Helping Families Make Difficult Decisions

Spokane Perinatal & Neonatal Conference
Spokane Valley, Washington
October 19-20, 2017

Jonathan M. Fanaroff MD, JD
Professor of Pediatrics
Case Western Reserve University School of Medicine
Co-Medical Director, NICU & Director, Rainbow Center for Pediatric Ethics
Rainbow Babies & Children’s Hospital – Cleveland, OH

Objectives

• Characterize ethical conflicts between parents and providers surrounding the care of critically ill infants
• Demonstrate strategies that promote communication between members of the healthcare team
• Apply approaches to improve communication between parents and providers

Yann Forget
Clinical Situation

- Ronnie is a 10-day old 23 5/7 week male whose birth weight was 522 grams.
- Pregnancy was complicated by poor prenatal care (2 visits) and a history of placental abruption.
- Mom got betamethasone 10 minutes prior to delivery

Clinical Situation

- Rupture of Membranes was at delivery with foul smelling fluid.
- Vaginal delivery
- Apgars 1 / 4 / 410
- Intubated in the Delivery Room

NICU Course

- Central Nervous System (CNS)
  - Initial head ultrasound was negative
  - Day 7 head ultrasound = Grade II IVH on the Right
- Respiratory
  - Severe Respiratory Distress Syndrome (RDS)
  - Pulmonary Interstitial Emphysema (PIE)
  - Respiratory failure:
    - On high amount of ventilatory support & 65% oxygen
- Cardiovascular
  - Blood pressure stable
  - Trivial Patent Ductus Arteriosus on ECHO
NICU Course

- Fluids / Electrolytes / Nutrition
  - Receiving Total Parenteral Nutrition (TPN)
  - Mom refused to provide milk and would not consent to donor milk. Premie formula was started on DOL 2 but trophic feeds were not tolerated and feeds were held. Currently NPO.
- Hematologic
  - Anemia requiring blood transfusions
- Sepsis
  - On Vancomycin / Gentamicin / Acyclovir

Code Status

- DNAR (Do Not Attempt Resuscitation)
  - No chest compressions
  - Ventilatory support is not to be increased significantly in the event of further decompensation

Social Situation

- Ronnie’s parents married 1 week after he was born.
- Mom is 37
  - 2 grown children
- Dad is 49
  - 1 grown son
- Together they have a 2 year old daughter
Social Situation

- In the Social Work Consult it is noted that the parents “appear to have a limited understanding of baby’s medical issues.”

Ethical Situation

- Initially parents were in favor of aggressive treatment for Ronnie.
- They were visiting, but the visits were described as limited in number and brief.
- After obtaining an update on Thursday, the parents did not contact the NICU until Monday.
- They got married on Friday.

Ethical Situation

- On Monday the parents stated their wish to withdraw support, telling the neonatologist that they don’t want him to suffer.
Ethical Situation

- The medical team is somewhat ambivalent about this sudden request by the parents to withdraw.
- The neonatologist notes that the initial head ultrasounds were negative and that the patient was reasonably stable until five days ago.

Ethical Situation

- Jill, one of the primary nurses, is “upset” about the short visits and intermittent contact of the parents.
- Jen, the other primary nurse, is “sad” about the situation, although she feels withdrawal may be in Ronnie’s best interests.

Objectives

- Characterize ethical conflicts between parents and providers surrounding the care of critically ill infants
- Demonstrate strategies that promote communication between members of the healthcare team
- Identify approaches to improve communication between parents and providers
Types of Conflicts

- When Parents request care and Clinicians refuse to provide care
- Providing care against parents’ wishes (this case)
- Conflict between medical treatment and religious beliefs
  - Example: Blood transfusions
- Legal conflicts

Types of Conflicts

- Conflicts over particular treatments
  - Blood transfusion
  - Eye prophylaxis
  - Vitamin K
  - Newborn Screening
  - Vaccinations
- Research conflicts
- Conflicts between Services
- Conflicts within the Unit
- Personality conflicts - “I don’t want ____ caring for my baby!”
Balancing Considerations

Medical

Legal

Ethical

Core Ethical Principles

- Respect for the individual
- Autonomy
- Acting for the patient’s benefit
- Beneficence
- Avoiding unnecessary harm
- Nonmaleficence
- Truthful and fair treatment
- Justice

Newborns

- Patient autonomy is central to modern medical ethics
- Newborns obviously do not have competency to make decisions
- In the absence of a competent patient, surrogates are sought
- For newborns, the natural surrogates are parents
“[There is a] presumption, strong but rebuttable, that parents are the appropriate decision-makers for their infants.”

