OBJECTIVES

1. Increase awareness of the unique considerations for pediatric ethics to address in the NICU.
2. Become familiar with valid ethical analyses beyond the common principle-based approach.
3. Examine three common sources of ethical concern in the NICU.

So, What Does Ethics Add? And How Does it Work?

<table>
<thead>
<tr>
<th>Principles</th>
<th>Virtues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficence</td>
<td>Courage</td>
</tr>
<tr>
<td>Nonmaleficence</td>
<td>Fidelity</td>
</tr>
<tr>
<td>Autonomy</td>
<td>Prudence</td>
</tr>
<tr>
<td>Parental Authority</td>
<td>Compassion</td>
</tr>
<tr>
<td>Justice</td>
<td>Temperance</td>
</tr>
</tbody>
</table>

Care Ethics — Nell Noddings (1984); Carol Gilligan (1982)

- Requires us to "recognize human encounter and affective response as a basic fact of human existence."
- Relationships & stories matter – and lead to concern & compassion.
- Solutions to a moral problem are found in relationships & empathy.
- This allows:
  - (a) finding new options (not clearly discernible before)
  - (b) interpreting a problem in a new, more plural way.
- In this approach, committed care would allow and favor “ethical creativity” and “practical wisdom”

A Narrative Account?

- Perhaps an insistent demand for “everything” might reflect something else?
- Being a “good [enough] parent”
- Room for inquiry... ask and listen
- Are people “writing the story” that they are going to live with after the child is gone?
- Have we been invited to read it? Help write it? What a privilege.
- If not, we cannot presume to do so.
Challenges in Perinatal Healthcare Ethics - 1

1. Ethical Issues Around Periviability
   - Definitions, meanings, and responses
     - Parental
     - Public & Policy-makers
     - Patient
     - Providers

2. Sensitivity to goals & values held by individuals
   - What is the “right” response in the “grey zone”
   - When might palliation/an approach oriented to comfort be reasonable?
     - What is ‘comfort care’?
     - Is there a role for advance directives?

Across NRN centers--Rysavy et al, NEJM 2015

<table>
<thead>
<tr>
<th>Completed gestational weeks</th>
<th>Rate of active treatment in delivery room</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>22%</td>
</tr>
<tr>
<td>23</td>
<td>72%</td>
</tr>
<tr>
<td>24</td>
<td>97%</td>
</tr>
<tr>
<td>25</td>
<td>99.6%</td>
</tr>
</tbody>
</table>

Guidance from Professional Organizations

“The goal of family counseling...is to provide:
1. **objective information**, in a
2. **compassionate manner**, to permit
3. **shared decision making**, and to
4. **support the family.**


Guidance from Professional Organizations

“Effective counseling includes three components:
1. **assessment of risks**
2. **communication of those risks**, and
3. **ongoing support.”


How are neonatology fellows trained for antenatal periviability counseling?


Methods: IRB-approved as exempt; online, anonymous survey Spring 2016; Program Directors of all 98 U.S. Neonatal-Perinatal Medicine Fellowships. Questions included:
1. Policies on care for extremely premature newborns
2. Mechanisms of antenatal consultation
3. Consultation training methods
Overview of Institutional Approaches

<table>
<thead>
<tr>
<th>Institutional approaches to options for mothers threatening delivery by gestational week</th>
<th>22</th>
<th>23</th>
<th>24</th>
<th>25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written policy</td>
<td>32%</td>
<td>32%</td>
<td>34%</td>
<td>32%</td>
</tr>
<tr>
<td>Group agreement</td>
<td>43%</td>
<td>52%</td>
<td>57%</td>
<td>61%</td>
</tr>
<tr>
<td>Varies by neonatologist</td>
<td>25%</td>
<td>16%</td>
<td>9%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Delivery room options

<table>
<thead>
<tr>
<th>Only comfort care</th>
<th>Recommend comfort care</th>
<th>Make no recommendations</th>
<th>Recommend life-sustaining treatments</th>
<th>Only life-sustaining treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>20%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Recommend comfort care</td>
<td>66%</td>
<td>27%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Make no recommendations</td>
<td>13%</td>
<td>43%</td>
<td>29%</td>
<td>2%</td>
</tr>
<tr>
<td>Recommend life-sustaining treatments</td>
<td>2%</td>
<td>25%</td>
<td>39%</td>
<td>20%</td>
</tr>
<tr>
<td>Only life-sustaining treatments</td>
<td>0%</td>
<td>5%</td>
<td>32%</td>
<td>79%</td>
</tr>
</tbody>
</table>

