Pediatric Palliative Care: Ethical Considerations From an Internist’s Perspective

Jason Morrow, MD, PhD
University Health System
UT Health Science Center at San Antonio
I have no financial disclosures

Objectives

- Examine core ethical values, legal standards, and analytical tools related to pediatric palliative care, including relief of suffering, informed assent, and double-effect.
- Illustrate ethical challenges affecting providers coping with advanced or life-threatening illness, including moral distress, compassion fatigue, and burnout.
- Identify strategies for collaboration in the provision of pediatric palliative care.

Outline

- Introduction
- Ethical values
- Ethical analysis
- Ethical challenges
- Collaboration
- Case discussion

Introduction: what is palliative care?

- Pain and symptom management
- Emotional and spiritual support
- Decision support
- Compassionate communication
- Access to resources
- Complementary to curative treatment
- Interdisciplinary

Introduction: supportive and end-of-life care

Primary palliative care
Outpatient Palliative Care
Advance Care Planning
Bereavement
Hospice
Inpatient Palliative Care
Introduction: total pain

Introduction: facts of life

- We are vulnerable creatures
  - Inborn and acquired genetic errors
  - Cancer
  - Trauma
  - Infections
  - Dysregulation
  - Organ failure
- Development, aging, lifespan, connectedness

Facts of life

Facts of life

Facts of life

Facts of life
A case...

• Robert was a healthy 17 year-old until he suffered blunt-force trauma to his head and lost consciousness.
• Admitted with minimal responsiveness and evidence of SDH and loss of white-gray matter interface.
• Treated with mechanical ventilation, craniotomy, and AEDs.
• Course complicated by refractory seizures and absence of alertness or responsiveness.
• Palliative care consult to address goals of care and to facilitate family meetings.

Ethical values in Palliative Care

• Relief of suffering and beneficence
  – Respect for life and living well
  – Pain and symptom management
  – Emotional and spiritual support
  – Family and social support
• “Do no harm” and nonmaleficence
  – Prudent use of technology
  – Professionalism
  – Knowing the ethical limits of the role of physician
• Empowerment
  – Respect for personhood, family, community, culture, and faith
  – Informed and voluntary decision-making
  – Access to services and relationships

Legal standards: informed consent

• 1914 in re Schloendorff:
  – “Any human being of adult years and sounds mind has a right to determine what shall be done with his own body.” Chief Justice Cardozo
• 1947 Nuremburg Code
  – Voluntary
  – Legal capacity to give consent
  – Sufficient knowledge and comprehension
• 1957 Soligo
  – Risks
  – Alternatives
  – Battery without “informed consent”
• 1972 Canterbury v Spence
  – Reasonable person standard
  – Relative to the needs of the patient

Legal standards: capacity

• Capacity
  – Ability to understand the nature and consequences of one’s actions
  – One requirement of legally valid agreements or contracts
  – Applies to a particular treatment option
• Mental capacity requires the ability to:
  – Understand information
  – Retain information
  – Weigh options
  – Communicate preferences
• Mental capacity
  – Is both developmental and fluctuating
  – May represent a spectrum
  – May be proportionate to the treatment
  – Unreliable capacity is grounds for “incompetence”
Legal standards: assent

- Children can consent to specific decisions
  - “mature minors”
  - STDs and psychiatric conditions
  - Varies by state
- Assent
  - “Affirmative agreement”
- Emancipation
  - Partial versus complete
  - “Age of majority,” marriage, and military
  - What are best interests?
  - Financial independence

Legal standards: non-beneficial treatment

- 1999 Texas Advance Directives Act (Texas Health and Safety Code, Section 166) includes mechanisms for:
  - Advance Directives
  - Durable Power of Attorney for Healthcare
  - Out of hospital DNR policy
  - “Procedure if not effectuating a directive or treatment decision.”
- 2005 Sun Hudson
- 2007 Emilio Gonzalez

Ethical analysis

- Four-step method:
  - Medical indications
  - Patient references
  - Quality of life
  - Contextual features

Ethical analysis

- Permissible/Required/Forbidden
- Consequentialism
- Principle of double-effect


Ethical analysis

- Permissible/Required/Forbidden
- Consequentialism
- Principle of double-effect
  - An alternative to consequentialism
  - A foreseeably harmful act is permissible if:
    - The act itself is either morally good or neutral
    - Harmful outcomes are not the means to the good ends
    - The agent intends the good and not the bad outcomes
    - The intended good outcomes are proportional to the foreseeable bad outcomes
  - Ambiguities (direct intentions, duty to foresee)
Ethical challenges for providers

Compassion fatigue?

