Pediatric Palliative Care

Pediatric palliative care is about the journey that a patient and family are on when the child is not expected to survive through childhood.

- This journey may include aggressive and/or curative treatments.
- End of life care is only a part of palliative care.

Definition Of Pediatric Palliative Care

“The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.”

National Consensus Project for Quality Palliative Care 2009

Family Centered Care - Comparison of Principles

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<th>Family Centered Care:</th>
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<td>- Recognizes each family &amp; situation is unique</td>
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<td>- Open &amp; honest communication</td>
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<td>- Empowers families to be involved in their child’s health care journey</td>
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<td>- Acknowledges families as allies for providing safe, quality care</td>
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<th>Palliative care:</th>
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<td>- Helps families determine their goals of care</td>
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<td>- Help families identify things they can control about their child’s care</td>
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<td>- Focuses on the unique needs, hopes, beliefs of the family</td>
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<td>- Foster communication</td>
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<td>- Multidisciplinary team</td>
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The Palliative Care Model

Why talk about palliative care for neonates and infants?
- Infants under a year of age have the highest mortality rate of any pediatric group.
- Approximately 15,000 to 20,000 infants are born each year in the U.S. with conditions that could lead to death within the first year of life.
- Approximately 26,500 infant and child deaths per year
  - 56% of these were admitted to the hospital (ED deaths not included) 86% die in critical care units
  - 53% in PICU
  - 33% in ICN (Intensive care nursery)

Top 4 Common Childhood Causes of Death by Age

Infants: Congenital anomalies
- Low birth weight
- Sudden Infant Death Syndrome
- Complications of pregnancy

Age 1-4: Accidents
- Congenital anomalies
- Malignant Neoplasms
- Homicide

Age 5-14: Accidents
- Malignant Neoplasms
- Homicide

Age 15-24: Accidents
- Homicides
- Suicides
- Malignant neoplasms

Some Palliative Issues unique to Pediatrics

Sibling emotions
Sibling Bereavement
Extended Bereavement
Family Crisis
Growth and Development
Pre-natal diagnosis
Fears of Parent
Parental Role
Societal Expectations
Redefining "normal" life for patient/family
Extended family, grandparents

A NICU Case Study - "The Gray Zone"

- Baby Girl Smith
  - Birth at 37 weeks gestation
    - 1650 gm at birth
  - Mother 40 yo G5 P5
  - APGARS 3, 7, 7

- Prenatal studies abnormal
  - U/S, fetal echo, and MRI- suspected AVSD and agenesis of corpus callosum

- No genetic testing done prenatally
- Postnatal- multiple anomalies including:
  - SGA, TEF/ EA (long gap), VSD, bicuspid aortic valve, thickened pulmonic valve, Ni brain, M halsery, dysmorphic facies
  - Surgery on DOL #1 to ligate TE Fistula and place G-tube

- DOL #2 Chromosomes confirmed Trisomy 18

Case Study - BabyGirlIS continued

- Diagnosis and prognosis presented to parents in several discussions over the next few days; including info that 95% of T18 babies die by 1 yr of age.
- Withdrawal of support and Allowed Natural Death was recommended.
- Full care conference held with multiple specialists and parents. Message reinforced that there were no surgical options to offer unless she survived for several months and that surgeries wouldn’t change the prognosis.
Case Study- Parents’ Decision

- Parents denied wanting extreme measures like tracheostomy and ventilator support
- However, parents wanted to give BabyGirlS every opportunity to live, to try to get to the point of full surgical repair, and then go home.
- Parents moved whole family into Ronald McDonald House as mom home schooled the siblings. Parents visited daily and were very involved with BabyGirlS’s care.

Isolation

- Child and family often must leave their home community for their child’s care
  - Loss of home support
  - Additional stresses of living apart
  - Job stressed
  - Financial stresses
  - = crisis

Case Study- Outcome

- BabyGirlS did come off of the ventilator going between NC and NCPAP. She always tolerated GT feeds.
- At 3 months, she developed e.coli urosepsis. Infection was successfully treated but BabyGirlS continued to need increased O2 on NCPAP, remained febrile and agitated.
- Intubated 3 wks later. Echo showed Cor pulmonale.
- Allow Natural Death code status ordered 5 days later. Withdrawal and death occurred 2 days later.

Challenges to providing Palliative Care in the NICU

- ICU environment and health care team beliefs
- Very difficult to predict outcomes with neonates
- Inconsistent communication
- Parents level of understanding, grief, denial...

Probably the biggest challenge...

