. Time to ask questions
6. Ready access to staff members, including physicians (for information and support)
7. Genuine expression of kindness and compassion from staff, including treating the child or adolescent as an individual and exploring the family's emotions

Shared Decision Making (SDM)

- **SDM process includes:** exploring patient and family values, providing medical information in an individualized way, and then recommending a treatment course to align with what matters most to the patient and family.
- SDM at the end of life requires attention to cultural and community norms, religious beliefs, impact on siblings and extended family, and prior experiences with death.

Advance Care Planning (ACP)

- ACP requires the clinician, family, and patient (when developmentally appropriate) to review the natural course of the disease and predicted quality of life while exploring patient and family hopes, worries, goals, and values.
- ACP discussions should be documented in the medical record.

Indication for Initiating or Revisiting Advance Care Planning

- Serious fetal diagnosis
- A catastrophic injury
- New diagnosis of a condition with a poor prognosis
- When disease-directed treatment is no longer effective
- Incomplete response to escalating medical care or life support
- Disease progression or relapse
- Increase symptom burden and/or secondary complications
- Increasing periods of time spent unwell or in the hospital
- Reaching the age of majority
- Family request:
 - Not wanting “heroic measures” to be taken
 - Acknowledgment that prior goals may be unachievable
 - Change in quality of life
 - Concerns about suffering

Key Components of Pediatric Advance Care Planning

- Build a partnership with family
- Discuss prognosis and predictions for the future
- Explore the patient and family's values related to quality of life
- Assess goals and worries and global family strengths, values, and needs
- Understand family concepts of what it means to be a "good parent"
- Articulate the possible treatment benefits and burdens, and weigh the implications of these with the patient and family
- Offer treatment recommendations
- Explore child and family preferences for the final days, such as symptom management and location of death

As End of Life Nears

- **Location of Death:** consideration should be provided to the preferred place of death
- **Role for Interdisciplinary Team:** The wrap-around support of an interdisciplinary team is needed to address the physical, spiritual, social, emotional, and psychological needs of the child or adolescent and the family.

Providing Care in the Final Days

- **Plans for Life-Sustaining Medical Treatment:** Language is important; clinicians should avoid talking about “withdrawing care” or “withdrawing support,” because care and support continue regardless. Instead, language should focus on forgoing treatments and interventions that do not promote comfort.
- **Preparing for the Dying Process:**
 - Many families want clinicians to prepare them for what their child or adolescent is likely to experience as death approaches.
 - Some patients and families want very detailed information shared early; others want only “big picture” information as death nears.
 - most family want to know what physical changes they may see, what symptoms are expected, and how those symptoms (especially pain) will be managed

Symptom Management

Sign or Symptom	Examples of Anticipatory Guidance: "As your child nears death, he or she..."
Decreased appetite	"...will probably not be hungry or even thirsty because..."
Decreased alertness	"...may sleep a lot, especially in the final days because..."
Changes in breathing: slow, fast, apnea	"...may have changes in breathing that are generally not uncomfortable, though we will have medicines to give him or her if we are worried about comfort."
Noisy breathing because of oral secretions	"...will swallow less, and the saliva in the back of the throat may make a noise that may sound uncomfortable to us but will not bother him or her."
Skin changes	"...will begin to feel cooler and may start to appear pale or even slightly blue."
Cardiac insufficiency	"...will have slower and maybe irregular heart rate, and weaker pulses."
Loss of bowel and bladder control	"...may not hold his or her urine or stool, so we will use a diaper to keep him or her comfortable."

After Death

- **Death Pronouncement:**

- The declaration of death is ideally done by a clinician familiar to the family
- The examination itself includes auscultation to confirm the cessation of breathing and absence of heart sounds and palpation to confirm loss of carotid or radial pulse.
- Supplementary testing to confirm no pupillary light reflex may be considered, especially if the death was unwitnessed.
- Declaration of death does not need to occur at the precise moment of death; if the family is holding the patient or amid intense bonding or emotion, defer the death examination until the family appears ready.
- Clinicians should offer an expression of condolence (“I am sorry for your loss...”) and allow time and space for the family to ask questions

After Death

- **Death Certificate;**

- death certificate is the permanent record of death and must be completed in a timely manner, as it is necessary for burial and settlement of personal estates.

- **Supporting Families**

Recommendations

- Palliative care ought to be engaged early, when possible, to facilitate communication and decision making with families of children with serious illnesses.
- Shared decision making regarding pediatric end-of-life care requires a partnership with children, adolescents, and families.
- Pediatric advance care planning ideally begins soon after a serious diagnosis
- clinicians should help families reconcile how life-sustaining medical therapies align with the goals of care at the end of life.
- discussion with the patient and family for the location of the child's final days or hours.
- Clinicians should provide families with straightforward anticipatory guidance about the end of life: treatments and monitoring that may or may not be continued, the physical signs of dying, and postmortem care of the patient and of the family.
- Families value support from clinicians during and after the dying period



Guidance for Pediatric End-of-Life Care

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THE SECTION ON HOSPICE AND PALLIATIVE MEDICINE

The final hours, days, and weeks in the life of a child or adolescent with serious illness are stressful for families, pediatricians, and other pediatric caregivers. This clinical report reviews essential elements of pediatric care for these patients and their families, establishing end-of-life care goals, anticipatory counseling about the dying process (expected signs or symptoms, code status, desired location of death), and engagement with palliative and hospice resources. This report also outlines postmortem tasks for the pediatric team, including staff debriefing and bereavement.

STATEMENT OF NEED

Each year, approximately 45 000 infants, children, and adolescents (ages 0–19 years) die in the United States.¹ More than half of these deaths are in children younger than 1 year, and many are attributable to congenital disorders or prematurity.¹ Medical problems diagnosed in the first year of life may become complex chronic conditions and continue to contribute to pediatric mortality, even as unintentional injury becomes the most common cause of death through childhood and adolescence.²

This clinical report aims to outline practical components of quality end-of-life care with a focus on the final hours, days, and weeks of the child or adolescent's life. This information is meant to serve as a pediatric palliative care (PPC) primer for general pediatricians, hospitalists, and pediatric specialists caring for dying patients and their families. Considerations are offered for the time leading up to death, as death nears, and after death. Throughout this report, the term "family" is used to be inclusive of parents and extended family and friends. Additionally, throughout this report, the terms "child" and "adolescent" are used to be inclusive of pediatric patients from birth through 21 years of age, and specific age or developmental groups are highlighted where relevant.

BACKGROUND

Some pediatric deaths happen within minutes to days of the cause (eg, unintentional injury, extremely preterm birth, catastrophic illness). Others occur days to years after an initial diagnosis or injury,

abstract

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A serene sunset scene over a calm ocean. The sun is a large, bright, glowing orb in the upper center of the frame, casting a shimmering path of light across the water's surface. The sky is a clear, pale blue. On the horizon to the right, there is a small, dark silhouette of a structure with a flat roof, possibly a buoy or a small boat. A single yellow buoy is visible in the water to the right of the sun's reflection.

THANKS FOR YOUR ATTENTION