Creating One Life to Save Another

Lesson Plan

playing god? in the classroom is an educational resource designed to accompany the *playing god?* podcast, for use by instructors to introduce bioethics concepts and facilitate discussions of ethics among high school and above students. The *playing god? in the classroom* resources are free and available for non-commercial uses, with attribution to the Johns Hopkins Berman Institute of Bioethics. For other uses and more information, please contact playinggod@jhu.edu.

This Lesson Plan accompanies Episode 6, Season 1 of *playing god?*

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Summary

When Laurie Strongin's son Henry was born with the rare, often fatal disease of Fanconi anemia, doctors told her that the best way to save his life was with an umbilical cord blood transplant from a genetically matched sibling. But Henry had no matched siblings. Laurie and her husband then learned about a novel idea of combining three technologies to have a child who was guaranteed to be a genetic match, raising the question: is it ethical to create a life in order to save another?

This Lesson Plan uses the Podcast Episode about a controversial story from the 1990s to illustrate the ethics implications of new medical technologies and new uses of existing technologies. Students will deliberate about acceptable and unacceptable uses of genetic technologies. They can apply ethics concepts from this Episode to other emerging technologies. This Lesson Plan can also facilitate a discussion about political and moral theories of liberalism and respect for autonomy (in this case, parental autonomy).

Vocabulary

The following are key terms used in the Episode and their definitions. The terms are marked in bold when they appear elsewhere in the Lesson Plan.

Eugenics

The desire or actions taken to change or improve the genetic qualities of a population toward some desired goal. Historically, **eugenics** has been used by state actors to promote discrimination and exclusion of groups based on religion, race, ethnicity, and ability.

Liberal Society

A society based on a political philosophy that values protecting the rights and freedoms of individuals, with a government democratically chosen by the people. It is the predominant political ideology of the nations of the world, including the United States.

"Mere Means"

According to the philosopher Immanuel Kant, it is immoral to use other people solely to fulfill an individual's ends or goals (as **mere means** to an end), thus suggesting a limit on how individuals or society can treat others.

Savior Sibling

An informal term coined for a child who is conceived as a genetic match to treat or cure a disease or health condition in their sibling, for example, by having umbilical cord blood collected after birth to be used in a stem cell transplant.

Slippery Slope

A metaphor for a situation in which some actions or decisions are viewed as part of a chain of events that will inevitably lead to undesirable outcomes or consequences. The metaphor is a slippery hill: once you begin sliding down, it is difficult if not impossible to stop.

→Some people argue against choosing IVF embryos for certain genetic characteristics because it is a **slippery slope** to **eugenics.**

Discussion Guide

The following Assessment Questions can be used by instructors to evaluate student comprehension of Andrea's story and the bioethics concepts featured in the Podcast Episode. The Discussion Questions can prompt students to make claims and provide evidence and their reasoning. Student comprehension and views can be assessed before and after listening to the Episode and/or participating in the group activity.

Assessment Questions

- What were the motivations for the Strongins to have another child?

- How did they know if the new baby would be a match for Henry?

- Why did some people think that having a baby this way to help save Henry's life would be unethical to the **savior sibling**?

- What were the risks (and to whom) of using IVF and PGD to try to have a **savior sibling**?

Discussion Questions

- For what purposes should people be allowed to use **PGD?** What traits should they be allowed to choose? What traits should they NOT be allowed to choose? Why?

- Do you think that a savior sibling is being used as a **"mere means"**? Why or why not?

- Below are examples of recent technologies and scientific advancements. What are the intended benefits from this technology? What are the potential harms? Are these harms inevitable? How might they be avoided? What is lost by prohibiting the technology? How might you counter a slippery slope argument? *Examples provided.*
    - *Gene editing*
    - *Medically assisted death*
    - *Censorship and social media content moderation*
    - *Artificial Intelligence and surveillance*
    - *Assisted reproductive technologies*
    - *Biometrics and personal data*
    - *Neurotechnologies*
    - *Cloning*
    - *Nanotechnology*
    - *Bioweapons and "dual use" research*

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Sample Activities

The activities allow students to actively engage with the bioethics questions at the center of the Episode. Students will develop critical thinking skills and reason-based judgment by citing evidence from the Podcast and other sources. In bioethics, there often isn't a single "right" answer to a particular question; ideally, students will express and evaluate diverse viewpoints about complex, real-world problems.

Large Group Activity: Acceptable Traits

Instructions:

Have students think about genetic traits that parents might choose for their babies. This can range from health-related traits (reduced risk of disease or disability) to physical features (eye color, height), to aptitudes (musical, athletic).

Draw a line on the board and have the class review each trait. As a group, decide whether it is acceptable for parents to use PGD to choose an embryo with the trait at hand. Place the acceptable traits on one side of the line, and unacceptable traits on the other side.

Try to define what makes some traits acceptable and others unacceptable. Should PGD only be used to prevent disease? To prevent premature death? Should it be limited to physical traits? Should parents be free to choose any trait or combination of traits that they want?

Individual Activity: Research & Writing

1. *ELA writing assignment:* Research a genetic disease. Describe the disease, how it is inherited, its prevalence, its symptoms, and prognosis. Describe any treatments, their success, and availability. What are the challenges to finding a cure or a better treatment for this particular disease? Make research or policy suggestions for making needed progress. Find a patient advocacy organization that represents patients and families who have been affected by this disease. Describe their mission and how they do their work.
   o *Some examples would include diseases where **savior siblings** have been proposed as a treatment:*
      ▪ *Fanconi anemia (in the Episode); Diamond-Blackfan anemia; beta-thalassemia; leukemia*

Additional Resources

Further readings about key topics covered in the Episode.

More About Fanconi Anemia

Fanconi anemia | About the Disease, NIH Genetic and Rare Disease Information Center.

More Ethics Analyses from the Time of the Case

Creating a Stem Cell Donor: A Case Study in Reproductive Genetics, Kennedy Institute of Ethics Journal, 2004.

Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person, The British Medical Journal, 2001.

Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & limits, The Journal of Law, Medicine & Ethics, 2003.

Similar Contemporary Issues

IVF bans like Alabama's could cost the lives of children already born, STAT, 2024.

Could editing the DNA of embryos with CRISPR help save people who are already alive? STAT, 2019.

Careers Mentioned

Physician:
John Wagner, MD (pediatric hematology and oncology)

Bioethicist:
Jeffrey Kahn, PhD, MPH (philosophy and public health)

About This Lesson Plan

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