Lesson Module III – Ethical Issues

Ethical Issues

Part I

TEACHING RESOURCES

Lesson Plan: Building and Evaluating Ethical Arguments

Science Content

Students will acquire the skills needed to analyze ethical issues surrounding the use of molecular technology to select for specific genes.

Science Education Standards

Science as Inquiry, Content Standard A

– Abilities necessary to do scientific inquiry (p. 175)
– Understandings about scientific inquiry (p. 176)

Science in Personal and Social Perspectives, Content Standard F

– Personal and community health (p. 197)
– Natural resources (p. 198)
– Natural and human-induced hazards (p. 198)
– Science and technology in local, national, and global challenges (p. 199)


Science Process Skills

• Relating
• Inferring

Life Skills

• Learning to learn
• Problem solving
• Decision making
• Communicating

Time

Copying optional handouts: 10 minutes
Doing activity: 40 minutes each of two days

Materials


Background for Educators

This lesson will familiarize students with the terms used in the study of ethics and provide experience in building and evaluating ethical arguments. The skills learned in this lesson can be applied to any controversial ethical issues.

Ethics can be defined as critical thinking about right and wrong action. In this definition, the bolded words are key concepts. Ethics involves careful, thoughtful study of values, not just reliance on intuition or what our friends think. The values being studied refer not to finances or money, but to figuring out what is ethically important and what makes actions ethically right or wrong. The end goal of an ethical model is action-oriented. It helps us determine what we ought to do.

Developing the skills necessary to formulate and evaluate ethical arguments can help people think through ethically controversial situations and help them develop and defend their own views on particular topics. The ethical arguments that students will construct in this lesson have three parts:

Empirical Claims + Ethical Claims = Ethical Conclusion

1. Empirical claims are, or are said to be, statements of fact. Statements about risks and benefits are empirical claims. Statements about what something is made of or how something functions are empirical claims.

2. Ethical claims are about ethical values, such as, “It is good to respect the rights of others, care for the environment, promote human health, and reduce poverty.” Ethical claims set forth what is good to do and what is bad to do in general and are not addressing a specific case.
3. The **ethical conclusion** is the specific course of action that should be followed, if the empirical claims and ethical claims are accepted as true. That is when evaluation enters the picture. If a person challenges the empirical claims or ethical claims and does not accept them as true, the specific course of action in the conclusion is likely to be rejected. In this lesson, students will be asked to evaluate ethical arguments constructed by their fellow students.

The first two parts of an ethical argument, the empirical claims and ethical claims, are referred to as “claims” or “evidence.” The claims or evidence provide support for the conclusion.

**Lesson Plan**

**Day One**

1. Use the optional handout *Learning More About Ethics, Ethical Issues-1* on p. 157-159 or the overhead transparency masters Ethics-a through Ethics-n beginning on p. 167 to introduce the terminology and concepts of ethics and ethical arguments.

2. Ask students to complete the handout *See for Yourself: Ethical Arguments, Ethical Issues-2* on p. 161-162 and discuss their answers.

   **Answers to the handout:**

   **Empirical Claims**
   
   1. Fanconi’s anemia is a rare blood condition with no known cure.
   
   8. There are no proven risks to embryonic development resulting from **pre-implantation genetic diagnosis** (PGD).
   
   9. PGD will benefit carriers of genetic diseases.
   
   10. Many children suffer from diseases that could be treated by cells from a sibling donor.
   
   14. PGD gives parents unprecedented control over the genetic attributes of their children.
   
   16. PGD is a very expensive procedure.

3. **Tell students that during the next class period, they will construct their own ethical arguments.**

**Day Two**

1. Divide the class into four groups. Give each group a copy of optional student handout *See for Yourself: A Matter of Ethics, Ethical Issues-3* found on p. 163-166.

17. Currently, thousands of unused embryos leftover from IVF procedures are still frozen in fertility clinics around the country.

**Ethical Claims**

2. PGD should not be used at all because of potential associated risks to embryonic development.

3. Using PGD to give birth to a donor for Molly is the best thing that could have been done under the circumstances.

4. **In vitro fertilization** (IVF) should not be used because it results in extra human embryos that end up being discarded.

5. Science should be used to help cure illness.

6. We should try to prevent childhood sickness and death.

7. Parents should be allowed to use PGD because no alternative cures are available right now.

11. PGD should be used to select sibling donors because it will cure many children currently suffering from terminal illnesses.

12. The use of PGD to select sibling donors is unfair to the person ultimately born as a result of the process.

13. We should never use a person merely as a means to improve the welfare of someone else.

15. We should not choose which children will live depending on whom they can help.

18. Even when we know that we can do something, we should still ask whether we should do it.
2. Ask the students to read the scenario near the top of the handout. Tell two of the groups that their job is to construct an ethical argument that supports the ethical conclusion that Molly's parents were ethically right to use PGD to become pregnant with a potential donor for Molly. Tell the other two groups that their job is to construct an ethical argument that supports the ethical conclusion that Molly's parents were ethically wrong to use PGD to become pregnant with a potential donor for Molly.

Instruct all the groups that they should write as many empirical and ethical claims as they can in support of their assigned ethical conclusion. Emphasize to the students that they do not have to personally agree with the position that they have been assigned in order to write a convincing ethical argument. Give the groups about 10 minutes to write their ethical arguments.

Possible claims for the “ethically right” argument include the following, and student groups may think of others:

**Empirical Claims**
- Molly was ill with a fatal condition.
- PGD could select an embryo that would develop into a healthy child who could donate umbilical cord blood to help cure Molly.
- Neither in vitro fertilization (IVF) nor PGD has been shown to harm embryonic development.
- It is legal to use PGD to select a donor child.

**Ethical Claims**
- Parents should try to help their sick children.
- Technology should be used to make people’s lives better.
- It is morally wrong not to help a sick child when it is possible to do so.
- If an action is legal, it is ethically OK to do it.
- Parents have a right to have children for many reasons besides curing a sick child.

