End of Life: Care of the Pediatric Patient, Family, and Self
Deana Deeter, CRNP, CHPPN, CPON
Hummingbird Program Manager
Penn State Hershey Children’s Hospital
Touching the Future of Children
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Palliative Care
• World Health Organization
  – Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
  – It begins when the illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Palliative Care

Grief & Bereavement
Ethics & Legal Concerns
Communication & Critical Conversations
Symptom Management
End-of-Life Care
Overview

- Care of the pediatric patient
  - Background information
  - Pain & symptom management
  - Final days & palliative sedation
  - Autopsy & organ donation

- Care of the family
  - Parental decision-making & perspectives
  - Advice from bereaved parents
  - Siblings & grandparents
  - Bereavement support

- Care of yourself
  - Compassion fatigue vs. burnout
  - Staff debriefing
  - Funeral attendance
  - Professional boundaries

End of Life

CARE OF THE PEDIATRIC PATIENT

Epidemiology

- Over 53,000 infants and children die annually in the United States
  - Represents 2.2% of all deaths (2005)
  - Slightly more than 50% of these deaths occur during infancy

Location of Death

- Over 80% of pediatric deaths occur in the hospital
  - 1%-2% of total admissions
- Two thirds of pediatric deaths occur in an ICU setting
- Two thirds of pediatric ICU deaths are the result of withdrawal of support


Concurrent Care for Children

- Patient Protection and Affordable Care Act (PPACA), March 23, 2010
  - Section 2302, “Concurrent Care for Children” Requirement (CCCR)
    - All state Medicaid programs are required to pay for both curative and hospice services for children under age 21 who qualify.

Pain & Symptom Management

- Wolfe, et al.
  - 2000
    - 89% of patients were reported to have suffered “a lot” or “a great deal” from at least one symptom in their last month of life
    - Treatment was successful in only 27% of those with pain and 16% of those with dyspnea
  - 2008
    - Almost half of all children in follow-up cohort received PACT consult
    - Reports of “a great deal” or “a lot” of suffering decreased in the follow-up cohort

Pain Management
• Pain assessment (PQRST)
  – Provoking (Aggravating/Alleviating)
  – Quality (sharp, aching, tingling, etc.)
  – Region/location, Radiation
  – Severity (Pain scale—behavioral or self report)
  – Timing/duration

Pain Management
• Pharmacologic
  – Acetaminophen
  – NSAIDs
  – Opioids (strong, weak)
  – Adjuvant medications
    (steroids, anticonvulsants, antidepressants, bisphosphonates, etc.)

Pain Management
• Non-Pharmacologic
  – Ice/heat
  – Positioning
  – Distraction
  – Psychologist
  – CAM

Pain Management
• Nursing Interventions
  – Pharmacologic & non-pharmacologic interventions
  – Reassessment following interventions
  – Anticipating & educating families about side effects of pain medication
  – Advocating for patient pain control
### Symptom Management

**Anorexia/cachexia**  
- Fatigue  
- Nausea/vomiting

**Anxiety/agitation**  
- Pruritus

**Bleeding**  
- Secretions

**Constipation**  
- Seizures

**Cough**  
- Skin breakdown

**Depression**  
- Sleep disturbance

**Diarrhea**  
- Urinary retention

**Dyspnea**

*Remember alternate drug administration routes!*

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### Symptom Management

**Fatigue**
- Energy conservation, sleep hygiene, nutrition
- Steroids, psychostimulants; transfusion

**Dyspnea**
- Emotional support, elevate HOB, relaxation, fan
- Opioids, anxiolytics, bronchodilators, oxygen

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### Symptom Management

**Constipation**
- Dietary modification, activity, abdominal massage, routine toileting, digital rectal stim
- Laxatives, suppositories, enemas, methylnaltrexone

**Secretions**
- Positioning, suction, modify fluid intake, skin care, mouth care, sugarless candy
- Glycopyrrolate, scopolamine, atropine, ipratropium, guaifenesin, artificial saliva, antifungals
Symptom Management

