

Ethics of Fetal Medicine

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Why ethics?

- There are no right answers
- It's so wishy-washy
- It has nothing to do real medicine

- YOU HAVE TO MAKE DECISIONS
- YOU HAVE TO ACT
- YOU HAVE TO LIVE WITH YOUR DECISIONS
- YOU HAVE TO BE ABLE TO DEFEND YOUR ACTIONS

When is a fetus a patient?

- Even harder – When is a fetus a person?
 - Some believe even a very young fetus has moral status as a potential person.
 - Others believe that reaching a gestational age of viability is morally significant (depends on technology).
 - Still others argue that a fetus achieves significant moral status only once it becomes a newborn.

When is a fetus a patient?

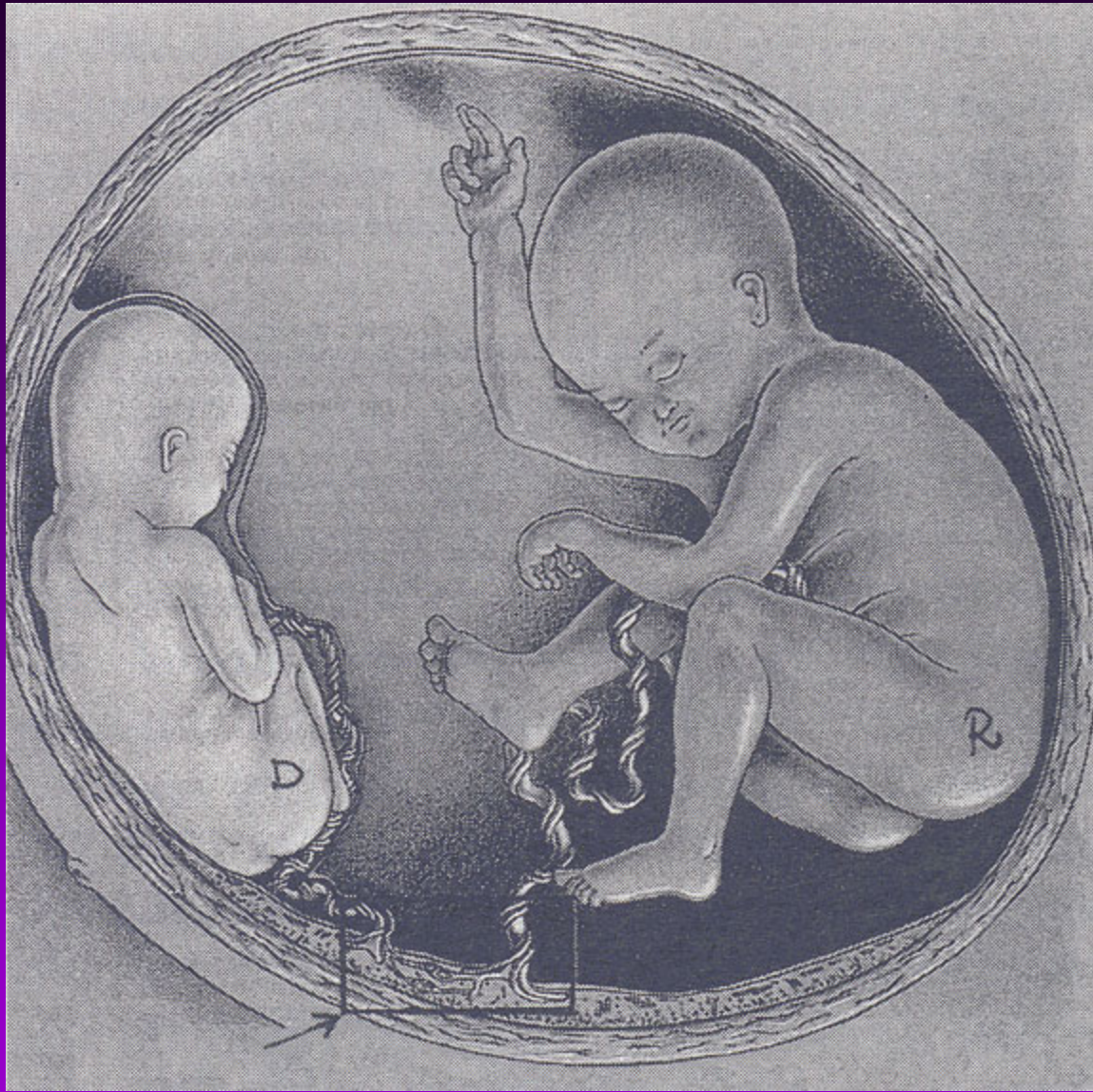


- When a woman presents her fetus for care, she's decided she wants to maintain the pregnancy.
- Practically speaking, a fetus is a patient when a woman presents it for care.
- Some controversy – is every viable fetus a patient if the mother is receiving care?