Possible claims for the “ethically wrong” argument include the following, and student groups may think of others:

**Empirical Claims**
- It has not been proven that PGD never harms embryonic development.
- IVF creates “extra” embryos that must be stored indefinitely or discarded.
- Adam would not have existed if his birth could not help his sister.
- PGD could be used for non-medical purposes, such as selecting for desirable traits.

**Ethical Claims**
- We should not impose risks on one person merely for the sake of benefit to someone else.
- It is wrong to create human embryos only to discard them.
- It is never ethical to treat a human being merely as a means to help another person.
- Just because an action is legal does not make it ethically right.

3. Ask the “ethically right” groups to exchange their ethical arguments with the “ethically wrong” groups. Instruct the groups to evaluate the validity of the arguments by completing the evaluation section. Students will need to decide (1) whether the empirical and ethical claims are true and (2) whether the claims support the ethical conclusion.

4. At the end of the class period, ask the groups to share with the rest of the class their evaluation of the ethical argument they were assigned to critique.

**For More Information**

Bioethics at Iowa State University
http://www.biotech.iastate.edu/Bioethics/classroom_resources.html

This site has a number of ethical case studies on a variety of topics. Some of the case studies may not be appropriate for high school use, so teachers should preview a case study before using it.
A Definition of Ethics

Ethics can be defined as critical thinking about right and wrong action. The three most important concepts of this definition are:

Critical Thinking
Ethics involves careful, thoughtful study. Ethical study does not rely on your intuition or just knowing what is the right thing to do. When you are studying an ethical question, you should not simply accept what your friends believe. Ethics is about determining for yourself what is right and wrong.

Right and Wrong
When you are studying an ethical question, you are thinking about values. These values are not about money or finances, but about whether an action is right or wrong. Examples of things that people value include cultural and religious freedom, honesty, and taking responsibility for their own actions. Because we value these things, it is generally a good inference that actions that promote and protect these values are right, and actions that threaten these things are wrong.

Action
The end goal of studying an ethical question is action-oriented. Thinking about ethics helps us determine what we ought to do, either personally or as a society, from an ethical point of view. If a healthy environment is an important value, actions that promote and protect a healthy environment are more likely to be right than actions that threaten a healthy environment.

A Model for Ethical Decisions
A model is a framework that can be used to help accomplish a task or clarify a situation. For example, weather forecasters use computer-generated models of air masses and their interactions to help predict the weather. Soil scientists use models to clarify how rain water moves through a crop field.

In this activity, you will learn about a decision making model that can help you think through controversial issues that involve ethics and arrive at a decision. This model involves constructing an ethical argument.

In this case, the word “argument” does not mean a disagreement. It means a logical presentation of the facts leading to a conclusion, like the arguments given by attorneys in a criminal trial. At the end of a trial, the judge asks for the attorneys’ closing arguments. Each attorney reviews the facts of the case and tries to convince the judge or jury that those facts support a conclusion about the innocence or guilt of the accused person.

Constructing Ethical Arguments
An ethical argument has three parts. The first two parts of the argument, the empirical claims and ethical claims, are referred to as “claims” or “evidence.”

Empirical Claims + Ethical Claims = Ethical Conclusion

1. Empirical claims are facts, or statements that someone wants you to believe are facts. Statements about risks and benefits are empirical claims.
Statements about what something is made of or how something functions also are empirical claims.

2. **Ethical claims** are claims about values, such as “It is good to respect the rights of others, care for the environment, promote human health, and reduce poverty.” Ethical claims set forth what is good to do and what is bad to do in general and are not addressing a specific case.

3. The **ethical conclusion** is the specific action that should be done, if the empirical claims and ethical claims are accepted as true. That is when evaluation enters the picture. If a person challenges the empirical claims or ethical claims and does not accept them as true, the specific course of action in the conclusion is likely to be rejected.

Here is an example of four statements that can be used to construct a simple ethical argument against genetic engineering:

- We should never do any genetic engineering.
- Genetic engineering moves genes between species.
- We should never do anything unnatural.
- Moving genes between species is unnatural.

In this example, the second and fourth statements are the empirical claims. The third statement is the ethical claim. The first statement is the ethical conclusion. The finished ethical argument would look like this:

- Moving genes between species is unnatural. *(empirical claim)*
- Genetic engineering moves genes between species. *(empirical claim)*
- We should never do anything unnatural. *(ethical claim)*
- We should never do any genetic engineering. *(ethical conclusion)*

This ethical argument used only two empirical claims and one ethical claim to support a conclusion. Using multiple empirical and ethical claims tends to strengthen an ethical argument. Assuming that the claims are true, a conclusion is more difficult to challenge if it is supported by several empirical and ethical claims.

### Evaluating Ethical Arguments

Even though the genetic engineering example sounds like a reasonable ethical argument, let’s evaluate it. Here are three steps to take in evaluating an ethical argument:

1. **Do the claims support the conclusion?**

   If the empirical and ethical claims are true, does that give us good reason to accept the conclusion that we should never do any genetic engineering? In this example, the conclusion is supported by the claims. That is, if it is true that doing unnatural things is unethical, and genetic engineering is an unnatural thing, then it must be true that genetic engineering is unethical. It’s important to remember that claims can support a conclusion even if not everyone agrees that they’re true. In this step, we are only evaluating whether the claims support the conclusion, not whether the claims are true.

2. **Are the claims true?**

   If the claims are not true, then the argument should not lead us to accept the conclusion. In our example, could the empirical claims be challenged? The description of genetic engineering is true, so it could not be successfully challenged. However, the claim that moving genes between species is unnatural could be challenged. A possible challenge might involve asking, “What is natural or unnatural? Viruses move genes between species ‘naturally.’ Human beings are a part of nature, so maybe everything we do is natural.”

   Could the ethical claim be challenged? A challenger could question the claim that we shouldn’t do unnatural things by asking, “Should we never drive cars, use penicillin, or do surgery? Should we never have bred plants and animals to suit our purposes?”

3. **Are there alternative actions or other ethical values to consider?**

   While constructing and evaluating ethical arguments can be a helpful tool in ethical decision making, there are other considerations. Before making a final decision about what to do, a person should consider possible alternative actions or ethical values other than those contained in the argument. Making an ethical decision should involve examining as many sides of an issue as possible before choosing a course of action.
And the Point Is?

