

Lesson 3

Case Study: One Family's Dilemma

Objectives

Students will be able to:

- Describe major biomedical ethical principles.
- Analyze how a particular position relates to the principles.

Class Time

About 1 class period, depending on the amount of discussion and how much is given as homework before the lesson.

Prior Knowledge Needed

- An understanding of *in vitro* fertilization techniques.
- How to have a discussion in which it is safe to have different opinions from classmates.

Introduction

In this lesson, students are introduced to the major principles of biomedical ethics: respect for persons, beneficence / nonmaleficence, and justice (definitions are provided on the next page). Next, they examine a case study in which the parents of two children born with the help of *in vitro* fertilization techniques are asked to decide the fate of their remaining frozen embryos. Students identify the bioethical principle given priority in their own solution to the dilemma posed in the case study.

Key Concepts

- Ethics is a discipline, or organized system of thought, concerned with questions about what is right and wrong and what kind of person each individual should strive to be.
- Bioethical dilemmas can be evaluated using various ethical perspectives. The bioethical principles introduced are:
 - Respect for Persons (Autonomy)
 - Beneficence (Do good)
 - Nonmaleficence (Do no harm)
 - Justice (Be fair)
- It is important to provide a sound justification and argument for choosing an ethical perspective when options in a bioethical dilemma are identified.

Materials

Poster Paper and Marker

Student Handouts:

3.1 – *Case Study: One Family's Dilemma*

3.2 – *Decisions, Decisions*

3.3 – *My Perspective*

3.4 – *Bioethical Principles and Embryonic Stem Cells*

Teacher Resources:

Sample answers for Handout 3.2 and 3.4

Skit Improvisation List

Procedure

A. Introduction to the Principles of Bioethics through Skits

- 1 Up to this point, we have been focusing on the science behind the use of stem cells for research. As we enlarge our view to include societal issues and examine the debate over the use of stem cells, students will be exposed to many valid and conflicting viewpoints. Tell students that many bioethical dilemmas are evaluated using various ethical perspectives. Introduce ethics as a discipline or organized system of thought that reflects on and studies the moral life. It is concerned with questions about what is right and wrong and what kind of person each individual should strive to be.
- 2 As students are exposed to conflicting points of view, it is important to find a way to keep discussions manageable in the classroom. Some suggestions for conducting classroom discussions and setting norms can be found in the Appendix.
3. In this activity, students perform skits first, then derive the ideas underlying the Principles of Bioethics taught in this unit during a teacher-led discussion. The skits provide a way for students to show their awareness of concepts supporting the Principles of Bioethics even though they may not have the precise vocabulary to explain it as such. The teacher will know which bioethical principle is being introduced (in parentheses after 1-6, below) but the students will not. After each set of skits and class discussion, the teacher should name the principle and write it down for the class to see.
 - a. Choose 6 pairs of students to come to the front of the class to improvise 30-second role-plays of interactions between a parent and child. These are groups 1-6. Groups 5 and 6 can choose a third student to act as the sibling, if desired.
 - b. Give each group of students one of the scenarios 1-6, found below in 'c', and as a Teacher Resource.
 - c. Give the students about 2 minutes to prepare to simulate the following interactions between a parent and child. Tell students that it is helpful for them to 'give voice' to the ideas inside a person's head by saying them out loud.

The skits (also found in as a Teacher Resource) are:

1. Parent respecting the child's career choice
(respect for persons, or autonomy)
2. Parent NOT respecting the child's career choice.
(respect for persons, or autonomy)
3. Parent helping child with her homework
(maximizing benefits/minimizing harms)
4. Parent NOT helping child with her homework
(maximizing benefits/minimizing harms)
5. Parent being fair between siblings
(justice)
6. Parent NOT being fair between siblings
(justice)

- d. Have students from groups 1 and 2 present their skits. Ask students, “What code or standard is being honored (or not)?” Students may say ‘respect’ or ‘right to choose for him/herself’. Tell students that one of the bioethical principles is called **Respect for Persons** and that it emphasizes the inherent worth and dignity of each individual, and acknowledges a person’s right to make his or her own choices.
 - e. Write the principle on a poster paper for all to see. This is your class Principles Poster.
 - f. Have students from groups 3 and 4 present their skits. Ask students, “What code or standard is being honored (or not)?” Students may say ‘helping’ or ‘being good’. Tell students that another of the bioethical principles relates to **Doing Good/Doing no Harm**. It asks how we can maximize benefits and minimize harms.
 - g. Add this principle to the poster.
 - h. Have students from groups 5 and 6 present their skits. Ask students, “What code or standard is being honored (or not)?” Students may say ‘fairness’ or ‘equality’. Tell students that the third bioethical principle is called **Justice**. It considers how we can treat people fairly and equitably.
 - i. Add this principle to the poster.
 - j. Leave the Principles Poster with the three bioethical principles up for the remainder of the unit.
4. Introduce these principles to the students:

‘Respect for Persons’

This principle focuses on respect for individuals and their **autonomy**. It acknowledges a person’s right to make choices, to hold views, and to take actions based on personal values and beliefs. It emphasizes the responsibility individuals have for their own lives and the right to self-determination. The rules for informed consent in medicine are derived from the principle of respect for individuals and their autonomy. In medicine, there is also a special emphasis on respecting individuals from vulnerable populations.