Case #1

- An experienced, talented pediatric surgeon feels she has the technical skills necessary to perform fetal surgery for Twin-Twin Transfusion Syndrome and has read all the literature available on the subject.
- [In TTTS blood can be transfused disproportionately from one twin to the other twin. Without treatment, most would not survive.]



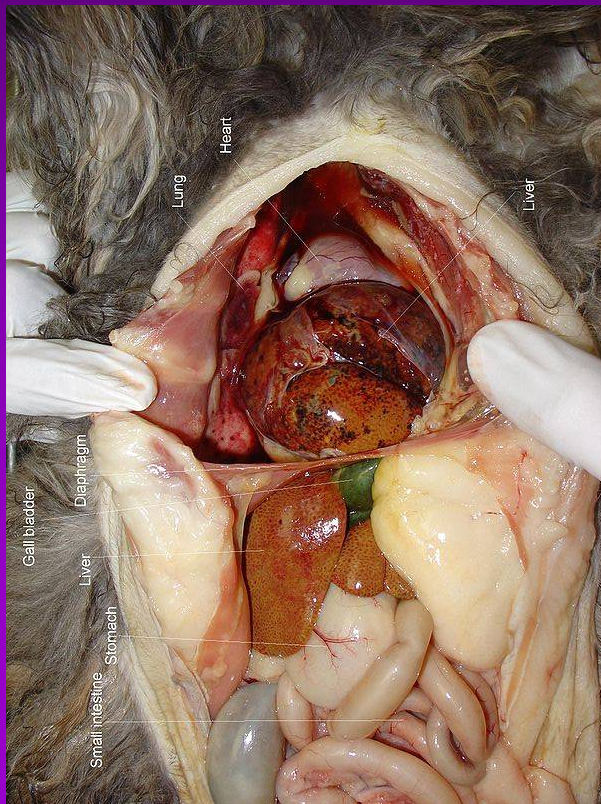
Case # 1

- The surgeon receives a call from an OB/GYN about a case of twin-twin transfusion syndrome that might benefit from surgery.
- Should the surgeon perform the procedure?