By this time, you may be asking why you should bother to learn how to construct and evaluate ethical arguments. Ethical arguments are a tool you can use for the rest of your life to help you think through controversial issues and determine what actions you think are right.

Sometimes constructing an ethical argument can show you inconsistencies between what you say you believe (your ethical principles) and your actions. Sometimes ethical arguments can help you decide what position to take on an issue when you were undecided before. As you research the facts about an issue and carefully think about your ethical principles, you will learn more about the issue and about yourself.

Learning how to evaluate an ethical argument takes careful thought. People who want to convince you to believe and act a certain way often present information as “facts.” Knowing how to verify the truth of their “facts” and how to understand the values involved in their argument can help you decide whether you think the action they are recommending is right or not.

Learn the Language

Claims
Empirical claims and ethical claims presented as evidence to support the conclusion of an ethical argument

Controversial issue
An issue for which there is strong disagreement

Critical thinking
Carefully evaluating the evidence offered in support of a claim

Empirical claim
Information presented as truth that often can be independently verified

Ethical argument
A framework for making ethical decisions consisting of empirical claims and ethical claims that support taking a specific action

Ethical conclusion
The specific action recommended in an ethical argument – what people should do relating to a specific problem or issue

Ethical claims
General statements of values about what is right or wrong

Ethics
Critical thinking about right and wrong action

Credit Note
The information in this handout was provided and/or reviewed by Kristen Hessler, Bioethics Outreach Coordinator, Office of Biotechnology, Iowa State University.
Building and Evaluating Ethical Arguments

Ethics is different from science because we cannot test the truth of statements about ethics in a laboratory. But this does not mean that people should not try to support their ethical views as best they can. For example, if people tell you that you have an ethical duty to support or not to support the use of pre-implantation genetic diagnosis, those people should be able to back up their claims with good evidence.

In doing so, they should offer two different kinds of evidence: empirical claims and ethical claims. Empirical claims are, or are presented as if they are, facts about the world. Ethical claims are claims about ethical values. “We ought to respect other people's rights” is an ethical claim.

Instructions

Read the following scenario that is based on a real-life controversy about whether it is ethical to use pre-implantation genetic diagnosis to select for a cell donor for an existing child. After reading the scenario, read the numbered statements on the next page. Using what you have learned about empirical claims, ethical claims, and ethical conclusions, categorize the statements by writing the number of each statement in the appropriate column.

Scenario

A couple in Minnesota gave birth to their first child, Molly, in 1996. Molly was diagnosed with Fanconi's anemia, a rare blood condition with no known cure. Sufferers of Fanconi's anemia usually die in their 20s.

Molly's parents used in vitro fertilization (IVF) to conceive their next child. Once IVF had produced several embryos, pre-implantation genetic diagnosis was used to screen them both for absence of Fanconi's anemia and also for suitability as a donor for Molly. Molly's younger brother, Adam, was born in 2001, and his umbilical cord blood was used for an infusion that cured Molly.

Was it ethical for Molly's parents to use PGD to produce a sibling donor for Molly?
Using what you have learned about empirical claims and ethical claims, categorize the statements by writing the number of each statement in the appropriate column below.

1. Fanconi’s anemia is a rare blood condition with no known cure.
2. PGD should not be used at all because of potential associated risks to embryonic development.
3. Using PGD to give birth to a donor for Molly is the best thing that could have been done under the circumstances.
4. *In vitro* fertilization should not be used because it results in extra human embryos that end up being discarded.
5. Science should be used to help cure illness.
6. We should try to prevent childhood sickness and death.
7. Parents should be allowed to use PGD because no alternative cures are available right now.
8. There are no proven risks to embryonic development resulting from pre-implantation genetic diagnosis.
9. PGD will benefit carriers of genetic diseases.
10. Many children suffer from diseases that could be treated by cells from a sibling donor.
11. PGD should be used to select sibling donors because it will cure many children currently suffering from terminal illnesses.
12. The use of PGD to select sibling donors is unfair to the person ultimately born as a result of the process.
13. We should never use a person merely as a means to improve the welfare of someone else.
14. PGD gives parents unprecedented control over the genetic attributes of their children.
15. We should not choose which children will live depending on whom they can help.
16. PGD is a very expensive procedure.
17. Currently, thousands of unused embryos leftover from IVF procedures are still frozen in fertility clinics around the country.
18. Even when we know that we can do something, we should still ask whether we should do it.

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The Nash Case

In this activity, you will practice building and evaluating ethical arguments. Your group's job is to read the following scenario and build an ethical argument supporting the ethical conclusion that your teacher assigns to your group. Write your assigned ethical conclusion and your claims under the appropriate underlined headings below. Use another sheet of paper if you need more space. Do not write anything under the Evaluation section for now.

Scenario

A couple in Minnesota gave birth to their first child, Molly, in 1996. Molly was diagnosed with Fanconi’s anemia, a rare blood condition with no known cure. Sufferers of Fanconi’s anemia usually die in their 20s.

Molly’s parents used in vitro fertilization (IVF) to conceive their next child. Once IVF had produced several embryos, pre-implantation genetic diagnosis was used to screen them both for absence of Fanconi’s anemia and also for suitability as a donor for Molly. Molly's younger brother, Adam, was born in 2001, and his umbilical cord blood was used for an infusion that cured Molly.

Was it ethical for Molly's parents to use PGD to select for a healthy donor for Molly?

Ethical Argument

Built by (names of group members)

Empirical Claims
Ethical Claims

Ethical Conclusion

Evaluation

Evaluated by (names of group members)

1. What empirical claims, if any, do you challenge and why?
2. What ethical claims, if any, do you challenge and why?

3. Do you accept the ethical conclusion as being true? Why or why not?
4. How would you improve this ethical argument?
Ethics

Ethics can be defined as **critical thinking** about **right and wrong action**.

- **Critical thinking** means careful, thoughtful study and not relying on intuition alone or friends’ opinions.

