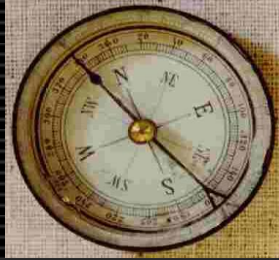


Northwestern University

Center for Bioethics

Science
and Society

Feinberg School
Of Medicine



Ethics and Science

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What I am going to talk about :

- I will describe what ethics means
- I will talk about the ethical issues in the research you are learning about
- I will give you some cases to think about

What is ethics?

- How do you know what is good?
- How do you decide the right thing to do?
- How do you know if something is wrong?

Ethics is not like “morals”

- A set of rules for what to do when we don't agree

Two ways to decide

- How it turns out.
- What are the promises, rules and intentions that you have

What is bioethics?

- ❑ 'Bioethics' started as a national conversation:
 - Genetics
 - Organ transplants
 - Fair treatment of people in medical research
 - people who no longer want medical care and are dying
 - Health care for everyone who needs it
 - Other things we disagree about in medicine or science
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A NEW question in bioethics!

- ❑ Is doing oncofertility research a good idea?
 - ❑ Is it a good act and what makes it so?
 - ❑ Are there ethical problems?
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First thing to think about

- ❑ Having cancer does not mean you are sure to die.
 - ❑ It could also be a life-threatening, but treatable sickness that needs rehabilitation.
 - ❑ But cancer treatment can destroy or reduce your fertility.
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Second thing to think about

- ❑ People want to be able to have genetically related children.
 - ❑ Infertility is a medical problem with a medical solution.
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Some Ethical Problems

- ❑ Not all—you may think of more!
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Ethical Issues I: Cancer and childhood consent

- ❑ Abnormal to think of little kids as moms or dads
 - ❑ Confronting death is difficult and scary
 - ❑ It may be hard to have an operation
 - ❑ Can a kid really understand what is happening
-

Ethical Issues II: What if it doesn't work?

- We can't yet do what we want, and what we can do is always changing
- So how do you make sure people understand this?
- Is it fair to ask them if you don't know how it will turn out?

Ethical Issues III

- Yuck factors and slippery slopes
- What does it mean to be a family?
- What will this lead to?

Justice issue I. Should the technology be limited?

- For cancer survivals alone? (Why only for cancer?)
- Are other uses in other life-threatening events permissible?
- What about preserving eggs for social or protective reasons? (an "insurance policy")
- We are led to consider the limits of the use of this technology.
- Is this therapy, or does it go beyond therapy?
- If such interventions are limited, how could this be done, and how should such regulation be defined and maintained?

Justice Issue II. How are goods distributed?

- What should be the role of economic factors, incentives, and distribution costs in access to trials and treatment?
- How should the project seek to address health care and social disparities driven by race and ethnicity, class or gender?
- Who should bear the cost of research. Who should profit, if anyone?
- Who owns the tissue? Patents?
- Is this research just, given other possible uses of scarce resources (such as money, time, equipment)?
- How can vulnerable subjects be assured of continuing access to health care and support?

Conclusion:

- How do we make rules about this?
- What should they be?
- Who should decide?
- How do we enforce them?

1. Are there reasons in principle to say no?
2. Is America a fair and safe place to do the research?
3. Are there some ideas that are ok, but some that are wrong?
4. How do you decide what is right when we all disagree? Should only scientists decide, or everybody?

Some ways of thinking about this

- Is freedom to choose the most important thing about America?
- What might be more important?
- Should we care if this is natural or not?

Asking the right people

- The patients say they want this very much.
- That it would not have harmed or scared them.
- That they wish they had the choice to learn all about it when they had cancer.

Is the research right?

Should we do it?

Short answer:

Yes

Why do we think this?

- Healing suffering people is the point of medical research.
- Good doctors restore parts of bodies that are hurt in therapy, or try to.
- The patients tell us it is important.
- It would be better medically for them—avoids hormones that might make cancer worse.

Thank you very much

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