

2. ETHICS OF FETAL MEDICINE

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SOME APPROACHES TO ETHICS AND BIOETHICS

Duty-Based Ethics (Kant)

We all have duties, says Kant: to tell the truth, not kill etc...

Physicians have a duty to care for their patients.

In bioethical discussions about duties, rights come up as well, e.g. rights to well-being, to act freely, to information, etc...

There is no easy solution when conflicting rights and duties exist in a given situation

Virtue-Based Ethics (Aristotle)

Involved parties (especially health care providers) should possess virtues, such as compassion, honesty, and integrity.

Tough to apply clinically. It's often not obvious what the virtuous decision would be.

Utilitarianism (Mill)

The good act brings out the greatest total happiness.

Relies on predictions probable outcomes.

It's often difficult to quantify happiness and calculate totals.

Justifies seemingly unethical acts (e.g. murder me to donate my organs to 5 people – greatest good to greatest number).

Feminist Ethics

Focuses on context (especially the particular relationships involved).

Emphasis on caring.

Attention to power differentials (men-women, rich-poor, educated-uneducated).

Rejects paternalism.

Case-Based

Ethical reasoning based on precedents.

Starts with something you KNOW to be right (or wrong) and looks for similarities to the present case.

Veil of Ignorance (John Rawls)

Approach a situation from behind the “veil of ignorance.”

Deliberate as if you don't yet exist and don't know who you'll be when you do.

Capitalizes on self-interest – choose what will maximize the best interests of all parties, because you don't know which party you may become.

Principal-Based Ethics (Beauchamp and Childress)

- Autonomy – decision-making capacity
- Beneficence – provide benefits
- Nonmaleficence – avoid causing harm
- Justice – fairness in the distribution of benefits and risks

Principlism is helpful in that it provides a concrete way to evaluate difficult situations.

Limited in that principals often conflict, making it difficult to apply them clinically.

No one of these approaches is perfect, but together they can help sort through the important relevant issues in a given case.

QUESTIONS IN MATERNAL-FETAL ETHICS

When is a fetus a patient?

The more difficult “When is a fetus a person?” is controversial.

Some believe that even a very young fetus has moral status as a potential person.

Others believe that reaching a gestational age of viability (the ability to exist outside the mother) is morally significant. [Viability though, is not a characteristic intrinsic to the fetus – it depends on technology.]

Still others argue that it is not until a fetus becomes a newborn that it has meaningful moral status.

“When is a fetus a patient?” is easier, although there is still controversy.

When a woman presents her fetus for care, she has already decided (at least for that moment) that she wants to maintain that pregnancy.

She consents to care of her fetus.

In other words, practically speaking, a fetus is considered a patient when a pregnant woman presents it for care.

There is some controversy over whether or not the viability of the fetus is relevant, i.e., is every viable fetus a patient if the mother is receiving care?

How is experimental medicine justified?

Ideally, innovative therapies evolve something like this:

1. Someone comes up with a great idea
2. Extensive animal testing is performed
3. The new therapy is tried on a few humans
4. Equipoise is reached
5. Clinical trials are performed
6. It's determined that the new therapy works (or doesn't)
7. The new therapy is offered routinely (or isn't)

What is equipoise?

Equipoise is reached when it is truly unclear which course of therapy carries the greatest risks or benefits to an individual patient.

This is tricky in maternal-fetal medicine because it may be unclear which therapy is better for the fetus, but the vast majority of the time it is less risky for the mother if the pregnancy goes to term and the fetus is repaired post-birth.

Advances maternal-fetal surgery should ideally be conducted as research.

Enrollment should be voluntary.

Data should be collected and evaluated to assess the effectiveness of the experimental therapy.

Pregnant women should be given the protection of research subjects.

Informed consent must be clear and explicit about expectations of benefit.

What if a woman demands care outside a study protocol?

A surgeon does not have an obligation to provide unproven therapy.

A surgeon does have an obligation to promote responsible use of that therapy, including supporting formal studies.

Offering maternal-fetal surgery off protocol reinforces the therapeutic misconception for that particular patient and others contemplating enrollment.

Should fetal surgery be reserved for lethal conditions?

It is difficult to justify both maternal and fetal risks for nonlethal conditions.

Attitudes towards people with disabilities should be examined, particularly when the disability is compatible with a good life.

Cosmetic surgery currently being postponed until maternal-fetal surgery can be performed safely.

Where should maternal-fetal surgery be performed?

Major centers exist.

The learning curve for new centers puts patients at higher risk.

Having too many centers makes research difficult

If a major center is doing a study and a pregnant woman is randomized to standard treatment, she may go elsewhere to be receive experimental therapy.

Travel to major centers may make care for some women impossible.

How should research funds be distributed?

If there are limited research funds available, research on rare conditions occurs at the cost of studying diseases that affect many more children.

Likewise, funds could instead be spent on prevention (folic acid for spina bifida).

But kids with rare conditions have rights to treatment too, and their parents don't care if their disease is rare. They want help to be available for their kids.

Which patient's interests should take precedent when there is a maternal-fetal conflict?

Note: using the word "interests" instead of "rights" gets around the difficulty of when (if) fetuses have rights. Even without rights, fetuses have genuine interests.

What if a pregnant woman refuses care that would help the fetus (e.g. cesarean delivery, AZT, or proven effective fetal surgery)?

- Recommendations must be understandable by the patient.
- Physicians must keep in mind that medical knowledge is fallible and predictions can be difficult (and wrong).
- Physicians have an obligation to the pregnant women's well-being as well as the fetuses'.
- Persuasion is generally okay, coercion is not. It's a fine line.
- Abiding by the woman's wishes is generally best for the pregnant woman and the fetus.

Should pregnant women ever be taken to court to protect a fetus?

It's not encouraged, but if it's being considered, the following conditions should be met:

- High likelihood exists that serious harm will result to the fetus by respecting the woman's decision.
- High likelihood exists that intervening will prevent serious harm to the fetus.
- There is minimal risk and some benefit to the pregnant woman.
- The benefits to fetus and pregnant woman outweigh harm done by violating the pregnant woman's autonomy, including loss of trust in the system by her and others.

What about twins?

As an example, take a pregnancy in which one fetus is healthy and would do better if the pregnancy went to term. The other fetus is sick and would benefit from early delivery.

With twins, even more hard questions arise:

- How much, if any, risk should the healthy fetus be exposed to in order to improve the chance of a good outcome for the sick twin?
- Are you harming the sick fetus by *not* intervening? (i.e. Does "harm" require action?)
- Does the healthy twin have a right to be left alone?
- Does the sick twin have a right to maximize its chances?
- Does either twin have a duty to help its sibling?
- Can the net quality of life for the twins be increased?
- If so, should it?
- Is the healthy fetus directly benefiting from helping his sib?
- When should the twins be delivered?