- **Right and wrong actions** are those actions that we should or should not do from an ethical perspective.
A Model for Making Ethical Decisions

A model is a framework that can help accomplish a task or clarify a situation. For example:

- Weather forecasters use computer models of air masses to help predict the weather.
- Soil scientists use models to clarify how water moves through a crop field.
A Model for Making Ethical Decisions

• An ethical argument is a model used to help people think about controversial questions and arrive at a decision that is right for them.

• Ethical arguments have three parts:
  – Empirical claims
  – Ethical claims
  – Ethical conclusion
Constructing An Ethical Argument

Empirical Claims + Ethical Claims = Ethical Conclusion

- **Empirical claims** state information alleged to be true, such as the risks or benefits of an action.

- **Ethical claims** are general claims about values, such as “It is good to respect the rights of other people.”

- The **ethical conclusion** is the specific action to be done if the empirical claims and ethical claims are accepted as true.
Example of An Ethical Argument

Which of the following statements is

- an empirical claim?
- an ethical claim?
- an ethical conclusion?

1. We should never do any genetic engineering.

2. Genetic engineering moves genes between species.

3. We should never do anything unnatural.

4. Moving genes between species is unnatural.
Example of An Ethical Argument

**Empirical Claim**
Moving genes between species is unnatural.

**Empirical Claim**
Genetic engineering moves genes between species.

**Ethical Claim**
We should never do anything unnatural.

**Ethical Conclusion**
We should never do any genetic engineering.
Three Ways to Evaluate An Ethical Argument

Empirical Claims + Ethical Claims = Ethical Conclusion

1. To evaluate an ethical argument, determine if the conclusion is supported by the claims (empirical claims and ethical claims).

2. If the claims support the conclusion, determine if the claims really are true.

3. Determine if there are possible alternative actions or other ethical values to consider before making a final decision.
Evaluating An Ethical Argument

A strong ethical argument has several true claims to support the conclusion.
Evaluating an Example
Ethical Argument

Evaluating the truth of the claims in the ethical argument about genetic engineering reveals several points to challenge:

Empirical Claim

Moving genes between species is unnatural.

Possible challenges:
• What is natural or unnatural?

• Viruses move genes between species “naturally.”

• Human beings are a part of nature, so maybe everything we do is natural.
Evaluating an Example
Ethical Argument

Empirical Claim

Genetic engineering moves genes between species.

Possible challenges: None. This claim is true because that is the description of genetic engineering.
Evaluating an Example
Ethical Argument

Ethical Claim
We should never do anything unnatural.

Possible challenges:
• Should we never drive cars?
• Should we never use penicillin?
• Should we never do surgery?
• Should we never have bred plants and animals to suit our purposes?
Evaluating an Example
Ethical Argument

We should never do any genetic engineering.

True or Not?
Because the claims support the conclusion, if the claims are true, the conclusion must be true.
Evaluating an Example
Ethical Argument

Ethical Conclusion
We should never do any genetic engineering.

True or Not?
If you reject any of the claims, you should consider alternatives. For example:

Alternative Ethical Conclusion
Moving genes between species is ethically OK, if it does not put the environment at risk.
And the Point Is?

Why should you learn how to construct ethical arguments?

• They are a tool you can use for the rest of your life to think through controversial issues and determine what actions you think are right.

• They can help you see inconsistencies between your ethical principles and your actions.

• As you research an issue and carefully think about your ethical principles, you can learn more about the issue and yourself.
Ethical Issues: Pre-Implantation Genetic Diagnosis

Part II
BACKGROUND INFORMATION

Introduction
Scientists can create a human embryo by fertilizing an egg cell in a petri dish in the laboratory. This process is called in vitro fertilization, or IVF (“In vitro” is a Latin phrase that literally means “in glass.”) The first baby conceived using IVF, Louise Brown, was born in England in 1978. Since then, more than 20,000 babies have been born who began life as embryos created using IVF.

During a pregnancy, there are several ways to determine whether the fetus is healthy. Two well-known screening procedures for the fetuses of pregnant women include ultrasound, a non-invasive procedure that uses sound waves to produce an image of the fetus in the womb, and amniocentesis, a procedure in which cells are extracted from within the placenta.

Teachers may wish to show students an image of an ultrasound that can be found at www.ob-ultrasound.net/frames.htm.

When an embryo is created using IVF, it can be genetically screened in the laboratory before a pregnancy has begun. This screening process is called pre-implantation genetic diagnosis, or PGD. The PGD process would begin by fertilizing several eggs using IVF. The resulting embryos can be screened at about three days old, when they are comprised of about eight identical cells. Alternatively, the embryo may be screened at the blastocyst stage, when it is about five days old and consists of about 100 cells. In each case, one cell is removed from the embryo for genetic analysis.

PGD can help carriers of genetic diseases avoid passing on these conditions to their offspring. For example, cystic fibrosis (CF) is a disease caused by a single defective gene. The disease produces mucus that clogs the lungs, leading to lung infections and difficult breathing that worsens as time goes on. While medical treatment has improved in recent years, people with CF generally do not survive long past age thirty.

CF is a recessive genetic condition, which means that a person would have to inherit two copies of the defective gene (one from each parent) in order to suffer from CF. People who inherit only one copy of the defective gene are carriers for the disease, but they are not affected by the symptoms of CF. Because it is a recessive condition, two parents who are both unaffected carriers have a 25% chance of producing an affected child, a 50% chance of producing a carrier, and a 25% chance of producing a normal child.

Because the most common genetic defect that causes CF is known, it is possible to screen an embryo to determine whether it will result in an affected (cc) child.

Other conditions that can be diagnosed using PGD include the following:

**Tay-Sachs**
Like cystic fibrosis, Tay Sachs disease is a monogenic recessive condition. Affected persons cannot produce an essential enzyme, with the result that the central nervous system accumulates a fatty substance that destroys cells. Most affected children die from this disease by age five.