The President’s Commission for the Study of Ethical Problems in Medicine (1982)

**Surrogates**

- Speak for the incompetent patient
- Not an unlimited right
- Much different from someone making a decision for themselves
- Especially in children

“Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children.”

Prince v. Massachusetts 321 U.S. 158 (1944)
AMA Code of Medical Ethics - 2.215

The primary consideration for decisions regarding life-sustaining treatment for seriously ill newborns should be what is best for the newborn. Factors that should be weighed are as follows:

- The chance that the therapy will succeed
- The risks involved with treatment and nontreatment
- The degree to which the therapy, if successful, will extend life
- The pain and discomfort associated with the therapy
- The anticipated quality of life for the newborn with and without treatment

AMA Code of Medical Ethics - 2.215

Best Interests of the Child

- Parent’s role in decision-making
  - Important
  - Must be respected
  - But there are limits
- Health Care Professionals obligation to the child
  - Their first responsibility
- Known as the BEST INTERESTS STANDARD
**NOT Ethically Required**
(even if parents demand)

- **Provide** inappropriate treatment
- Harmful
- Of no benefit
- Futile
- Merely prolonging dying
- **Withhold** beneficial treatment

---

**Neonatology**

- Neonatology has always been about pushing boundaries
- Sixty years ago infants <1000g were classified as “stillborn”
- After Apgar scores introduced, changed to born alive but “pre-viable”
- With adaptation of mechanical ventilation in the 1970s, the edge of viability began to change
- With the changing of limits, the inevitable question

---

**How Small is too Small?**
How Small Is Too Small?

- From how small is too small to how much is too much. Ethical issues at the limits of neonatal viability.
- How small is too small? Considerations in evaluating the outcome of the tiny infant.
- For the 1980s: how small is too small?

The New York Times

Premature Babies May Survive at 22 Weeks If Treated, Study Finds

Continued Progress?

- Outcomes for high-risk newborn infants have greatly improved with advancing medical technology
- Is this true ????????????
The Downside of Modern Medicine

- It is now possible to keep some terminally ill, severely ill, or extremely preterm infants alive for long periods of time
- Dying/suffering may be prolonged
- Infant may survive with profound neurologic or other problems

Survival to Discharge Without Major Morbidity

Trends in Survival
The Treatment Dilemma

Severely Ill
Extremely Premature
Terminally Ill

Intensive Treatment
Comfort Care

Survival with an Acceptable Quality of Life

Obvious Choice

IN PART BECAUSE TREATMENTS WITHHELD
Survival with Significant Neurodevelopmental Disability
Death

The Treatment Dilemma
Categories of decisions

1. When early death is very likely and survival would be accompanied by a high risk of unacceptable severe morbidity

   Intensive Care is **NOT** indicated

Categories of decisions

2. When survival is likely and risk of unacceptably severe morbidity is low

   Intensive Care **IS** indicated

Categories of decisions

3. When the prognosis is uncertain but likely to be very poor and survival may be associated with a diminished quality of life for the child

   Parental **Desires** should determine the Treatment Approach
Strategy for Care - Factors

- Infant's physiologic maturity
- Infant's medical condition
  - Serious birth defects
  - Medical complications
- Probabilities of death and severe disability based on the best available data

Benefits versus Burdens

Neonatal Resuscitation Program

- “In most circumstances, it is ethically and legally acceptable to withhold or withdraw resuscitation efforts if the parents and health care professionals agree that further medical intervention would be futile, would merely prolong dying, or would not offer sufficient benefit to justify the burdens imposed.”