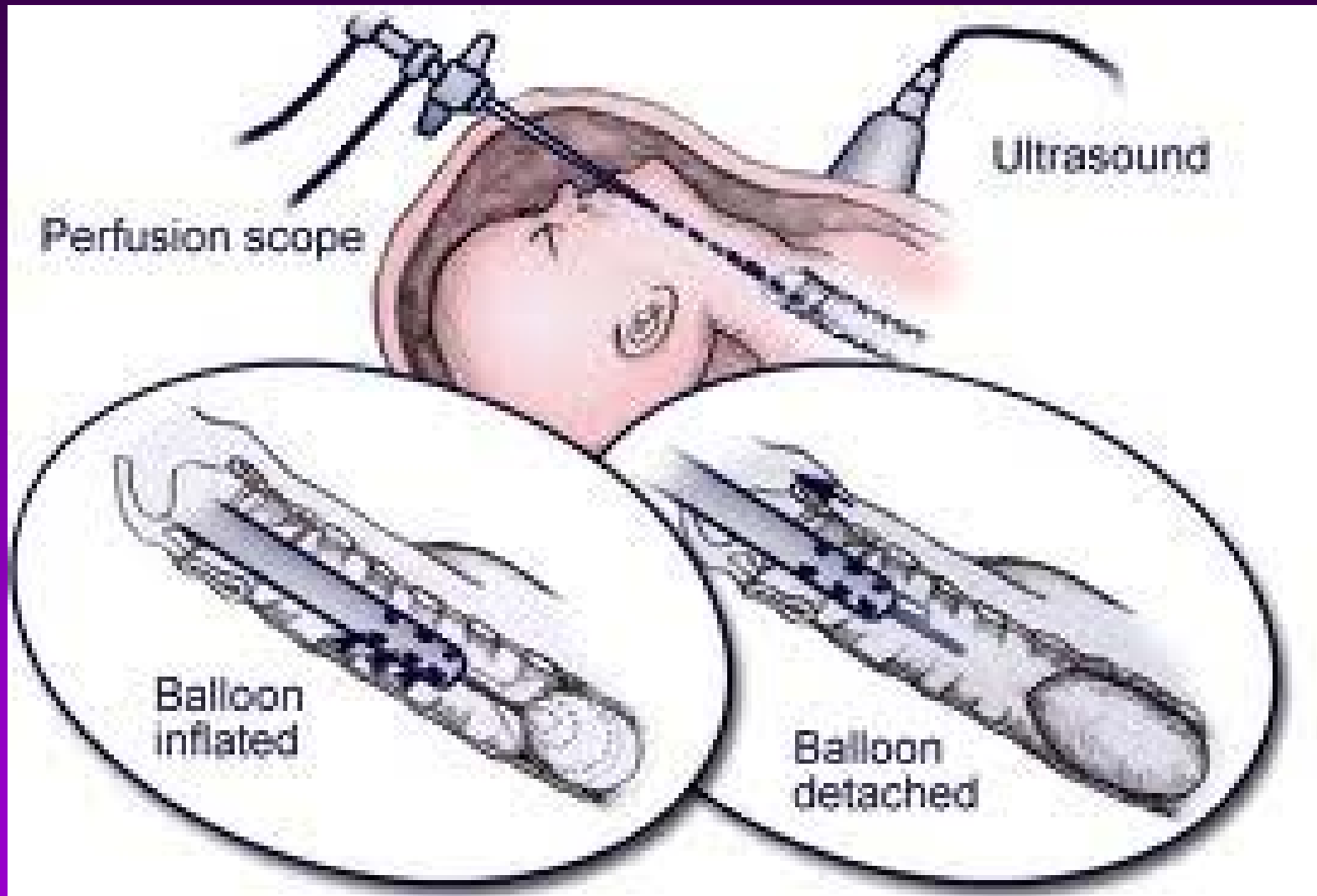


Case # 2

- A fetus is diagnosed with a severe diaphragmatic hernia and lung hypoplasia.



Tracheal Occlusion



Case # 2

- A study is being conducted to determine which is better – tracheal occlusion or standard therapy.
- The mother was randomized to standard therapy (repair after delivery).
- She insists on getting fetal surgery to occlude the trachea.
- Should the surgery be done?

Case # 3

- Parents approach a fetal surgeon about performing a cleft lip and palate repair.
- They've heard that their child could be born without any scars.
- Should the surgery be done?



Case # 4

- A pregnant woman with HIV refuses to take AZT.
- [AZT dramatically reduces the rate of transmission of HIV to the fetus.]
- The intern suggests she be put in custody until the baby is born so she can be forced to take the medicine.
- Should you call the police?



Case # 5

- A woman gives birth to conjoined twins who share one heart.
- Together, both twins will eventually die of heart failure.
- Apart, one could live and the other would certainly die.



Case # 5

- The parents don't want to separate the twins. They say it would go against their religion.
- Should you get a court order to potentially save one of the twins?

Groups

Case #1

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- [In TTTS blood can be transfused disproportionately from one twin to the other twin. Without treatment, most would not survive.]

Case # 1

- The surgeon receives a call from an OB/GYN about a case of twin-twin transfusion syndrome that might benefit from surgery.
- Should the surgeon perform the procedure?

Where should MFS be done?

- Major Centers exist.
- At those centers, procedures have been practiced on many patients.
- The learning curve for new centers puts patients at higher risk.
- Most innovations have not yet proved effective at major centers.
- Too many centers make research difficult.

Where should MFS be done?

- BUT!
- Each center started new at some point.
- How many major centers are enough?
- Who is to say that a talented surgeon should not be allowed to learn a new skill?
- Shouldn't as many centers as possible be available so pregnant women can be close to home/support systems?

Case # 2

- A fetus is diagnosed with a severe diaphragmatic hernia and lung hypoplasia.
- A mother knows about tracheal occlusion and wants to have it done for her fetus.
- She is randomized to standard therapy, but insists on being in the occlusion group.

How is experimental medicine justified?