**Down Syndrome**
Down Syndrome occurs when a person has three copies of a chromosome (usually chromosome 21) that is referred to as Trisomy 21. Affected persons experience varying degrees of intellectual impairment and show other physical symptoms. Teachers may wish to show students images obtained through amniocentesis of a normal set of chromosomes compared to Trisomy 21.
Hemophilia A
The most common type of hemophilia is caused by a gene on the X chromosome. It is a recessive disorder that affects only males. The condition is marked by incomplete clotting, leading to excessive bleeding. Using IVF, embryos can be sorted by sex and only female embryos implanted.

Non-medical sex selection
PGD can be used to select the sex of a baby for non-medical reasons.

Ethical Issues
Pre-implantation genetic diagnosis (PGD) makes it possible to screen an embryo before a pregnancy has begun. PGD, therefore, provides a reproductive option for parents who are not willing to risk the chance of delivering a baby with a serious genetic condition.

In the process of in vitro fertilization (IVF), especially where IVF is used primarily to avoid a pregnancy with a genetically defective fetus, more embryos are created than are actually implanted in the woman’s uterus. This means that some embryos will be left over, either because they are extras or because PGD has shown that they contain the genetic defect the couple is trying to avoid passing on to their offspring. These embryos will either be discarded or remain frozen indefinitely. It is estimated that over 200,000 frozen embryos currently exist in the United States alone as a result of IVF procedures.

It is possible that there are risks to children that develop from embryos that have been subjected to PGD. In the process of PGD, a single cell from the embryo is removed at the blastocyst stage. In theory, this should not affect further development of the embryo. However, conclusive evidence on this issue is not available.

PGD can be used for purposes other than avoiding a pregnancy with a fetus with a serious genetic condition. For example, there have been several cases in which parents have used PGD in order to give birth to a child who could serve as a cell donor for an existing sick child. PGD also is used to select the sex of children for the sake of “family balancing.”

Some people are concerned about potential uses of this technology. As the genetic basis for more traits is discovered, some fear that parents will use PGD to select embryos for their genetic dispositions to be tall, intelligent, athletic, or artistic.

Eugenics
It is important to understand the history of the eugenics movement to fully understand the ethical controversy surrounding the use of PGD today. The word “eugenics” derives from Greek words meaning “well-born” or “good genes.” Proponents of eugenics programs hoped to improve the human race, in much the same way that animal breeders try to develop superior breeds of animals, either by eliminating characteristics deemed undesirable or by creating a greater number of people that possess exemplary characteristics.

Proponents of the eugenics movement adopted a highly biased conception of what traits were “desirable” or “undesirable.” This problem had both scientific and ethical elements. The ethical problem with many eugenicists’ determinations of which traits were desirable or undesirable was that traits likely to be displayed by the affluent upper classes, such as “scholarship,” were deemed desirable, and families exhibiting them were encouraged to grow. Traits more likely to be displayed by less affluent classes, such as illiteracy, were deemed undesirable. Many eugenicists also associated such traits with entire races. Whites, especially those deriving from northern European stock, were deemed superior to other races. It is this racial connection that explains why eugenicists in the U.S. favored immigration restrictions that allowed fewer immigrants from countries whose people displayed “undesirable” traits. Scientifically, it is unclear what some traits, like “feeblemindedness” or “scholarship,” actually meant. They were used as general terms of condemnation or approval.

When considering how or whether PGD should be used to diagnose genetic defects, it is important to keep in mind that this decision involves a judgment about which genes ought to be reproduced. This is not necessarily unethical. However, given the history of the eugenics movement, it is important not to repeat the mistakes of the eugenics movement, especially the mistakes of assuming that we know more than we do about the inheritance of complex behavioral traits and of making biased judgments about which traits are desirable or undesirable.
Genetic Counseling

Although eugenics has been discredited both scientifically and ethically, it can be an important service to help people understand how their genetic inheritance may affect their own lives or the prospects for their children. In the late 1940's, a doctor named Sheldon Reed at the University of Minnesota described a new profession called genetic counseling, which would provide information about genetic inheritance and support to couples and families in which genetic conditions are an issue.8

In Dr. Reed's view, genetic counseling would provide pregnant women and couples with genetic information relevant to their reproductive decisions, including analyzing family pedigrees where appropriate. Genetic counselors would leave all reproductive decisions up to the particular family or couple seeking counseling. This contrasts with the intentions of eugenicists, who felt that they could determine objectively which traits were good or bad and who wanted to restrict people's reproductive decisions rather than help them make their own decisions.

Today, genetic counseling is a growing profession. Genetic counselors work with people with a history of genetic disease who are starting a family, people who might have a genetic predisposition for disease, and many others.

Footnotes

1 Gregory Pence, Classic Cases in Medical Ethics (McGraw-Hill, 2000), Chapter 5.

2 Georgia Reproductive Specialists: www.ivf.com/ivffaq.html

3 www-medlib.med.utah.edu/WebPath/TUTORIAL/PRENATAL/PRENATAL.html

4 President's Commission on Bioethics, "Reproduction and Responsibility: The Regulation of New Biotechnologies," Chapter 3

5 National Tay-Sachs and Allied Diseases Association: www.ntsad.org/pages/t-sachs.htm

6 National Hemophilia Foundation: www.hemophilia.org/bdi/bdi_types1.htm


8 www.accessexcellence.org/AE/AEC/CC/counseling_background.html

Resources

Human Genome Project Information, Genetic Counseling: www.ornl.gov/sci/techresources/Human_Genome/medicine/genecounseling.shtml


University of Minnesota, Genetic Testing and Screening Resources: www.bioethics.umn.edu/resources/topics/genetest_screening.shtml

University of Minnesota, Reproductive Technologies Resources: www.bioethics.umn.edu/resources/topics/reproductive_tech.shtml
Ethical Issues: Pre-Implantation Genetic Diagnosis

TEACHING RESOURCES

Lesson Plan: Ethics Review Board Role Play

Your class will play the role of the Ethics Review Board for General Hospital. The review board has to determine a policy for the hospital regarding whether pre-implantation genetic diagnosis should be permitted for certain purposes.

