End-of-Life Care in the NICU

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What Pregnancy Means

- **Hope** – for the family, the future and the baby
- **Dreams** – of a good life
- **Future** orientation
- **Fulfillment**
  - of motherhood, womanhood, parenting
- **Value laden**
- **Joy**
What Comprises ‘GOOD’ Perinatal Palliative Care?

- People – Providers, Patients, Patient Families
- Place (Environment of Care)
- Physical Plant/Products (Equipment)
- Philosophy of Care
- Past Experiences
- Proof
- Professionalism
- Protocols, Policies & Procedures
- Priorities
- Patterns & Processes of Work
As time passes, we still encounter the following myths expressed by the public (and some clinicians) concerning palliative care (as distinct from hospice):

1. If you accept palliative care, you must stop treatment...“if we never tried, we’d never be where we are today!”

2. Palliative care is the same as hospice...“the baby’s not dying, yet.”

3. Electing palliative care means you’re giving up...“we’re intensivists!”

4. Palliative care shortens life expectancy...“it’s a self-fulfilling prophecy”

5. There isn't need for palliative care because my doctor will address pain anyway... “you guys are always pushing morphine”
The Physician's Responsibility Toward Hopelessly Ill Patients

Wanzer, et al. NEJM 1984;310: 955

"Technology competes with compassion, legal precedent lags, and controversy is inevitable."
Medical technology has grown from being a tool to becoming a companion and, in some cases, the master of physicians. Examples:

- Imperative of possibility & action: Whatever is possible has to be done.
- Imperative of commitment: Once on the treatment train we cannot stop – we’re committed.
- Imperative of procedure attends to the complex procedural use of technology.
- Imperative of demand – an informed patient; or a physician’s own notion of what is demanded.
- Imperative of the unknown – we don’t like not knowing, so maybe technology will help.
- Imperative of a means as ends itself - we tend to seek technological solution/fix to all our problems
- Imperative of implementation; of proliferation; and of inappropriate use.
Inhaled Nitric Oxide Use in the NICU: Rising Costs & the Need for a New Research Paradigm


- RCTs have demonstrated the safety & effectiveness of iNO as a *Rx* for PPHN.
- Premature neonates do not clearly benefit from iNO either.
- Despite NIH & AAP consensus opinions to guide neonatologists practice...
  - The use of iNO among the most premature neonates is on the rise.
  - Increasing iNO use has evolved among neonates with CDH.
  - Based on current use/cost estimates these 2 practices may cost $196 to $236 million annually.
- At present, it is unclear *why* there exists such discordance between these 2 practice patterns and the evidence that is intended to inform them.

*Perhaps it is the case that some neonatologists, when facing these gravest of circumstances, initiate iNO therapy in an act of hopeful desperation...*

*It’s better to try something than to do nothing, even if it is unlikely to work.*
5 Inappropriate Applications of Technology

1. Technology is applied *unsuccessfully*.
   – *Technological methods are* applied in conditions that are too advanced to respond to intervention.

2. Technology may be used in an *unkind* manner.
   – *Example:* when applied to prolong life of poor quality & thus actually prolongs the process of dying.

3. Technology is applied *unsafely*
   – When used in situations where expected complications > anticipated benefits.

4. Technology is utilized *unwisely*
   – When it diverts resources from alternative healthcare activities that have better results.

5. Technology may be employed when it is *unwanted*.
   – When used against the wishes of the patient, and when the autonomy of the patient is not respected.
Technology and an Ethical Limit

“An ethics of nonpower is obviously that human beings agree not to do everything they are able to do.”

Ellul J. *The Ethics of Nonpower*. In, Kranzberg (1980). *Ethics in an Age of Pervasive Technology*
What is *Possible*, What is *Right*?

Parental Determination

Zone of Uncertainty

- Non-treatment obligatory
- Non treatment optional
- Treatment optional or investigational
- Treatment is obligatory

Risk Averse

Burden exceeds benefit

DON’T TREAT

Risk Tolerant

Benefit exceeds burden

TREAT

Where are *you* on this line? Whose *voices* are speaking?
Knowing the statistics is different than **understanding**
Neonatal-Pediatric Death Trajectories

**Health Status**

- **Good Health**
  - TIME (hours – days)
  - Sudden / Unexpected

- **Death**

- **Health Status**

  - Potentially curable, but with declines
  - (Extreme prematurity)

  - TIME (weeks – months / years)

- **Health Status**

  - Progressive (neuromuscular)

  - TIME (months – years)

- **Health Status**

  - Trisomy 13/18

  - TIME (hours – weeks)
3 Legal Criteria for Withholding or Withdrawing Treatment


1. Based on the present & future *quality of life* of the child
2. The inability of the present treatment to accomplish the ends for which it was originally initiated (*physiologic futility*), and

These legal principles may facilitate difficult ethical decisions.
WD/WH of Life-Sustaining Medical Treatments: Things to Attend To

• Provide compassionate, comprehensive, open and empathic communication about the child’s condition. Direct attention to the child but support the family, too.

• Engage in goals clarification along the trajectory of the illness and through the dialogue about what LSMT is acceptable/beneficial/not harmful or burdensome and is desired. Early conversations (anticipatory guidance) is preferable.

• **Values inventories, family histories, stories** and **religious beliefs** may all be important and warrant attention and understanding on the part of clinicians. However, no single factor will necessarily trump others as the reality of the present situation may never have been anticipated or imagined, or it may be so unique that the focus on the child’s comfort ultimately reigns supreme.