Neonatal Resuscitation Textbook
7th edition (2016)
Objectives

✓ Characterize ethical conflicts between parents and providers surrounding the care of critically ill infants

• Demonstrate strategies that promote communication between members of the healthcare team

• Identify approaches to improve communication between parents and providers

Team Work

Team Based Approach
Team Meeting

Team Members
- Nurse Practitioners
- Social Workers
- Dieticians
- Pharmacists
- Residents
- Fellows
- Clergy
- Primary pediatrician
- Obstetrician
- Ethics

The Primary Nurse
- Has spent the most time with the family
- Highly trusted by the family
- Has spent the most time with the patient
Primary Attending

- Families need and want to relate to one physician
- Ideal traits
  - Maturity
  - Sound judgment
  - Experience
  - Empathy

Team Meetings

- Organize clinical information
- Incorporate subspecialist findings
- Synthesize the parent’s day-to-day encounters with various members of the team

The Skill of Communication

“Don’t worry about missing that class. You can’t learn ethics or compassion. You either have ‘it’ or you don’t.”

“A new study published in this month’s issue of Academic Medicine proves that effort does matter and that learning is possible. Even established clinicians can be re-inspired to adopt new humanistic skills, becoming better teachers and role models in the process.”

“The Hidden Curriculum of Medical School” by Pauline Chen. NY Times 1/29/09
The Skill of Communication

“Health care communication is a critical, but generally neglected, component of pediatric and pediatric subspecialty practice and training and is a skill that can and must be taught.”


Communication Skills – Three Broad Domains

- Communication with the patient
- Communication about the patient
- Communication about medicine and science

Macy Initiative in Health Care Communication
Acad Med 2004 79(6):511-520

Improving Communication Skills

- Keep up on the literature (Read about it!)
  - Evidence based descriptions
  - Conferences / Lectures
- Simulation exercises (Practice it!)
  - Practice skills and receive feedback
  - Videotaping and review
- In vivo (Just Do It!)
  - Regular reinforcement by preceptors and application of skills during patient encounters

Gordon B. Assessment of Physician-Patient Communication Conference
Introspection

- Self-examination of your feelings
- Pressure to “succeed” in American Culture & NICU
- Death feels like failure
- In addition to personal feelings of failure, the medical team is often attacked by the family or relatives

Objectives

- Characterize ethical conflicts between parents and providers surrounding the care of critically ill infants
- Demonstrate strategies that promote communication between members of the healthcare team
- Identify approaches to improve communication between parents and providers

ICU Family Centered Communication & Support

- Communicate early and frequently
- Train practitioners in meeting facilitation and conflict management
- Use open-ended questions and have the families repeat info back
- Be hopeful but honest and clear; acknowledge uncertainty

ICU Family Centered Communication & Support

- Discuss likely and hoped-for outcomes
- Use numeric terms when describing probabilities; use drawings and models
- Provide timeframes for improvement and future discussion
- Families should participate in clinical bedside rounds and caregiving for their child
- Should they be able to stay with their child during invasive procedures?


ICU Family Centered Communication & Support

- Listen to and involve the nurse, chaplain, and social worker in the information loop
- Open visitation, including sibling visitation
- Consistent caregivers; if this is not possible, ensure consistency of the message


ICU Family Centered Communication & Support

- Inform parents promptly of transitions, such as a change of location, condition, treatment plan, assignment of attending physicians or residents
- Shared decision making rather than autonomy; encourage the parents to involve their family, friends, and medical home pediatrician to help them to understand information and make decisions

ICU Family Centered Communication & Support

- Written, audio taped, and computerized education for families
- Discussion and support of coping mechanisms, including religious and spiritual values
- Initiation of palliative care at the time of admission

The Family Meeting

“A decision to withdraw life supports or limit resuscitation in a newborn tests the basic sense of trust between the parent and physician. The elements of this trust – the physician’s honesty, medical experience, warmth, ability to listen, empathetic tone, and commitment to the family – in sum hold the parents through the agonizing process of facing loss, decision making, and grieving.”