Science Education Standards

Science as Inquiry, Content Standard A
- Abilities necessary to do scientific inquiry (p. 175)
- Understandings about scientific inquiry (p. 176)

Life Science, Content Standard C
- The molecular basis of heredity (p. 185)

Science and Technology, Content Standard E
- Abilities of technological design (p. 192)
- Understandings about science and technology (p. 192)

Science in Personal and Social Perspectives, Content Standard F
- Personal and community health (p. 197)
- Science and technology in local, national, and global challenges (p. 199)

History and Nature of Science, Content Standard G
- Science as a human endeavor (p. 200)


Science Process Skills
- Observing
- Comparing/measuring
- Relating
- Applying

Life Skills
- Communication
- Science processing

Time
Preparation: One hour
Activity: Two one-hour class periods, plus a 20-minute follow-up session.

Materials
Make copies of the material from the section labeled “Activity Resources” on p. 199. These are all available online, so educators can simply print them out for distribution to students. Alternatively, students may be sent to the Web sites listed as resources for their respective subcommittees. Make four copies, one for each group of students, of the handouts Ethical Issues-6, -7, and -8 on p. 207-212.

Optional: Make one copy for each student of student handouts Ethical Issues-4 and -5 on p. 201-206. Make overhead transparencies from the masters, Ethical Issues-o through -s on p. 213-221.

Procedure

Day 1

1. Present background information on pre-implantation genetic diagnosis. Teachers may wish to use the student handout Learning More About: Pre-Implantation Genetic Diagnosis, Ethical Issues-4 on p. 201-204.

2. Tell the class that they will play the role of the Ethics Review Board for General Hospital, a local public hospital. The Review Board has to determine a policy for the Hospital regarding whether pre-implantation genetic diagnosis should be permitted for the following purposes:

   a. To help two cystic fibrosis carriers avoid passing on this disease to their offspring
   b. To help a couple produce umbilical cord cells for an existing child with Fanconi’s anemia
   c. To help a couple select the sex of their child for family balancing
   d. To help a short couple produce a taller child

3. Explain to the class that the Ethics Review Board will form subcommittees to study each of these issues. Tell the students that, in addition to serving
on the Ethics Review Board, they will also serve on one of these subcommittees. Each subcommittee must prepare a five-minute presentation explaining their policy recommendation on the particular application of PGD that they studied.

4. Divide the class randomly into four groups. Provide each group with the role play resources and a copy of the Subcommittee Worksheet, Ethical Issues-6 on p. 207-208, and the Subcommittee Report form, Ethical Issues-7, on p. 209-210. Ask each group to use the Subcommittee Worksheet to help them analyze their issue and to fill out the Subcommittee Report form and use it as a basis for their presentations. Use any remaining time for the groups to begin their research.

Day 2

1. Each subcommittee will make a five-minute presentation to the class, summarizing the ethical considerations of allowing the particular use of PGD that they studied. The subcommittee should also make a recommendation to the Ethics Review Board regarding the policy they think is most ethically defensible for the specific application of PGD.

2. After each presentation, the rest of the class (representing the Ethics Review Board) will have 10 minutes to discuss the presentation and to question the subcommittee members. At the end of the 10 minutes, the entire Ethics Review Board will vote on whether to allow the application of PGD under discussion at General Hospital. On the basis of the discussion and vote, the Ethics Review Board will compose a report for each proposed use of PGD. Use the Ethics Review Board Final Report form, Ethical Issues-8 on p. 211-212, for this purpose.

Activity Resources

For Ethics Review Board


- BioTeach, “Preimplantation Genetic Diagnosis and Our Future.” Available online: http://bioteach.ubc.ca/Bioethics/PreimplantationGeneticDiagnosisAndOurFuture/index.htm

For Subcommittee on Use of PGD to Avoid Passing on CF

- Cystic Fibrosis Foundation, About Cystic Fibrosis. Available online: www.cff.org/about_cf/what_is_cf/


For Subcommittee on Use of PGD to Produce Cord-Blood Donor


- WebMD, “Sibling Selection.” Available online: http://my.webmd.com/content/article/33/1728_82311?printing=true

For Subcommittee on Use of PGD to Select the Sex of the Child


For Subcommittee on Use of PGD to Produce a Taller Child

- Tania Simoncelli, “Pre-Implantation Genetic Diagnosis and Selection: From Disease Prevention to Customized Conception.” Available online: www.genetics-and-society.org/resources/cgs/index.html
For Further Exploration

Eugenics Archive
www.eugenicsarchive.org/eugenics/

EIBE Unit: Issues in Human Genetics
www.eibe.info/

MoSt GeNe
www.mostgene.org/index.htm
Introduction

Scientists can create a human embryo by fertilizing an egg cell in a petri dish in the laboratory. This process is called in vitro fertilization, or IVF (“In vitro” is a Latin phrase that literally means “in glass.”) The first baby conceived using IVF, Louise Brown, was born in England in 1978. Since then, more than 20,000 babies have been born who began life as embryos created using IVF.

During a pregnancy, there are several ways to determine whether the fetus is healthy. Two well-known screening procedures for the fetuses of pregnant women include ultrasound, a non-invasive procedure that uses sound waves to produce an image of the fetus in the womb, and amniocentesis, a procedure in which cells are extracted from within the placenta.

When an embryo is created using IVF, it can be genetically screened in the laboratory before a pregnancy has begun. This screening process is called pre-implantation genetic diagnosis, or PGD. The PGD process would begin by fertilizing several eggs using IVF. The resulting embryos can be screened at about three days old, when they are comprised of about eight identical cells. Alternatively, the embryo may be screened at the blastocyst stage, when it is about five days old and consists of about 100 cells. In each case, one cell is removed from the embryo for genetic analysis.

PGD can help carriers of genetic diseases avoid passing on these conditions to their offspring. For example, cystic fibrosis (CF) is a disease caused by a single defective gene. The disease produces mucus that clogs the lungs, leading to lung infections and difficult breathing that worsens as time goes on. While medical treatment has improved in recent years, people with CF generally do not survive long past age thirty.

CF is a recessive genetic condition, which means that a person would have to inherit two copies of the defective gene (one from each parent) in order to suffer from CF. People who inherit only one copy of the defective gene are carriers for the disease, but they are not affected by the symptoms of CF. Because it is a recessive condition, two parents who are both unaffected carriers have a 25% chance of producing an affected child, a 50% chance of producing a carrier, and a 25% chance of producing a normal child.