... is when the parents and the medical team are not on the same page.
This can lead to frustration for families as well as the medical team. The family may feel they aren’t being heard and the medical team may consider the parents to be unreasonable or overly optimistic.
Understanding Parental Advocacy when facing non-curable illness

- One of the primal instincts of a parent is to protect their child. In modern culture, this translates to advocacy.
- Parents who are not given the choice to care for their child by focusing on quality of life, will choose “everything” rather than “nothing”.

What are the parents thinking?

- Parents may believe that doing anything less than the maximum available technology makes them bad parents.
- They may view stopping treatment as abandoning their infant.
- They may misunderstand and believe that it is the withdrawal of treatment that causes death rather than the underlying medical condition.
- Parents may believe that it is only for God to decide one’s time of death.
- There are few absolutes in medicine. The parents believe that this uncertainty means there is always hope.
- Parents may feel that by agreeing to limit treatment that this suggests that they don’t have enough faith.

The New Normal for New Parents

What is normal when you have never known anything else?

Neonates for whom Palliative Care should be considered

- Neonates born with lethal congenital anomalies.
- Neonates at the limit of viability.
- Neonates who are not responding to aggressive medical and/or surgical therapy or for whom treatment may prolong suffering and postpone anticipated death.

(Bhatia, 2006)

Lethal anomalies

Prolonging life, prolonging dying

Thirty year trend is for “children with non-neoplastic, chronic, progressive, life threatening illnesses to live longer, and for their deaths to occur less suddenly and often to be delayed with significant extension of life. This creates more of a need and opportunity for palliative interventions.” (Bartell and Kissane, 2005)

Palliative goal is to add meaning and reduce suffering during this time.

Pediatric Palliative Care

Helping children and their families through the difficulties of an advanced illness - five areas of care provide support:

- Relief of Pain and other Symptoms
- Supportive Care
- Advanced Care Planning
- Coordinated Communication
- Bereavement
Relief of Pain, Continued Caring

• Relief of pain and other symptoms-
  – Important
  – Beyond the scope of this presentation
• Continued supportive caring
  – Focus on sharing the journey with the family
  – The “Ministry of Presence”

Supportive Care

Continued caring

“When Rosario Maria was born with severe brain injury, she was given two days to live. She survived eight years. ... It was noticeable that when we finally decided to take the inevitable steps that would lead to her death, the medical staff stopped considering her as a priority.”

Rosaria Avila, Parent

Pediatric Palliative Care

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Advanced Care Planning

• Goal- Help patient/family to verbalize goals of care
• This is a process, not a one-time discussion to determine “code status”
• Items to discuss may include:
  – “I know your goal is cure, my goal is also cure. What other goals do you have for your child’s care”
  – What ways can parents show their love for their child when cure is not possible
  – What can parent control? What can medical team control? How can we help with what we can control.
  – How to maintain “hope” if cure is unlikely

Advanced Care Planning and Decision Making

Ethical decision making is
  – inextricably linked to the physician’s primary task
  – helping patients to choose the best interventions to meet their needs in specific situations
  – then providing patients with the best

Advanced Care Planning:

To guide the patient through the labyrinth of treatment choices, the physician and team are charged with integrating their
  – specialized knowledge about the illness, symptoms and treatment options
  – understanding of the parents’ goals and values

The patient with life-limiting illness are
  – frail and/or vulnerable
  – facing a complex medical system with little but their trust in their physician & team to guide them
Advanced Care Planning: Obstacles to decision making

- Uncertainty in prognosis
  - The patient’s course and prognosis seem to fluctuate from day to day, sometimes hour to hour
  - Fear of making a prediction that is not correct
- Patient unable to express wishes
- Uncertainty or resistance from other physicians

Advanced Care Planning: Ethical Considerations in Decision Making: Best Interest of the Child

- Amount of suffering; potential for relief
- Severity of dysfunction and potential for restoration of life
- Expected duration of life
- Potential for personal satisfaction and enjoyment of life
- Possibility of developing the capacity for self determination

Advanced Care Planning: Best Interest Standard

- Stakeholders may differ in what is the “best interest.”
- Those who bear the burden should have a major role in the choice. (IPPC, 2003)

Advanced Care Planning: Allow Natural Death

- Preferable language to DNR
- Replaces language that implies that providers are withholding a potentially helpful treatment
- Focus on natural process - health care providers cannot prevent death for many conditions, death is not under our control

Allow Natural Death Communication

- “Allow Natural Death” is not just a change in language
- It should help physicians communicate with families about the potential benefit versus burden of resuscitation
- Communication/documentation tools helpful

Exploring Choices to make Care Decisions
Wouldn’t it be nice

If all babies came with directions
And sick babies came with a sign that said
“Go this way”

Advanced Care Planning: Competing Goods

• Most ethical conflicts are not about what is right and what is wrong but arise from competing goods.
• Alleviation of suffering and quality of life may be competing goods.
• Quality of life and preservation of life may be competing goods.

