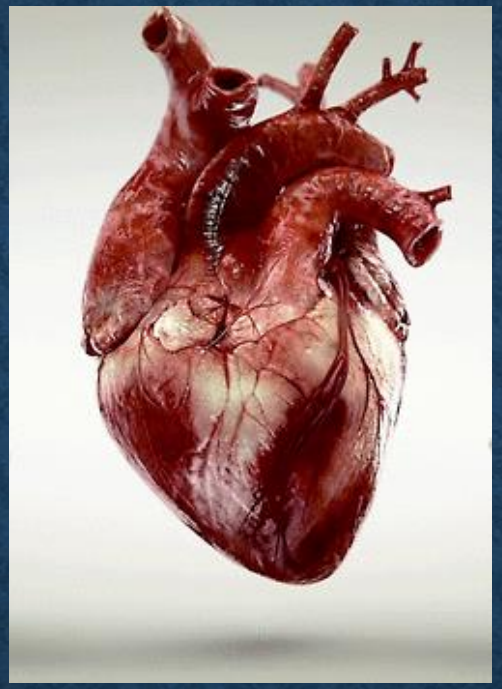

ETHICAL DECISION MAKING IN THE NICU

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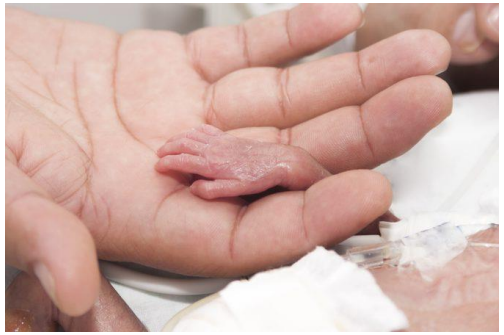

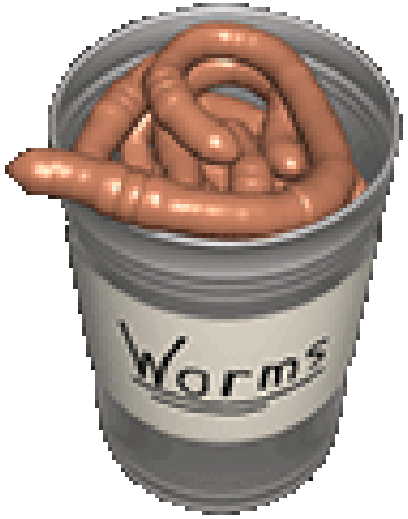

AGENDA

- Introduction
- Ethical Principles
- Hope
- Take home message
- Questions

DECISIONS IN THE NEONATAL ICU: ETHICAL PRINCIPLES

Why Ethical Principles Matter

- Neonatal care often involves *high-stakes, complex, and emotionally charged* decisions.
- Ethical principles provide a **structured framework** for balancing medical realities, parental perspectives, and the infant's best interests.
- Ethical principles *guide practitioners beyond clinical facts*, ensuring that choices remain compassionate, consistent, and defensible.

DECISIONS CONCERNING INTERVENTION

- Who decides?
  - Parents
  - Physicians
  - Medical staff/administration
  - State
- How do we decide?
  - Medical knowledge
  - Hospital policy
  - Legal requirements
  - Ethical/Religious values

ETHICS IS SIMPLE

"The ability to simplify means to eliminate the unnecessary so that the necessary may speak." - Hans Hoffman

AUTONOMY

Responsibility	• Patient
Principle	• Patient choice – consent or refuse treatment • Based on personal interest and not necessarily benefit of treatment itself
Obligations	• Healthcare Practitioner – to ensure understanding and context.
Rationale	• Complements Beneficence and Non-Maleficence • Rests in the concept of dignity

NON-MALEFICENCE

Responsibility	• Health Practitioner/ Team
Principle	• Doing no harm is the basis of all medical decisions • It is more important not to harm than just to do good
Obligations	• Limit options of care to those that have been proven • Are free of moral grey areas
Rationale	• Big picture – using up to date, best care principles • Using legally and available resources wisely and to good effect

BENEFICENCE

Responsibility	• Health Practitioner/ Team
Principle	• Benefitting or doing good
Obligations	• Balance – benefits vs risks and costs of treatment • Acting in the best interests of the patient
Rationale	• Balance between non-maleficence & beneficence

JUSTICE

Responsibility	• Health Practitioner/ Team
Principle	• Impartial patient treatment: gender, race, sexuality, wealth, disability etc. • Distributive justice
Obligations	• Who gets medical treatment when there are scarce or finite resources.
Rationale	• Prognostic decision making: Viability vs Futility. • Who gets the treatment is then not the ethical question.

CORE ETHICAL PRINCIPLES IN PRACTICE

- **Beneficence** – Acting in the best interest of the infant, prioritizing survival with quality of life.
- **Non-Maleficence** – Avoiding harm from unnecessary or futile interventions.
- **Autonomy (via parents/guardians)** – Respecting parental role in consent and shared decision-making, while remembering your priority is the infant.
- **Justice** – Fair and equitable use of scarce resources in the ICU. Don't waste to make people happy/ give in to demands

IS FOSTERING HOPE ETHICAL IN THESE CASES?

- Bizarre – hope is a positive force
  - Zechariah 9:12
  - Hope springs eternal in the human breast
- Jerome Groopman - a hopeful attitude and fostering hope is an integral part of the physician's role
- Whose hope?
- What are we hoping for?
  - Merely life
  - Or life with the possibility of becoming a person able to interact with other persons

ETHICS OF HOPE

- Autonomy – Health Practitioner's role
- Is it ethical to raise parents hope when the outcome will be tragic?
- Is it appropriate for healthcare professionals to always operate on the basis of hope in their professional actions? Realism?
- **Ethics of principled conviction** = intent is the most important factor. If you have good principles, then you will act ethically. Hence beneficence.
- **Ethics of responsibility** challenges this, = that you must understand the consequences of your decisions and answer to them. The medical maxim 'do no harm' is based in the outcome-oriented ethics of responsibility.

WHAT IS BEING HOPED FOR?

- Futility – the value of hope?
  - Futility: a goal-relative notion. Nothing is inherently futile, therefore
  - Futility is only relative to the goal that one is trying to achieve.
- That goal is important because there are values associated with it.
- Value assumptions are integral to the notion of futility because they are integral to a goal-oriented point of view.
- Who defines the notion of futility? Health Practitioners? Parents? Society? Budget?

Hope must end before it

- undermines the four ethical pillars
- Prevents the facilitation of a healthy grieving process leaving the parents with minimal regrets. And
- while it preserves the integrity of the medical team enabling them to continue to function effectively.

TAKE HOME MESSAGE

- Sometimes the most ethical thing to do is to gently remove hope, and do what is ultimately best for the baby – and the family – and the healthcare practitioners themselves – and let go.

QUESTIONS?