Some ethicists also add:

Care – Focus on the maintenance of healthy, caring relationships between individuals and within a community. The principle of care adds context to the traditional principles and can be used in a complimentary way alongside them.

‘Do Good’ / ‘Do no harm’

‘Do Good’ (beneficence) stresses directly helping others, acting in their best interests, and being a benefit to them. It requires positive action.

‘Do No Harm’ (nonmaleficence) relates to one of the most traditional medical guidelines, the Hippocratic Oath (*First of all, do no harm*). The Hippocratic Oath requires that physicians at least do no harm—even if they cannot help their patients.

Justice- ‘Be Fair’

This principle relates to ‘*Giving to each that which is his due*’ (Aristotle). It dictates that persons who are equals should qualify for equal treatment, and that resources, risks, and costs should be distributed equitably.

B. Case Study: One Family’s Dilemma

1. Ask students to read Handout 3.1 — *Case Study: One Family’s Dilemma*. This can be given as homework the night before.
2. Using Handout 3.2, students can list the various options Kathleen and Tom have, and tie these to an ethical principle.

List the options and complete the first column of Handout 3.2 together as a class. Then divide the class into small groups and have each group brainstorm the ethical principle given the most weight for each option, as well as the reason they chose that principle.

Provide an example for illustration. A sound justification and argument is more important than the selection of a particular principle for any one option. The sheet can be completed in small groups, individually in class, or as homework.

Homework

Have students complete Handout 3.3, *My Perspective: Embryonic Stem Cells*. This allows students to reflect more deeply on their particular perspective and allows for reinforcement of the principles discussed in class. Students may want to keep their own position private – writing about their position as homework allows them to do so.

Handout 3.4, *Bioethical Principles and Embryonic Stem Cells*, can also be used as homework. Students complete a chart practicing the application of the principles to the overall question of the use of embryonic stem cell research. This is suitable for advanced classes or those with background in bioethics.

More about the Lesson

Ethicists defend (or justify) their positions using different ethical perspectives and theories. The three principles introduced in this lesson (Respect, Do Good/Do No Harm and Justice) fall under the umbrella of the “Biomedical Principles” ethical perspective. For more information on this ethical theory and others, *An Ethics Primer* is available to download from the Northwest Association for Biomedical Research. It can be found at: <http://www.nwabr.org/education/ethicslessons.html>

In addition, an on-line ethics training course from Family Health International can be found here: <http://www.fhi.org/en/RH/Training/trainmat/ethicscurr/RETCCREn/pr/Contents/SectionIV/b4sl32.htm>

Kathleen and Tom’s story is based on an actual story written for the Boston Globe in 2004. In that case, the couple involved in the decision-making process decided to donate their excess embryos for research. This information should not be revealed to students until they have finished the lesson.

Extensions

Provide students with opinion pieces (articles, letters to the editor, etc...) that they can analyze in order to identify individual positions on stem cell research, and to identify which ethical theory they may be using.

Skit Improvisation List

Cut out the following interactions between a parent and child. Choose 6 pairs of students to improvise 30-second role-plays. Students in groups 5 and 6 can choose a third student to be the sibling, if desired. Give the students about 2 minutes to prepare their scenes.

Skits 1 and 2 relate to *Respect for Persons* (autonomy), skits 3 and 4 relate to *'Do Good'/Do No Harm*, skits 5 and 6 relate to *Justice*.

1. Parent respecting a child's career choice
2. Parent NOT respecting the child's career choice
3. Parent helping child with her homework
4. Parent NOT helping child with her homework
5. Parent being fair between siblings
6. Parent NOT being fair between siblings

One Family's Dilemma

Kathleen knew that there was quite a bit of controversy regarding stem cell research in the news, but it didn't occur to her that it really affected her in any way. Then again, she had never thought the word 'infertility' would apply to her either. Kathleen and Tom were both raised in conservative religious households. She and Tom both came from large families; their parents now have 27 grandchildren. It wouldn't appear that there are any problems with reproduction. How could there be?