• Nausea/Vomiting
  – Minimize odors, small/frequent meals, favorite foods, clear liquids or bland foods, relaxation
  – Antiemetics (mechanism of action!), address constipation and secretions

• Anxiety/Agitation
  – Calm environment, routines, open communication, validation & reassurance, psychologist, chaplain
  – Lorazepam, diazepam, haloperidol

Final Days

• Signs/Symptoms
  – Increased sleep
  – Confusion/delirium
  – Withdraw
  – Decreased intake
  – Incontinence
  – Moist/congested breathing
  – Altered breathing pattern/apnea
  – Restlessness/agitation
  – Cool/mottled extremities
  – Edema
  – Fever

Final Days

• Interventions
  – Include siblings
  – Positioning
  – Mouth care
  – Talk to patient even if they are not able to respond
  – Soothing touch
  – Night light
  – Play favorite music
Palliative Sedation

- **Definition**
  - The monitored use of medications that induce sedation to control refractory and unendurable symptoms near the end of life when control of these symptoms is not possible with less aggressive measures

- **Purpose**
  - To control symptoms (not to hasten death!)


Palliative Sedation

- **Recommendations**
  - Initial dose of sedatives should be small enough to maintain the patients’ ability to communicate if possible
  - Advice from palliative care specialists is strongly recommended
  - For continuous and deep PST, condition should be irreversible and advanced, with death expected within hours to days
  - Midazolam should be considered first-line drug choice


Autopsy

- Provides diagnostic information that was unknown in the antemortem period
- Valuable teaching tool and quality assurance measure

- **Newton, et al.**
  - Overall autopsy rate of 40% at tertiary care children’s hospital
  - 20% revealed a major diagnostic discrepancy
  - 28% revealed a minor unexpected finding or additional diagnosis

Autopsy

• Alabran et al.
  – 93% of parents of deceased children did or would have consented to a research autopsy
  – Only half of these families were given the opportunity to donate autopsy tissue for research

Organ Donation

• Local organ procurement organization must be notified of any death or imminent death
• Cause of death (brain death vs. cardiac death) determines how donation can proceed
• Patients with HIV or actively spreading cancer are excluded from organ donation

Organ Donation

• National Organ Allocation Guidelines allow families of donors to designate recipients
  – Successful designated organ donations are rare
• Appearance of the donor is not affected by donation and open casket funerals are still possible
End of Life
CARE OF THE FAMILY

Parental Decision-Making
- Advance care planning in pediatrics
  - Child incompetence to make decisions
- Parents as surrogate decision-makers
- Important factors for parents:
  - Physician recommendations
  - Diagnosis
  - Expected neurologic recovery
  - Degree of pain and suffering


Parental Perspectives
- Mack et al.
  - Higher parental ratings of physician care:
    - Providing clear information about what to expect at EOL
    - Communicating with care and sensitivity
    - Communicating directly with the child if appropriate
    - Preparing the parent for circumstances surrounding the child's death
  - Parent reports of the child's pain & suffering were not significant correlates of their ratings of care
  - No association found between parent and physician care ratings

Parental Perspectives

• Meert et al.
  – Parents’ perceptions of their child’s death in the PICU and satisfaction with care provided
  – Dissatisfaction with care:
    • Child died of an acute illness
    • Felt uninformed about their child’s condition
    • Did not understand the cause of death
    • Did not have contact with hospital staff at home after the child’s death
    • Did not perceive staff as sympathetic
    • Did not perceive staff as kind


Advice from Bereaved Parents

• Steele et al.
  – Obtained advice for HCPs and researchers from bereaved parents and siblings following a child’s death from cancer
  – Five major themes:
    • Improved communication with the team
    • More compassionate care
    • Increased access to resources
    • Ongoing research
    • Offering praise
  – Continuity of care


Advice from Bereaved Parents

• Communication
  – Details about what to anticipate at EOL
  – Open and honest
    • Don’t sugarcoat
    • “seemed like…they didn’t want to say the whole truth or made it seem better than it was.”
  – Information should be repeated to ensure understanding
  – Acknowledge and respect parent perspectives
  – Include siblings in a developmentally appropriate manner

Advice from Bereaved Parents

- **Compassionate Care**
  - Special patient population
  - Treat child as an individual
  - Interact with siblings
  - Importance of professional boundaries
    - 13yo sibling—“You can get close to your patient, but don’t get really, really close...just close enough to know their name and what they do. Because if you are really, really, really close...then you’ll be sadder in life, ‘cause you’ll be treating them like they were your own.”