Because the most common genetic defect that causes CF is known, it is possible to screen an embryo to determine whether it will result in an affected (cc) child.

Other conditions that can be diagnosed using PGD include the following:

Tay-Sachs
Like cystic fibrosis, Tay Sachs disease is a monogenic recessive condition. Affected persons cannot produce an essential enzyme, with the result that the central nervous system accumulates a fatty substance that destroys cells. Most affected children die from this disease by age five.

Down Syndrome
Down Syndrome occurs when a person has three copies of a chromosome (usually chromosome 21) that is referred to as Trisomy 21. Affected persons experience varying degrees of intellectual impairment and show other physical symptoms.
Hemophilia A
The most common type of hemophilia is caused by a gene on the X chromosome. It is a recessive disorder that affects only males. The condition is marked by incomplete clotting, leading to excessive bleeding. Using IVF, embryos can be sorted by sex and only female embryos implanted.

Non-medical sex selection
PGD can be used to select the sex of a baby for non-medical reasons.

Ethical Issues
Pre-implantation genetic diagnosis (PGD) makes it possible to screen an embryo before a pregnancy has begun. PGD, therefore, provides a reproductive option for parents who are not willing to risk the chance of delivering a baby with a serious genetic condition.

In the process of in vitro fertilization (IVF), especially where IVF is used primarily to avoid a pregnancy with a genetically defective fetus, more embryos are created than are actually implanted in the woman's uterus. This means that some embryos will be left over, either because they are extras or because PGD has shown that they contain the genetic defect the couple is trying to avoid passing on to their offspring. These embryos will either be discarded or remain frozen indefinitely.

It is estimated that over 200,000 frozen embryos currently exist in the United States alone as a result of IVF procedures.

It is possible that there are risks to children that develop from embryos that have been subjected to PGD. In the process of PGD, a single cell from the embryo is removed at the blastocyst stage. In theory, this should not affect further development of the embryo. However, conclusive evidence on this issue is not available.

PGD can be used for purposes other than avoiding a pregnancy with a fetus with a serious genetic condition. For example, there have been several cases in which parents have used PGD in order to give birth to a child who could serve as a cell donor for an existing sick child. PGD also is used to select the sex of children for the sake of “family balancing.”

Some people are concerned about potential uses of this technology. As the genetic basis for more traits is discovered, some fear that parents will use PGD to select embryos for their genetic dispositions to be tall, intelligent, athletic, or artistic.

Eugenics
It is important to understand the history of the eugenics movement to fully understand the ethical controversy surrounding the use of PGD today. The word “eugenics” derives from Greek words meaning “well-born” or “good genes.” Proponents of eugenics programs hoped to improve the human race, in much the same way that animal breeders try to develop superior breeds of animals, either by eliminating characteristics deemed undesirable or by creating a greater number of people that possess exemplary characteristics.

Proponents of the eugenics movement adopted a highly biased conception of what traits were “desirable” or “undesirable.” This problem had both scientific and ethical elements. The ethical problem with many eugenicists’ determinations of which traits were desirable or undesirable was that traits likely to be displayed by the affluent upper classes, such as “scholarship,” were deemed desirable, and families exhibiting them were encouraged to grow. Traits more likely to be displayed by less affluent classes, such as illiteracy, were deemed undesirable. Many eugenicists also associated such traits with entire races. Whites, especially those deriving from northern European stock, were deemed superior to other races.

Scientifically, it is unclear what some traits, like “feeblemindedness” or “scholarship,” actually meant. They were used as general terms of condemnation or approval.

When considering how or whether PGD should be used to diagnose genetic defects, it is important to keep in mind that this decision involves a judgment about which genes ought to be reproduced. This is not necessarily unethical. However, given the history of the eugenics movement, it is important not to repeat the mistakes of the eugenics movement, especially the mistakes of assuming that we know more than we do about the inheritance of complex behavioral traits and of making biased judgments about which traits are desirable or undesirable.

Genetic Counseling
Although eugenics has been discredited both scientifically and ethically, it can be an important service to help people understand how their genetic inheritance may affect their own lives or the prospects for their children.
In the late 1940's, a doctor named Sheldon Reed at the University of Minnesota described a new profession called **genetic counseling**, which would provide information about genetic inheritance and support to couples and families in which genetic conditions are an issue.8

In Dr. Reed's view, genetic counseling would provide pregnant women and couples with genetic information relevant to their reproductive decisions, including analyzing family pedigrees where appropriate. Genetics counselors would leave all reproductive decisions up to the particular family or couple seeking counseling. This contrasts with the intentions of eugenicists, who felt that they could determine objectively which traits were good or bad and who wanted to restrict people's reproductive decisions rather than helping them make their own decisions.

Today, genetic counseling is a growing profession. Genetic counselors work with people who are starting a family, people who might have a genetic predisposition for disease, and many others.

**Footnotes**


2 Georgia Reproductive Specialists: www.ivf.com/ivfaq.html

3 www-medlib.med.utah.edu/WebPath/TUTORIAL/PRENATAL/PRENATAL.html


5 National Tay-Sachs and Allied Diseases Association: www.ntsad.org/pages/t-sachs.htm

6 National Hemophilia Foundation: www.hemophilia.org/bdi/bdi_types1.htm


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**Resources**

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University of Minnesota, Genetic Testing and Screening Resources: www.bioethics.umn.edu/resources/topics/gentest_screening.shtml

University of Minnesota, Reproductive Technologies Resources: www.bioethics.umn.edu/resources/topics/reproductive_tech.shtml

**Learn the Language**

**Amniocentesis**

A procedure in which cells are extracted from within the placenta

**Embryo**

In humans, the early stages of development between about two weeks after conception up to eight weeks of pregnancy, before most recognizably human physical features are present

**Eugenics**

Attempts to improve the human race either by eliminating characteristics deemed undesirable or by creating a greater number of people that possess exemplary characteristics

**Fetus**

In humans, the stage of development between the embryonic stage and birth

**Genetic counseling**

Providing information about genetic inheritance and support to people from families in which genetic conditions are an issue

**In vitro fertilization (IVF)**

Joining an egg and sperm in a laboratory
Pre-implantation genetic diagnosis (PGD)

The genetic screening of an embryo created using in vitro fertilization to determine whether the embryo should be implanted into a woman’s uterus to begin a pregnancy.