Compassion fatigue: definition

• Compassion fatigue: aka “secondary traumatic stress” and “cost of caring”; emotional stress and exhaustion acquired through caring for and wanting to help people who suffer trauma, illness, and loss

• Signs and symptoms:
  – Increased negative arousal
  – Intrusive thoughts/images
  – Difficulty separating work/life
  – Lowered threshold for frustration and anger
  – Dread of certain people
  – Depression

Compassion fatigue: sources

• Sources among family members:
  – Shared suffering and loss
  – Anticipatory grief
  – The burden of difficult choices

• Factors among clinicians
  – Altruism
  – Empathy
  – Unresolved personal trauma
  – May already be fatigued
  – High personal standards
  – “Bottled up”
  – Years of practice

Compassion fatigue: prevalence

• Hospice nurses: 78% at high or moderate risk
• ICU nurses/doctors: high sense of personal stress correlates with high compassion fatigue
• Oncology nurses: 38% had moderate compassion fatigue
• ER nurses: 33% met criteria for PTSD
• Social workers: 48% report high personal distress related to secondary trauma
Moral distress

- Moral distress: knowing the right action but feeling powerless to perform it
- Sources of distress among nurses:
  - Continued life support even though it is not in the best interest of the patient
  - Inadequate communication about end of life care between providers and patients and families
  - Inappropriate use of healthcare resources
  - Inadequate staffing or staff who are not adequately trained to provide the required care
  - Inadequate pain relief provided to patients
  - False hope given to patients and families

Burnout: definition and prevalence

- Burnout: a chronic exhaustion, depersonalization, and low sense of accomplishment in the workplace
- Common among physicians:
  - 35-48% of Oncology specialists
  - 50% of General Internists
  - 50% of Pediatric Intensivists
  - 72% Pediatric Oncologists
- 4% at start of Internal Medicine residency—55% by end of residency
- Nurses
  - 33% outpatient Oncology
  - 44% inpatient Oncology
- Social workers, therapists—all anyone in the trenches

Moral distress

- Sources among doctors:
  - Coping with end-of-life care and decision making
  - Pressure to “do everything”
- Signs of moral distress:
  - Frustration
  - Anger
  - Threatened integrity
- Consequences of moral distress:
  - Unable to recognize ethical challenges
  - Conscientious objection (productive or destructive)
  - Burnout

Burnout: consequences

- Providers
  - Depression
  - Suicidality
  - Cardiovascular risk factor
  - Substance abuse
  - Withdrawing from practice
- Patients
  - Adverse medical events
  - Fewer conversations with “the team”
- Practice settings
  - “Horizontal violence” and “hidden curriculum”
  - High absenteeism and turnover
  - Less experienced staff

Managing ethical challenges

- Compassion fatigue:
  - Education about self-care: sleep, exercise, nutrition, relaxation, family boundaries
  - Diversified patient or care load
  - Peer support groups and retreats
  - Culture of resiliency
- Moral distress:
  - Ethical environments: make it easy to do the right thing
  - Adequate staffing and embedded advocates or leaders
  - Ethics resources: chaplaincy, Ethics Committees/Consultants
  - Culture of disclosure and professional integrity
- Burnout
  - Improved work hours
  - Emotional intelligence training and “wellness teams”
  - Employee Assistance Program
  - Mentorship, debriefing, reflective writing, remembrance
  - Culture of engagement

Managing ethical challenges: collaboration

- Interdisciplinary care
  - Doctors and nurses
  - SW, CM
  - Chaplains
  - Psychologists and child life specialists
- Shared or pooled resources
- Inpatient, Outpatient, Transitions, Medical Homes
- Case review
  - “tumor boards”
  - Ethics Committee
  - Didactics
Case discussion

• 17 y/o with traumatic brain injury
• 19 y/o with severe cystic fibrosis
• Your cases...