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Advice from Bereaved Parents

- **Resources**
  - Financial assistance
  - Respite care
  - Formal support services/support groups
  - Support for siblings
- **Research**
  - Continued research focusing on disease & grief responses
- **Praise for Hospitals, HCPs & Research**

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Advice from Bereaved Parents

- **Continuity of care**
  - Communication between team members during hospitalizations
  - Communication during transitions between services or hospital units
  - Families’ desire to remain connected to staff after the death of their child
**Siblings & Grandparents**

• “The forgotten mourners”
• Grief is often neglected because the parents’ grief is the focus within the family

**Siblings**

• Response to the death of a brother or sister will vary depending on the developmental level of the sibling
  – Response will change as the sibling matures
• Survivor guilt
• Overprotection
• Idealization and the “Replacement Child”
• Assuming the Parental Role


**Grandparents**

• “Double pain”
  – Concurrently experiencing feelings of loss for their grandchild, as well as the pain associated with their own child’s grief
• “Cumulative pain”
  – Experience of pain from previous losses

• Mitigating factors
  – Acknowledging the deceased child and the grandparents themselves
  – Quality of the relationship w/bereaved son/daughter
  – Family dynamics
  – Support resources

Bereavement Support

• Anticipatory grief
  – Preparation of child and siblings
  – Reminiscing & memory-making activities
  – Religious & cultural rituals
  – Vigil trays

• Following death
  – Bereavement resources
  – Sympathy cards & phone calls
  – Review of autopsy results
  – Formal support groups & resources

• Duration of grieving

• Common parental fears
  – Abandonment by and loss of relationships with health care providers
  – Child will be forgotten


Helpful Phrases

<table>
<thead>
<tr>
<th>Helpful Phrases</th>
<th>Avoid...</th>
</tr>
</thead>
<tbody>
<tr>
<td>May I just sit here with you?</td>
<td>It was a blessing</td>
</tr>
<tr>
<td>Is there anyone I can call for you?</td>
<td>You have other children to think about</td>
</tr>
<tr>
<td>What might be helpful to you at this time?</td>
<td>I know how you feel</td>
</tr>
<tr>
<td>Would you like me to talk with your other family members, or be there with you when you talk with them?</td>
<td>This will make you a better/stronger person</td>
</tr>
</tbody>
</table>
Compassion Fatigue vs. Burnout

- **Compassion fatigue**
  - AKA Secondary traumatic stress (STS)
  - Closely parallels PTSD
  - Results from work with persons experiencing trauma or loss

- **Burnout**
  - Results from working in a stressful environment
  - Characterized by emotional exhaustion, depersonalization, and a reduced sense of accomplishment and achievement

Robins, et al. – 39% of participants were moderately to extremely high risk for compassion fatigue
- 21% or participants were at moderate to high risk for burnout
- Physicians had higher burnout scores compared to both nurses and mental health professionals

**Compassion Fatigue vs. Burnout**

- **Compassion fatigue**
  - Higher: more years in direct care, greater blurring of professional boundaries
  - Lower: greater cognitive empathy

- **Burnout**
  - Higher: more years in direct care, greater blurring of professional boundaries
  - Lower: nurses, mental health providers, cognitive empathy

- **Compassion satisfaction**
  - Non-trainee status, use of external coping strategies, greater cognitive and affective empathy, lower blurring of professional boundaries