Antenatal Counseling Methods of Sharing Information by Topic

Presence of changes in institutions’ delivery room options in the last 5 years

Neonatology Fellows’ Experiences

The good: strengths-information relay and growing physician empathy

The bad: weaknesses-supporting parents’ emotional and spiritual needs

The confusing:

- Fellows are exposed to different practices for counseling options at the very early ages
- Fellows learn from attending neonatologists who aren’t always there
What’s the Ethical Concern Here?

Do we really address Parental Concerns?
  • Content, tone, directedness, decision-making
  • Little correlation in perceptions of whether a treatment recommendation had been made
  • Parents of infants who had died of extreme prematurity or congenital anomalies rely on values...
    ▫ religion
    ▫ spirituality
    ▫ hope

Challenges in Perinatal Healthcare Ethics - 2

Communication
  • Who’s talking?
  • Who’s listening?
    - and how, through what filter?
    - can you identify your own bias?

“The single biggest problem in communication is the illusion that it has taken place.”

Three Components of Communication

1. Informativeness - quantity & quality of information shared
   Caution: Don’t expect that all facts will be heard or believed as truths
2. Attunement...Interpersonal sensitivity - affective behaviors in communication that reflect the healer’s attention to, and interest in, the patient’s [family’s] feelings and concerns
   Caution: Alone, this component merely reflects politeness
3. Partnership-building – the extent to which patient & family are invited to provide opinions and suggestions during the consultation
   Caution: This component requires the prior 2 (above) in order to establish a therapeutic [healing] relationship
   Together, these 3 build trust

Focusing on relationships, not information, respects autonomy

  • Clinicians need to explore individual patients’ lived experiences and engage in trusting empowering relationships.
  • Clinicians can enhance patients’ relational autonomy by becoming advocates for them & partnering with them.
  • Relational rather than Rational Individualistic Autonomy

  Self-determination
    ▫ relational moral agent
    ▫ reason and emotion
    ▫ facilitates information-delivery

  Situational awareness
    ▫ each person’s lived experience
    ▫ power imbalance
    ▫ contextual issues

Relationship between Health Care Professional communication, parental confidence & coping

Health-care provider communication with expectant parents during a prenatal diagnosis: an integrative review - Kratovil & Sullivan, J Perinatol (2017) 37, 2–12.
Pediatric Grand Rounds - UT Health SA

Parents & Staff Think, then Decide

But, how we think may vary...

- Personal Thinking
- Analytical Thinking
- Hypothetical Thinking
- Ethical Thinking
- Moral Thinking
- Sensing Judgmental Thinking
- Scary Thinking
- Reflective Thinking
- Practical Thinking
- Second Sight

Challenges in Perinatal Healthcare Ethics - 3

Decision-making
- Too often we address communication – and hence, frame decision-making – in neonatology as a process of informed consent.
  - Decisions may rest on other framing effects.
  - Decisions may be influenced by what's said to be the default option.
- Shared decision-making is the goal...what is it?
- Who shares what?
- What key component comprise SDM?

Personalized Decision Making

Personalized decision making - as opposed to standardized & neutral transfer of information, empowers parents both during and after the decision-making encounter.
Communication with parents should establish trust, and include attention to emotional & intuitive aspects of decision making.
Parents have varied preferences with regard to information, preferences for deliberation, and roles in decision making.
Personalizing shared decision making might improve both communication and decisions...trust...& mitigate regret

How certain are you, doctor?

Parents are afraid when their child is admitted to an ICU. They have profound (often realistic) apprehensions about the chances of their child suffering disability or even death.
  - They want to know what is going to happen to their child; and how certain the physician is about the outcome (whether or not they explicitly raise the question).
- Physicians too are often afraid...of responding truthfully to the parents’ craving for reassurance & certainty. So, they’re inclined to deflect the parents’ questions.
  1. Structure & Organization of Contemporary ICUs
  2. Neglect of Prognostication
  3. Failure to Distinguish Scientific Certainty From Practical Certainty

Technology

"Technology is not neutral. The choices that get made in building technology then have social ramifications."
— Melanie Sollars, professor at Brookings Inst., who’s developing a course on ethics in computer science (NY Times)

Neil Postman, in his 1993 book Technopoly notes how technology has changed our culture – and has become the driver (we succumb to its nuances & hidden meanings) and our solution.