- Evolution of fetal surgery
 - A great idea
 - Extensive animal testing
 - New therapy is tried on a few humans
 - Equipoise is reached
 - Clinical trials are performed
 - It's determined whether new therapy works
 - The new therapy is offered routinely (or not)

How is experimental medicine justified?

- What is equipoise?
 - When it is truly unclear which course of therapy carries the greatest risk to an individual patient.
 - Tricky because while there may be equipoise for the fetus, it's usually better for the woman for the pregnancy to go to term.



Fewer shunts
More development
More walking
Less hind brain herniation



Care outside study protocol

- A surgeon does not have an obligation to provide unproven therapy.
- A surgeon *does* have an obligation to promote responsible use of therapy, including supporting formal studies.
- Offering MFS off protocol reinforces the therapeutic misconception.

Case # 3

- Parents approach a fetal surgeon about performing a cleft lip and palate repair.
- They've heard that their child could be born without any scars.
- Should the surgery be done?

Non-lethal MFS

- It's difficult to justify both maternal and fetal risks for non-lethal conditions.
- Attitudes toward people with disabilities should be examined.
- Until MFS can be performed safely, cosmetics currently being postponed.



Case # 4

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- [AZT dramatically reduces the rate of transmission of HIV to the fetus.]
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- Should you call the police?

Maternal-Fetal Conflict

- Recommendations must be understandable by the patient.
- Medical knowledge is fallible.
- Physicians have obligations to the pregnant woman as well as the fetus.
- Abiding by the woman's wishes is generally best for the pregnant woman and the fetus.
- Generally okay to persuade, not coerce.

Maternal-Fetal Conflict

- Should pregnant women *ever* be taken to court to protect a fetus?
 - High likelihood of serious injury to the fetus
 - High likelihood intervening will prevent harm
 - Minimal risk and some benefit to woman
 - Benefits to fetus and woman outweigh harm done by violating woman's autonomy, including loss of trust in the system by her and others.

Case # 5

- A woman gives birth to conjoined twins who share one heart.
- Together, both twins will eventually die of heart failure.
- Apart, one could live and the other would certainly die.

What about twins?

- Why NOT separate them?
 - Killing is bad
 - Parental rights/Religious rights
 - Psychological effects on survivor and parents

What about twins?

- Parents have the right to make decisions about their children
 - What they wear, what they eat, what toys they play with, etc...
- Parents have the right to practice their religion and teach their kids the same

What about twins?

- Prince vs Massachusetts (1944)
- “Parents may be free to become martyrs themselves, but it does not follow that they are free to make martyrs of their children.”
- We can (and should) over-rule parents if they are putting their children at risk for serious harm or death

What about twins?

- Why NOT separate them?
 - The logic that it is better to save one patient than lose two is not applied elsewhere
 - Had the twins been born as separate conscious identical twins, but one with a bad heart and the other with a bad liver, it would not be decided to kill one girl to harvest an organ to save the other

What about twins?

- Why separate them?
 - Utility tells us to choose the outcome that brings about the greatest good
 - $1 > 0$
 - Yes, killing is bad, but there's the Doctrine of Double Effect

Doctrine of Double Effect

- A tool to help with decision making
- Developed by Catholic theologians as a part of “just war” theory
- Effects that would be morally wrong if intentional are permissible if foreseen and not intended
- The distinction between respiratory depression as a side effect of pain control and euthanasia is *intent*

What about twins?

- Why separate them?
 - She would have been dead if she were born as a single baby
 - She will be dead if the separation takes place
 - She will be dead if the separation does not take place.

What about twins?



- Analogous case: Sky-divers
 - Two skydivers jump from plane, but only one chute opens.
 - Rather than plummet to his death, one guy grabs onto the legs of the guy with the chute.
 - Together, both will die.
 - Can the one with the parachute kick the other guy off?

What about twins?

- Bottom line –compelling arguments on both sides
- Consider the potential quality of life of both twins
- There must be a very good chance for a good outcome to over-ride parental preference

Summary

- MFS should ideally be approached as research in places with skilled teams until proven effective.
- MFS should be reserved for lethal (or at least non-cosmetic) conditions.

Summary

- Respecting the pregnant woman's decisions is generally best for her and her fetus.
- Consider MFS research within a broad social and scientific context.

Summary

- Remember the end doesn't always justify the means.
- Try to respect parental wishes unless their child is at great risk of serious injury or death



**Ethical Issues in
Maternal-Fetal Medicine**

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