Advanced Care Planning: Parents need guidance

• Child’s illness puts parents under extreme stress
• Information can be fragmented if different specialties involved
• Parents know their child the best and are the best advocates, however…
  – Decision-making process can be clouded by denial
  – Parents are at a vulnerable time and can be “pushed” by the “experts” into interventions they do not want for their child

Advanced Care Planning: Parents need guidance

Family Centered ≠ Family Directed

Advanced Care Planning: What are the goals of care?

• Weigh the benefit and burden
• Include an assessment of the social, spiritual and psychological goals
• If cannot meet the first goal, what is the second goal?

Case Study Two “The Easy Case”

• CC was born at 34 wks gestation
• Suffered a huge intracranial hemorrhage that devastated his brain
• Massive amounts of blood in ventricles
• Prognosis- neurologically devastated, on vent, not initiating sustaining respirations on own
• If withdraw vent- death expected immediately
Case Two- "routine" case for NICU Why Involve Palliative Care Team?

- Why “easy” case- the parents and medical team agree
- Parents and team decide to withdraw vent
- Palliative Care consulted (parents request- not usual in this scenario)
- Memory making, parents hold child in special room overnight as he is expected to die

Case 2- Decision Making and Disposition

- Parents & medical team decide to place NJ
- Parents want to take CC home
- Hospice Consulted
- CC goes home after 12 days in NICU
- Pediatric Hospice Involved

Case 2- continues

- CC does not die overnight
- He is breathing adequately, moved back to isolette
- Next issue- decision making about feeding
  - Refluxes and vomits NG feeds
- Parents goal is comfort- decision making-
  - continue NG feeds, despite side-effects and risks
  - NJ tube, but need continuous pump and parents want to cuddle him without equipment
  - G-tube surgery?

Case 2 continues- to present

- CC does well at home
- Palliative Care team follows along with CC’s care and Hospice Team
- Palliative Care Team has parents’ trust, thus insights and guidance in further parental decision-making dilemmas
- CC is age 6 months, prognosis is now > 6 months so hospice not appropriate
- Palliative support, decision-making, goal setting and pain and symptom management continue

IT IS OUR JOB TO:

Help Parents Articulate their Goals
and
Share the Moral Burden of Decision Making

“Sometimes, being the very, very best parent -- which is what every parent wants to be -- does not mean fighting to cure, but fighting to do the best you can for your child’s quality of life...”

Ann Goldman
Great Ormond Street Hospital, London
The death of a child will never be easy to accept... Nonetheless, health care professionals... and others can do much to save children and families from preventable suffering.

(Pediatric Palliative Care)

Helping children and their families through the difficulties of an advanced illness - four areas of care provide support:
- Relief of Pain and other Symptoms
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Communicating with Parents

“Palliative care includes, not only symptom management, comfort care and family services, but also the timely delivery of information regarding diagnosis, prognosis, treatment effectiveness and burden of...”

Coordinated Communication

“What is happening to me/my child?”
“What are our choices?”
“How will you help?”

(Pediatric Palliative Care)

Coordinated Communication: Obstacles to communication

• Communication with families
  - Not enough time
  - Not reimbursed
  - Families may not want to hear news
  - Fear of family reaction or family denial
  - Fear that family’s anger (at the situation) will be projected onto the medical providers
Bereavement

- Anticipatory grief and loss is pronounced, grieving the loss of a healthy child from diagnosis.
- Bereavement is longer because of “out of season” nature of childhood deaths, parents grieve the future their child never will have
- Sibling bereavement

When should Palliative Care take on a larger role?

When palliative care and curative care are initiated simultaneously, families and caregivers will reach a point when there is a realization that the baby isn’t going to get better - the fork in the road. (Stokowski, 2010)

The Fork in the Road

Dr. Catlin offers these guidelines to help with making a decision to transition to end-of-life comfort-focused care:
- All appropriate curative attempts that are available have been tried
- There are physiological processes that can’t be altered
- Altering the physiology would not change the lethal prognosis
- Recognizing that there are infants that are going to die and that their death is not a reflection of failure by the neonatal care providers

Pediatric Palliative Medicine - some children need end-of-life care

“When a child dies, it is always out of season. When a child dies, dreams die and we are all diminished by the loss of human potential. Although dying is a part of life, a child’s death, in a very real sense, is unnatural and has a devastating and enduring impact. Nevertheless, we all have a mandate to ensure that their young lives do not end in preventable fear, pain and distress and that grieving families are comforted.”

Richard E. Behrman, M.D.
Committee Chair
IOM Committee on Palliative and End-of-Life Care for Children and Their Families