• **Address the concept of starving**, any experience or stories that imbue this word with inapplicable meaning in the context of the child’s dying need to be openly discussed.

• **Address the issue of time** and how withdrawal of ANH, unlike a ventilator/other LSMT, may not result in an ‘immediate’ death. But clarify that the removal of the ANH (or the ventilator for that matter) is not to bring about the death, it is to remove a burdensome, non-beneficial intervention that cannot attain its intended goal – and provide for unencumbered time.

• **Address pain** as evidence suggests that some parents believe it is inherent in the context of withholding ANH (and may be attached to the term ‘starving’ with attendant moral weight.

• **Decisional regret** is mitigated when parents are involved and respected in the decisional process.
The 8 Domains of Palliative Care

- Physical Care: Pain and Symptom Management
- Psychological & Emotional Aspects
- Social Aspects
- Spiritual & Existential Aspects
- Cultural Aspects
- Ethical Consideration
- Structure & Process of Care
- Care of the imminently dying

What if the Family “Demands” *Everything*?

- When hearing “Do everything!” take time to explore what *everything* means...
  - Everything available?
  - Possible?
  - Imaginable?
  - Beneficial?
  - That will help, but not hurt?
  - That you would do, or want, if this were your child?

- In other words, what (or who, or where) does this demand come from?
  - You may need to enlist the help of an ethics consultant, chaplain, colleague rendering a 2nd opinion, or even a palliative care consultant


**TABLE 1**

*Reasons That Some Families May Demand Apparently “Inappropriate Care”*

- Failure to comprehend prognosis.
- Religious beliefs about end-of-life decisions.
- Religious belief in miracles.
- Lack of confidence in medical diagnosis or prognosis.
- Belief that more can be done.
- Secondary gain.
- Disagreement about seriousness of outcome.
A Narrative Account?

- Perhaps an insistent demand for “everything” might reflect something else?
- Room for inquiry: ASK – LISTEN – ASK
- Are people “writing the story” that they are going to live with after the child is gone?
Perinatal Palliative Care

- Prenatal Diagnosis
  - Discovery
- Questions & Research
- Coping & Choices
  - Anticipatory Grief
  - Support
- Birth
- Life & Love
  - Learning What is Needed
  - Letting Go
- Bereavement
When Evy Kristine died there was a hailstorm, it was as if the Angels cried.
Challenges of symptom management

- Pain assessment & management
  - So many scales, which do I use?
  - Opioids & Adjunctive measures
- Seizures, myoclonic jerking & neuro-irritability
- The Death Rattle – Secretion control
- Intubate?
- Compassionate extubation
  - Managing the withdrawal & air hunger
- Skin & mucus membrane care
- Medically provided nutrition & hydration
Anabelle Grace

- Prenatal diagnosis
- Anticipated early death
- Discharge to hospice
- Lived
Re-accommodation and Re-goaling

- Dream(s)
  - What we aspire to & dream of
    - Pregnancy
    - Parenthood

- Realities & Events
  - Life Happens
    - Infertility
    - High-risk Pregnancy
    - Premature Birth

- Accommodate & Negotiate
  - Adjustment to the “new normal”
  - Negotiating a way forward

- Fact Finding
  - Learning about the condition
  - Learning to live with the news
“As sickness progresses toward death, measures to minimize suffering should be intensified. Dying patients require palliative care of an intensity that rivals even that of curative efforts...even though aggressive curative techniques are no longer indicated, professionals and families are still called on to use intensive measures - extreme responsibility, extraordinary sensitivity, and heroic compassion.”

Caring for Each Other

• Recurrent exposure to stress takes a toll
• Compassion satisfaction – a motivator
• Compassion fatigue – can we recognize it?
• Contributions of moral distress/angst
• Burnout (this job is the problem)
• Depression (I am the problem)
• Staff turnover/loss
• Suicide?
Strategies to Help

• Education
• Activities
• Self-care
• Appreciation or Staff Recognition
  – Sunshine Awards
  – Daisy Awards (IPFCC)
• Respite
  – Staff cross-covering
  – Time off for Funerals
  – Hospital Memorial Services
• “Good Mourning”
• “Tea for the Soul”
• “Comfort Carts”
• “Care Baskets”
Honesty matters.

Decisions are not the sole purview of the physician. To decide requires information – not the least of which is an end, or goal, of care for which decisions are being considered. Parents can, and desire to, make decisions for their child with the input from the clinical team. This is true even, perhaps especially, when decisions to limit or withdraw life-support are being made.

The NICU is a community; in it, we need to take care of each other. In so doing, we provide a space in which thoughts, words and actions can provide comfort and care for parents and staff, as well as babies, when needed. While the physical space may enhance a good environment, that environment first is set by the tone, posture and sensitivity of the people present.

Language matters. What is said cannot be taken back, and professionalism requires that self-interest be subsumed to patient-family interests, especially in such critical times and environments.

Presence is of utmost importance. Physicians, nurses, chaplains, social workers, child-life specialists and others can 'bear witness' through perinatal loss, and parents value this.

The interdisciplinary clinical team contributes to parental coping. This is true when nurses support families at the bedside, physicians conduct autopsy reviews and conferences with parents, chaplains/clergy assist with interpreting suffering & loss or assigning meaning, social workers aid parents in getting on with daily life and bereavement staff assist parents with bereavement support. Sometimes we may not always be cognizant of how we help parents cope.
“There are no great acts, only small acts with great love”

Mother Teresa
The following presentation is taken from the LCPC Symposium 2016:
When Caring Never Stops – Meeting the Needs of Vulnerable Babies