Recessive

An allele (r) that expresses itself in a phenotype only in homozygous individuals (rr)

Ultrasound

A procedure that uses sound waves to produce an image of a developing baby in the womb.
Pre-Implantation Genetic Diagnosis

In this activity, you will play the role of the Ethics Review Board for General Hospital, a local public hospital. The Review Board has to determine a policy for the hospital regarding whether pre-implantation genetic diagnosis (PGD) should be permitted for the following purposes:

a. To help two cystic fibrosis carriers avoid passing on this disease to their offspring
b. To help a couple produce umbilical cord cells for an existing child with Fanconi’s anemia
c. To help a couple select the sex of their child for family balancing
d. To help a short couple produce a taller child

The Ethics Review Board will form subcommittees to study each of these issues. In addition to serving on the Ethics Review Board, you also will serve on one of these subcommittees. Each subcommittee must prepare a five-minute presentation explaining their policy recommendation on the particular application of PGD that they studied.

Below are some Internet resources that you can use to prepare your subcommittee's presentation. As you are doing your research, fill out the Subcommittee Worksheet on p. 207-208 to help you analyze your issue. Complete the Subcommittee Report form on p. 209-210 to help you prepare your presentation.

Role Play Resources

For Ethics Review Board

- BioTeach, “Preimplantation Genetic Diagnosis and Our Future.” Available online: http://bioteach.ubc.ca/Bioethics/PreimplantationGeneticDiagnosisAndOurFuture/index.htm

For Subcommittee on Use of PGD to Avoid Passing on CF

- Cystic Fibrosis Foundation, About Cystic Fibrosis. Available online: www.cff.org/about_cf/what_is_cf/

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  Available online:
  www.genetics-and-society.org/resources/cgs/index.html
General Hospital Ethics Review Board

Subcommittee Worksheet

Use of PGD studied:

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<th>Decision: Use of PGD permitted at General Hospital</th>
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... and justice for all

The U.S. Department of Agriculture (USDA) prohibits discrimination in all its programs and activities on the basis of race, color, national origin, gender, religion, age, disability, political beliefs, sexual orientation, and marital or family status. (Not all prohibited bases apply to all programs.) Many materials can be made available in alternative formats for ADA clients. To file a complaint of discrimination, write USDA, Office of Civil Rights, Room 326-W, Whitten Building, 14th and Independence Avenue, SW, Washington, DC 20250-9410 or call 202-720-5964.

General Hospital Ethics Review Board
Subcommittee Report

Use of PGD studied:

Recommendations:

1. The results of the Subcommittee's deliberations are:

- [ ] No decision was reached (please skip to #3 on reverse side.)
- [ ] This use of PGD should be permitted:
  - [ ] Under any circumstances
  - [ ] Subject to the following conditions/exceptions:

- [ ] This use of PGD should not be permitted:
  - [ ] Under any circumstances
  - [ ] Subject to the following conditions/exceptions:

Conditions/exceptions (if any):

2. Explain the empirical and ethical claims that support your decision.
3. The Subcommittee did not reach a decision because we:

☐ Could not ascertain relevant empirical claims (list uncertainties below):

☐ Could not agree on relevant ethical claims (explain disagreement below):

☐ Could not agree about reasoning process (explain below):
General Hospital Ethics Review Board
Final Report on PGD

Subcommittee _______________________________
Class/Section _______________________________

Use of PGD:

Recommendations:

1. The results of the Ethics Review Board's deliberations are:

- [ ] No decision was reached (please skip to #3 on reverse side.)
- This use of PGD [ ] SHOULD [ ] SHOULD NOT be permitted
- Under any circumstances [ ] Subject to the following conditions/exceptions:

2. Explain the empirical and ethical claims that support your decision.


3. The Ethics Review Board did not reach a decision because we:

☐ Could not ascertain relevant empirical claims (list uncertainties below):

☐ Could not agree on relevant ethical claims (explain disagreement below):

☐ Could not agree about reasoning process (explain below):

... and justice for all

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**General Hospital Ethics Review Board**

**Subcommittee Worksheet**

**Lesson Module III – Ethical Issues**

Subcommittee _______________________________

Class/Section _______________________________

Use of PGD studied:__________________________

<p>| Decision: Use of PGD permitted at General Hospital |</p>
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*Lesson Module III – Ethical Issues*
Use of PGD studied:_______________________________________________________________________________

Recommendations:

1. The results of the Subcommittee's deliberations are:

| □ No decision was reached (please skip to #3 on reverse side.) |
| □ This use of PGD should be permitted: | □ This use of PGD should not be permitted: |
| □ Under any circumstances □ Subject to the following conditions/exceptions: | □ Under any circumstances □ Subject to the following conditions/exceptions: |

2. Explain the empirical and ethical claims that support your decision.
3. The Subcommittee did not reach a decision because we:

☐ Could not ascertain relevant empirical claims (list uncertainties below):

☐ Could not agree on relevant ethical claims (explain disagreement below):

☐ Could not agree about reasoning process (explain below):
General Hospital Ethics Review Board

Final Report on PGD

Use of PGD: ____________________________________________

Recommendations:

1. The results of the Ethics Review Board's deliberations are:

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This use of PGD ☐ SHOULDN'T ☐ SHOULDN'T be permitted

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<td>Subject to the following conditions/exceptions:</td>
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2. Explain the empirical and ethical claims that support your decision.

Lesson Module III – Ethical Issues

Iowa State University Extension and ISU Office of Biotechnology
3. The Ethics Review Board did not reach a decision because we:

☐ Could not ascertain relevant empirical claims (list uncertainties below):

☐ Could not agree on relevant ethical claims (explain disagreement below):

☐ Could not agree about reasoning process (explain below):