

Medical Ethics in Neonatal Care

Nicole Cacho D.O., M.P.H.

In a nutshell

- Balance of values and what is best for an infant who cannot express their own interests and values

Buzz words

- Best interests
- Values
- Moral
- Obligation
- Suffering
- Quality of life
- Decisions
- Human life
- Hope
- Love
- Faith
- Withdrawal
- “Everything”
- Communication
- Empathy
- Authority

Ethics

- Metaethics: where are ethical principles come from? What do they mean?
- Normative ethics: Arrive at moral standards that regulate right and wrong conduct
- Applied ethics: examining specific controversial issues such as abortion

Ethical issues

- Moral dilemma (physician feels there is an obligation to pursue more than one conflicting courses of action- example is conflict between action required by the principle of respect for autonomy and action required by the principle of beneficence-CPR of the dying ex 24 weeker with post hemorrhagic hydrocephalus). I don't agree but I want to respect the parents autonomy
- Moral uncertainty (presenting issue is unclear, pulmonary hypoplasia-terminate or not) what do you tell the parents? Are you sure? Is that the right decision?
- Moral distress (limits of viability) I do not agree with doing "everything"

Principles in Medical Ethics

- Autonomy “right of competent patients”
- Beneficence “do good”
- Nonmaleficence “don’t inflict harm”
- Justice “social cooperation”

Autonomy

- Respect that can be achieved by including parents in decision making with a trusting parent-physician relationship
- If parents wishes are unreasonable this may be challenged
- Not to resuscitate a 25 weeker who is AGA with maternal steroids

Beneficence

- Promote the best interests of the newborn
- Moral and legal standard of judgment that helps to establish the primacy of duties to infants, ensuring they be regarded as fully human individuals with interests, even when clearly unable to express their own value system

Nonmaleficence

- First do no harm
- Harm is generally interpreted as physical harm. Especially pain, disability or death
- No initiation or continuation of treatment be considered without regard to infants pain, suffering and discomfort
- In situations in which a treatment is perceived as overly burdensome or harmful without foreseeable benefit, it should not be undertaken

Justice

- How social benefits such as health care, are distributed via justified norms that are the product of human choices and value
- Broader view is to promote the greatest good for the greatest number for the distribution of resources (macro allocation)
- Narrower view is to provide equality of opportunity to each individual (micro allocation)

Communication with Parents

- The manner in which information is communicated influences parent' understanding of the situation, their ability to discuss moral issues and values openly and their ability to participate effectively in a decision-making process.
- Transparency in communication is crucial

Deliberative-interactive model

- Provide parents accurate and timely info
- Encourage and empower them to identify values and treatment preferences
- This model of relationship respects parental authority, encourages the physicians expression of his or her own clinical judgement and in doing so promotes the best interests of the newborn and the family

Use of interpreter

- Ensures parents views are available to the health care team
- Removes the burden on family members or friend of the transfer of information
- Limits potential for miscommunication

Prognostic uncertainty

Approaches

- 1) Statistical
- 2) Wait-until-certainty
- 3) Individualized prognostic

Objective

- 1) Avoid enhancing survival when profoundly poor
- 2) Treatment for every infant
- 3) Combination of 1 and 2

Moral Obligations: Physicians vs. Nurses

Physicians: Decision making with parents

NICU nurses: process and moment immediately surrounding death

- According to Storch and Kenny, a “shared moral work” is needed.
- Interprofessional practice implies that individual practitioners are aware of their own professional values and the need to work collaboratively, build understanding and work toward resolution with other professionals particularly when different perspectives threaten team function

Clinical Applications

- Refusal of treatment during pregnancy:
Principle of Autonomy prevails for mother
- Limits of Viability: Prenatal consult
 - Data + values → shared decision with med team
 - Neutral information model vs. Assent model

Withholding and Withdrawing

- Withholding: choice to omit treatment that is not considered beneficial
- Withdrawal: choice to remove treatment that has not achieved its beneficial intent

For many families there is a huge distinction, but morally these two choices are the same

Choice is usually based on:

- 1) Inevitability of death
- 2) Ineffective treatment
- 3) Poor quality of life (23%)

*These should be cited instead of futility

Withholding and Withdrawing

- When decision is made by family
 - Open discussion about the manner of death
 - Option for parents to be present
 - Performance of religious rituals
 - Anticipated grieving process
 - Supports available for bereaved parents

Providing analgesia

- Most physician provide opioids with the intent to alleviate pain and promote comfort
- May have “double effect” described by Partridge and Wall
- Groningen protocol in Netherlands, rare cases, legalizes deliberate ending of life in newborns with extremely poor prognosis

Artificial hydration and nutrition

- If baby cannot eat by mouth
- Is hydration and nutrition provided via other routes a medical treatment or an obligatory part of simple humane care?
- Artificial nutrition via NG tubes, IV needles, or surgical placement of Gtube are invasive to some extent and carry medical risks
- Most agree that artificial nutrition is a medical treatment and that it should not be held to a higher standard than other forms of life-sustaining treatment.

Cases

- Baby Doe
- Roe vs. Wade
- Feeding tubes

Goal of care

- Explore what underlies parents wishes
- Evaluate the complexity of the situation
- Underlying parental fears (abandonment)
- Balance between respect for parental autonomy and the physician's role and responsibility in any decision-making process
- Requires: insight, empathy, and great analytical and communication skills

Cases in our own NICU

- Withdrawal in a baby of with prenatally undiagnosed complicated heart defect-baby lived for a few days
- “Doing everything” for a 22/23 weeker when parents did not agree
- Surgery vs. no surgery on a PDA dependent congenital heart disease miracle baby
- Discharging neurologically devastated patient on hospice with no feeding tube
- Continuing care in a patient with Wolf-Hirshorn Syndrome IUGR, congenital heart disease
- CPR (per parents request) in a dying 24 weeker with post hemorrhagic hydrocephalus and NEC

Pearls

- Say the word “die”
- Ask “how would you like your son/daughter to die?” Encourage holding
- Ask why
- Tell the parents there is no right or wrong answer
- If parents want comfort care try with all your might to push for this!
- Never take away hope...because babies will surprise you