"...embedded in every tool is an ideological bias, a predisposition to construct the world as one thing rather than another.”

IS THERE a TECHNOLOGICAL IMPERATIVE in HEALTH CARE?

Medical technology has grown from being a tool to becoming a companion and, in some cases, the master of physicians.

Examples of this Imperative:
  - possibility & action: Whatever is possible has to be done.
  - commitment: Once on the treatment train we cannot stop – we’re committed.
  - procedure: attends to the complex procedural use of technology.
  - demand: by an informed patient; or a physician's own notion of what is demanded.
  - unknown: we don't like not knowing, so maybe technology will help.
  - means as ends itself: we tend to seek technological solution to all our problems
  - implementation; of proliferation; and of inappropriate use.
But, All Technology Limps...

- Many diseases can be cured, some impairments and disabilities can be accommodated, limitations are often temporary boundaries, and a significant majority of pain can be medicated or anesthetized.
- In spite of these advances, there still are limits.
  - At some point all technology limps.
  - No one has found a permanent means to avoid injury or death.


And ... Technology is Amoral

- Hofmann closed his paper by concluding that
  - There is no technological imperative (morally).
- Rather, technology promotes a moral imperative.
- In particular, it promotes a moral imperative to proper assessment:
  - Which patient, when, and how, and for how long, with what (and by whom) measurement of benefit or harm?

Affective Forecasting: An Unrecognized Challenge in Making Serious Health Decisions
Halpern & Arnold, JGIM 2008

- Affective Forecasting & Cognitive Distortions
  - Focalism: focusing narrowly on what will change in one’s life while ignoring how much of what one enjoys daily can still be continued.
  - Immune Neglect: Failing to recognize the extent to which your defense, or coping, mechanisms will buffer you (provide “immunity”) from emotional suffering.
  - Failure to Predict Genuine Adaptation: Research consistently shows people fail to predict adaptation, despite findings that, over time, most people are highly adaptive

Palliative Paternalism
When might directive counseling be beneficial?
Maladaptive Coping Risks

Cognitive
- Delayed
- Medically naive
- Extremes of one

Emotional/Psychological
- Emotionally fatigued: Magical thinking
- Harm: It is very likely that the baby is a risk
- Emotionally reactive: PTSD; Serious mental illness
- Authoritarian assertion despite possible harm to (baby)
- Substance abuse

Social/Cultural
- Misunderstanding of medical community (lack of understanding)
- Cultural differences (collective’s individual)
- Cultures that defer to authority
- Individuals who believe only option is a miracle

Values-based Shared Decision-making in the Antenatal Period.

- A neonatologist may perceive that a high likelihood of non-survival paired with a high chance of moderate-to-severe impairment among survivors as dismal, with a very low chance of the “desired” outcome of intact survival.
- Due to the statistical probabilities, the burdens of infant suffering and societal cost may appear to outweigh benefit of therapy, and comfort care may logically be recommended.

Values-based Shared Decision-making in the Antenatal Period.

- Parents may view these outcomes very differently. If any survival, even with significant impairment, is seen as a desirable outcome, the probability of a “good” outcome rises.
- If having a surviving, very impaired, child is considered the most undesirable outcome, the risk of this is quite low, as many of the sickest infants die.
- Finally, if dying following ICU care is perceived as more favorable than possibly missing an opportunity to have an intact survivor, the risk of the unfavorable outcome falls to zero if an attempt at resuscitation is made.
Decisions, Outcomes, & Decisional Regret
Stephanie Kukora, MD

Life-limiting or Life-threatening Conditions

Survival
Theoretically no regret; this is the goal
No regret; everyone knew & accepted the possible outcomes
Parental regret: "Chronic Sorrow," poor coping

Survival with Deficits

No regret; agreement between decision makers, no suffering

Planned Redirection of Care

Parental regret; despite honoring autonomy; guilt ["we gave up"]; lack of support

Death

No regret; "we did all we could"

Unexpected Death

Regret; guilt about causing suffering, missed opportunities

References