Kathleen and Tom made careful plans before their marriage so that they would be prepared for a family: researched career choices, accepted positions with growing software companies in the Seattle area, purchased a house in an area where the schools were highly recommended. Why couldn't she get pregnant? Two years passed, then three before they were able to bring themselves to discuss their apparent infertility and learn about the mind-boggling possibilities in fertility treatments, none of which they wanted to discuss with their seemingly problem-free siblings.

After a long journey through tests and research, Kathleen and Tom had two children through *in vitro* fertilization. The process was lengthy and expensive. After months of painful injections to boost her egg production, Kathleen underwent procedures to have 6-8 eggs removed. The eggs were then fertilized with her husband's sperm in a Petri dish, and the resulting embryos were incubated for several days in a carefully controlled environment.

Four blastocysts (embryos with about 150 cells) were implanted back into Kathleen. They were each smaller than a period at the end of a sentence, had no heartbeat and could not develop into a person without successfully implanting in a womb. Statistically, one out of every four implanted embryos results in a full-term pregnancy, but the first time none of Kathleen's embryos developed into a fetus. They had to repeat the procedure two more times. There were six potentially good embryos remaining when Kathleen became officially pregnant. The excess embryos were frozen and stored in a special tank.

At holiday gatherings no one would ever know that Kathleen and Tom's children had been conceived any differently than any other cousin running around the back yard. Yet the path to parenthood had put them at odds with their faith, which does not approve of *in vitro* fertilization (IVF) because of the risk to potential embryos and because of the use of technology for procreation. However Kathleen and Tom felt sure that they were meant to have children. Although there is more initial uncertainty with IVF than with a regular pregnancy (*What if the embryo doesn't implant? What if all four of them do?*), once the pregnancy is advanced it is no different than any other. Occasionally Kathleen and Tom remembered the excess embryos and were glad: if they decided to have a third child it would be possible. Then Kathleen learned that she was pregnant, after the years of fertility treatments she didn't even know to recognize the signs. Her doctor told her that it is not uncommon for women with infertility problems to be somewhat "cured" by having children. Their family is now complete. Their older children are five and three years old now, and the baby has just been born.

But they still have these excess embryos and the insurance company has notified them that the \$500/year storage is no longer covered. The notification letter came in the same mail with an invitation to yet another school fundraiser. However, the insurance company also included a letter from a research institute citing a desperate need for embryos. That's when Kathleen learned that the debate over stem cell research involves her family, and also the family of her best friend.

The letter stated that there are potential medical breakthroughs that can be made on virtually every disease known if researchers are able to use stem cells in their research. According to the information (from Harvard's Stem Cell Center, no less) the only source of human embryonic stem cells available for federally-funded research are those left over from IVF clinics. There are an estimated 400,000 unused embryos in storage tanks throughout the United States. The older stem cell lines used for research have been grown on feeder cells derived from mice. The paper cites the need for more human embryonic stem cell lines. In the letter, one researcher wrote about his personal stake in creating more stem cell lines for research. His son and daughter have diabetes and his son is insulin-dependent. He believes that scientists will be able to cure diabetes, perhaps using stem cells to grow insulin. Kathleen's best friend Clare has three children, and her oldest was diagnosed with Type I diabetes when she was just two years old. Clare practically devotes her life to raising money for diabetes research, in addition to trying to make her daughter's life seem as normal as possible. Kathleen knows that if Clare had embryos to donate she would do it in a heartbeat.

Kathleen and Tom find time to sit down together to discuss their options. The embryos belong to them, but they do not plan to use them. The storage cost is \$500 per year, which would pay for a lot of new shoes. They hate the idea of their embryos, the embryos similar to the ones that became Caitlin and Tom Jr., being discarded as medical waste. They believe those embryos have the possibility of life, even if they do not have heartbeats. Yet Kathleen also feels torn about donating the embryos to an infertile couple. How would she feel, letting somebody else raise their children? The position of their religion is that these stem cells are sacred and should not be used for research. The Stem Cell Center states that all embryo donations are voluntary and the donors would need to sign an informed consent document. The informed consent states that the donors understand that their embryos would be destroyed for research, and the donors would receive no payment for the donation. The Center also notes that they will make the stem cell lines available to any scientist in the field. They estimate that from 350 donated embryos they could significantly impact the number of stem cell lines available for research.