**Self Care**

- **Focused reflection**
  - Journaling, listening to music

- **Seek support**
  - Talking with friends & colleagues, staff debriefings

- **Celebrate**
  - Holidays & special occasions

- **Engage in distractions**
  - Reading, exercise, vacation, humor


**Staff Debriefing**

- **Bereavement debriefing sessions**
  - Aimed at providing emotional support and increasing one’s ability to manage grief following the death of a patient

- **Keene et al.**
  - Johns Hopkins Children’s Center

- **Bateman et al**
  - PICU at Umass Memorial Medical Center
Staff Debriefing

- Common themes
  - Debriefings offered after all patient deaths
  - Timely (within 1 week of death)
  - Interdisciplinary participation

- "Conductor"
  - Review norms for the session
    - Come on time, finish on time
    - Participate in one's own way: no one forced to talk
    - Only one person talks at a time
    - Speak from an "I" perspective; don't assume any experiences or feelings of any other person in the room
  - Listens for themes & acknowledges them
  - Regulates the emotive temperature of the group
  - Regulates participation, allowing all to speak
  - Remains neutral and compassionate for the participants


Staff Debriefing

- Structure
  - Introductions
    - "How were you involved in care for this patient and family?"
  - Review case & time of death circumstances
    - "What was it like taking care of this patient?"
    - "What was the most distressing/satisfying aspect of the case?"
  - Emotional/Grief responses
    - "What have you experienced since the death?"
    - "What will you remember most about this patient/family?"
  - Coping strategies
    - "How are you taking care of yourself so you can continue to provide care for other patients/families?"
  - Review lessons learned


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The image contains text related to staff debriefing in the context of patient deaths, highlighting common themes such as the timing of debriefings and interdisciplinary participation. It also outlines the role of a "conductor" in a debriefing session, emphasizing the importance of maintaining structure and facilitating a supportive environment. The text includes references to academic sources that discuss the implementation and effectiveness of debriefing sessions in managing grief and supporting healthcare professionals.
Staff Debriefing

- Reasons for debriefing
  - Professional distress
- Most distressing aspects of care
  - Long term relationship with patient/family
  - Provided aggressive treatment while patient was dying
  - Unexpected death
- Most satisfying aspects of care
  - Working as a team
  - Being instrumental in helping a patient die respectfully
  - Feeling a sense of closure


Funeral Attendance

- Borasino, et al.
  - 71.9% had attended funerals
  - 2.5% thought that funeral attendance was inappropriate
- Serwint et al.
  - 23% had attended a patient’s funeral
  - 42% expressed fear of attending


Staff Debriefing

- Participation vs. Non-participation
  - Improved HCP perception of their ability to manage their grief
  - Improved ability to maintain professional integrity

Professional Boundaries

- Protect the space between the professional’s power and the client’s vulnerability
  - HCPs in a position of authority
  - Viewed as “experts”
  - Decisions based on knowledge
  - Time-limited


Professional Boundaries

- Red flags:
  - Providing a home telephone or personal cell phone number
  - Working extra hours as a favor for patients/families
  - Making personal visits or phone calls outside of normal working hours
  - Doing personal favors
  - Personally providing gifts, clothes, toys, meals
  - Inviting patients/families to social events or accepting their invitation to such functions
  - Maintaining personal relationships after the professional relationship has ended
  - Imposing one’s personal or religious beliefs or initiating unsolicited discussion related to religious matters


Professional Boundaries

- Social networking
  - Landman, et al.

- 64% General Surgery Residents &
- 22% General Surgery Faculty with Facebook profile

- 50% of profiles were “public” for anyone to view

- 31% displayed work-related postings
- 14% of those postings were patient-specific
- Several “inappropriate” postings

Professional Boundaries

- Social Networking Personal Guidelines
  - Monitor your online reputation
  - Understand the privacy settings of the websites you use
  - Remember your audience (intended & unintended)
  - Be aware of the permanence of online content
  - Maintain professional boundaries

References

- www.giftoflife.org
- www.nhpco.org
- Steel, et al. (2011). Bereaved parents and siblings offer advice to health care providers and researchers. Journal of Pediatric Hematology Oncology; 34(9): 823-9

References


References