Facing the Family

- Culture
- Religion
- Intimacy
- Coping

Traditions

Facing the Family
Care of the Parents

- The parents must mourn the loss of their expected normal infant
- Parents are sometimes reluctant to become attached to their baby if they do not believe the baby will survive
- Decreased visitation
- Hesitant about physical contact

Multiple Traumas for NICU Parents
1. Early Delivery (often Unexpected)
2. Seeing their own infant having traumatic medical procedures and life-threatening events. Witnessing other infants going through similar experiences
3. Serial bad news

Posttraumatic Stress Disorder & NICU Parents

Shaw et al. The Relationship Between Acute Stress Disorder and Posttraumatic Stress Disorder in the NICU. Psychosomatics 50:2, March-April 2009
Stages of Grief

- Denial
- Anger
- Bargaining
- Grief
- Acceptance

Anger

- The most difficult aspect of the loss
- The family cannot blame their infant
- The family feel desperate to help, but can do little or nothing to help
- They often displace their anger onto the pediatric staff
- The anger is often focused on one member of the staff
- Tolerating this anger, not taking it personally, is difficult

Coping Strategies
Parents of the Critically Ill

- Focus on the positive (hope)
- Minimize the significance of the information
- Preoccupation with medical details
- Support - family, friends, and clergy
- Religious faith
- Hostility, depression, irritability
Key Ingredients of the Family Meeting

- Focused Setting
- Sincerity & Empathy
- Truthfulness & Honesty
- Listening

The Family Meeting Focused Setting

- Quiet
- Comfortable
- Private
- Pagers and Cell phones off
- Tissues available
- Translator if needed

Language Access Services must be provided

- JCAHO requires that an organization “respects the patient’s right to and need for effective communication.” (Standard RI.2.100)
- JCAHO requires that an organization “provides interpretation (including translation) services as necessary.” (RI.2.100, Element of Performance 3)
- Organizations are required by law to provide language access services to individuals who have limited English proficiency (Title VI of the Civil Rights Act of 1964)
Family Meeting

- Encourage an open atmosphere
- Articulate goals and objectives
- Describe treatment options
- Construct decision-making framework
- Delineate applicable principles
- Propose a range of acceptable options

Lapuma & Schiedermayer. Ethics Consultation: A Practical Guide

Family Meeting

- Show caring, compassion, and a sense of connection to the patient and the family
- Use the child’s name / get the gender right
- Pace the discussion to the parents’ emotional state; do not overwhelm them with information
- Do not use jargon


Family Meeting

- Name the illness and write it down for the parents
- Ask the parents to use their own words to explain what you have just told them to confirm effective transmission of info.
- Address the implications for the child’s future

Family Meeting

- Acknowledge their emotions and be prepared for tears and a need for time
- Be willing to show your own emotion; aloofness or detachment is offensive
- Give parents time to be alone to absorb the information, react, and formulate additional questions

Ronnie’s Family Meeting

- Mom
- Dad
- Primary nurse
- Nurse practitioner
- Charge nurse
- Neonatal Fellow
- Social Worker
- Neonatologist
- Ethics
- Social Worker
- Neonatologist
- Ethics

Ronnie’s Family Meeting
Mom’s Perspective

- Feels that withdrawal “would be best for [Ronnie]
- Concerned about his medical problems and their complications.
- She doesn’t “want him to suffer, now or in the future.”
- She has a handicapped sister.
- She was surprised that he had survived this long and had limited her visits to protect herself.
Ronnie’s Family Meeting
Dad’s Perspective

- Agrees with mom that he doesn’t “want him to suffer, now or in the future.”
- He is worried about “what is going to happen down the road” and notes that it is “rough” to make this decision.
- He states that he has been doing a lot of praying and that he hopes [Ronnie] “will understand and will forgive him.”

Ronnie

- Everyone noted how difficult this decision was, especially at ten days of life.
- Some members of the team had reservations about withdrawal of support, but ultimately felt that the decision was within the range of appropriate decisions and should best be left to the parents.

Concluding Quote

“We expect that technology will necessitate ongoing revisions of the legal / ethical guidelines but that the clinical goals of decision making will remain interpersonal, intimate, humane, respectful, and sensitive to long-term emotional concerns.”