Kathleen makes a list of possible actions to take, and then they read over the page again that gives specifics about research. It says that the embryos have been frozen for varying amounts of time; they do not always survive thawing. Those that survive may not develop into a stem cell line. The letter states that cells generated by the embryos cannot be identified with the donors. Kathleen and Tom talk about their own children and how they would feel if they were diagnosed with a disease. In the past they have talked about whether they would donate their organs if anything happened to them. They believe that life is sacred and that it begins at conception. Tom suggests that they pay the \$500 for another year, while they learn more, but Kathleen feels strongly that it is time for them to decide how they feel about stem cell research. Her children are like miracles, exhausting, but miracles. What research led to *in vitro* fertilization breakthroughs that allowed them to be born? She thinks to herself, "the embryos don't have heartbeats and they could help to save lives. But don't we have a duty to protect them? What should we do?"

Selected Sources:

Cook, Gareth, "After 2 Children Via IVF, Pair Faced Stem Cell Issue" *The Boston Globe*, April 4, 2004.
(*This case study was based loosely on the Dooley story*)

Dreifus, Claudia, "At Harvard's Stem Cell Center the Barriers Run Deep and Wide"
New York Times, January 24, 2006.

Wade, Nicholas, "Stem Cell News Could Intensify Political Debate" *New York Times*, July 24, 2006.

Decisions, Decisions

Options for Kathleen and Tom	Which ethical principle is given priority?	How does the option relate to the ethical principle?
1.		
2.		
3.		
4.		
5.		

Decisions, Decisions

Options for Kathleen and Tom	Which ethical principle is given priority?	How does the option relate to the ethical principle?
1. Continue to pay	Do No Harm Respect for Persons	The embryos will not be harmed if they are not taken out of storage In some views, embryos are granted full personhood and should be respected as such.
2. Donate embryos to research	Do Good	The research could benefit society
3. Donate embryos to other infertile couple	Do Good <i>or</i> Justice	Benefits somebody else Couple may not be able to afford IVF
4. Discard the Embryos	Respect for Persons	The embryos belong to Kathleen and Tom—they can choose to discard them
5. Use embryos to have more children	Respect for Persons	The embryos could grow to be children and have the right to self-determination

My Perspective: Embryonic Stem Cells

1. Does the source of the embryo matter?
For example, is it okay to use stem cells from IVF if:

	Yes/No	Reason why or why not
<ul style="list-style-type: none"> the embryo is left over from IVF and will be discarded the embryo was produced solely for research and was not intended to become a baby Genetic testing reveals a serious genetic flaw and the embryo will not be implanted. 		

2. Does the potential benefit of the research matter?
For example is it okay to use embryonic stem cells if:

	Yes/No	Reason why or why not
<ul style="list-style-type: none"> research could save some human lives (i.e. hundreds) research could save many human lives (i.e. thousands or more) research could reduce the suffering of some research could reduce the suffering of many research could decrease medical costs for some research could decrease medical costs for many 		

1. Refer to the Case Study, "One Family's Dilemma". What do you think Kathleen and Tom should do with the excess fertilized eggs?

2. Why?

3. Which bioethical principle (Respect for Persons, Do Good/Do No Harm, or Justice) is given the most weight in your solution?

4. Explain why you chose that ethical principle.

Bioethical Principles and Embryonic Stem Cells

	Respect for Persons	Do Good/Do No Harm	Justice
Description	Respect an individual's right to make self-determining choices	Doing good (beneficence) and not doing harm (nonmaleficence)	Treat others equitably, distribute benefits/burdens fairly
A person who DOES support embryonic stem cell research and who argues from this approach might say.....?			
A person who DOES NOT support embryonic stem cell research and who argues from this approach might say...?			

Bioethical Principles and Embryonic Stem Cells

	Respect for Persons	Do Good/Do No Harm	Justice
Description	Respect an individual's right to make self-determining choices	Doing good (beneficence) and not doing harm (nonmaleficence)	Treat others equitably, distribute benefits/burdens fairly
A person who DOES support embryonic stem cell research and who argues from this approach might say.....?	<p>Individuals should be able to choose for themselves what happens with their fertilized eggs.</p> <p>Our duty is to always try to help those individuals who are suffering with diseases. Although embryos should be accorded respect, we should give more respect to fully formed humans.</p>	<p>Sometimes, to achieve a greater good we must sacrifice some human life to benefit the lives of many other living and future human beings.</p> <p>If frozen IVF embryos are going to be thrown out anyway, we should use them for something good.</p>	It is only fair to use stem cells to try to improve better health care for all.
A person who DOES NOT support embryonic stem cell research and who argues from this approach might say...?	<p>Embryos deserve special protections, because they have the potential to become humans.</p> <p>We should not destroy human life, even if that life is at the embryonic stage.</p>	The consequences of destroying human embryos are not outweighed by the health benefits that may be achieved through their use.	I am concerned that the benefits of embryonic stem cell research will not be available equally to all persons.