# Playing god?

# in the classroom

## teaching bioethics through stories

# I Would've Let You Die, Too

# **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. For other uses and more information, please contact <u>playinggod@jhu.edu</u>.

This lesson plan accompanies Episode 1, Season 1 of playing god?

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# Summary

While Andrea Rubin lay unconscious and severely burned after a car fire, her father told doctors to do everything they could to keep her alive. She would need many surgeries to survive and if she did survive her injuries would greatly affect her quality of life. Her friends were outraged; they told the doctors that Andrea would not want to live under those circumstances. The question of whether to continue to treat Andrea was only possible because Andrea was being kept alive on a ventilator, a medical innovation that became widely available in the late 1960s. In this Podcast episode, listeners hear how families and doctors make life and death medical decisions for patients incapable of deciding for themselves.

This Lesson Plan facilitates discussions about patient autonomy, medical decision making, and conflict resolution in the hospital setting. Students will examine ethics concepts used when patients cannot make decisions for themselves. They will research policies related to surrogate decision making, explore the role of clinical ethicists and hospital ethics committees in difficult medical decisions, and articulate their own viewpoints on surrogate medical decision making.



# **Important Terms**

### Advance Directive

A legal document that provides guidance for medical decisions if someone loses the capacity to make decisions for themselves.

### Autonomy

"Self-rule," or the control someone has over their lives, bodies, and health. Medical professionals have an ethical and legal duty to respect patients' **autonomy**. **Autonomy** in medical decision making is respected when healthcare providers work with patients to reach medical decisions through the process of **informed consent**, and by respecting the informed decisions of patients even if the healthcare provider may disagree.

### Beneficence

Medical professionals have an ethical and legal duty to act in a way that benefits their patients, and to try and minimize suffering and harm to patients. The healthcare team tries to work with patients and their families to decide what course of action will have the best balance of benefit versus harm for the patients.

### **Best Interests**

Ideally, a patient's **surrogate decision maker** knows them well and can exercise **substituted judgment**. If the surrogate does not know what the patient's values and preferences are, then they should make a decision that they believe is in the patient's **best interests**. This may mean choosing the option that results in the best medical outcome, but it can also consider other **quality of life** factors in choosing what is best for the patient.

### Capacity

A patient's ability to understand and make decisions about their health care in a given situation. Healthcare providers assess **capacity** to ensure that patients are in a position to make informed decisions about their care.

→Andrea was unconscious and therefore did not have **capacity** to make decisions about her treatment.



### **Ethics Committee**

Every hospital has an **ethics committee** that can be called upon to help make difficult ethics decisions or to try to resolve conflicts that arise in medical decision making. The committees often include medical ethicists, doctors, nurses, social workers, lawyers, local community members, patient representatives, and others. The committee gives advice to medical decision makers to help inform their decisions.

### Informed Consent

Ethical and legal standards require **informed consent** in medical decision making. **Informed consent** requires "a discussion of the nature of the procedure, the risks and benefits, the reasonable alternatives, and an assessment of the patients' understanding of these items."<sup>1</sup>

 $\rightarrow$  If a patient has **capacity**, then they must give **informed consent** for any treatment. If a patient does not have **capacity** (like Andrea), then someone must give **informed consent** on their behalf.

### Medically Induced Coma

In cases like Andrea's where a patient has suffered an extreme injury or medical event, doctors may give them a drug that reduces brain function in a way that is similar to a coma. Once the drug is taken away, the patient can come out of the coma and regain brain function.

### Paternalism

In medical decision making, interfering with or overriding a patient's preferences or **autonomy**, claiming that this interference is in the patient's **best interests.**<sup>2</sup>

### Quality of Life

This term is used to describe the general well-being of a patient that considers all aspects of their life. Factors include "health (physical, mental, and spiritual), relationships, education status, work environment, social status, wealth, a sense of security and safety, freedom, **autonomy** in decision making, social belonging, and their physical surroundings."<sup>3</sup>

### Substituted Judgment

If a patient requires a **surrogate decision maker** and the surrogate knows the values and preferences of the patient, the surrogate should exercise **substituted judgment**. This means that, to the best of their ability, the surrogate should make the decision that the patient



would have made for themselves. If the patient's wishes are unknown, surrogates should make decisions in the patient's **best interests**.

### Surrogate Decision Maker (sometimes called Health Care Proxy)

Someone who is designated to make medical decisions on behalf of a patient who is unable to communicate their wishes. If the patient has not identified a **surrogate decision maker** in advance, state laws determine who will serve in that role.





# **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 role play activity.

### **Assessment Questions**

- Andrea was in a **medically induced coma** and did not have the **capacity** to make her own medical decisions. How were decisions made for her? How does this approach to **surrogate decision making** attempt to respect her **autonomy** as a patient?
- What did each party (Andrea's father, her friends, her doctors, the ethics committee) want to happen? Match each party's motivations to the following concepts, provide evidence to support your claim, and explain your reasoning:
  - Who was acting in Andrea's **best interests**?
  - Who was executing substituted judgment?
  - Who was considering Andrea's quality of life?
  - Was anyone being paternalistic?

### **Discussion Questions**

- In your opinion, who was in the best position to make decisions on Andrea's behalf? Do you agree with the decision that was made? Why or why not?
- When questions arise about medical treatment of someone in Andrea's position, who do you think should be involved in those discussions, and who should make the decisions?
  - What are the potential benefits and risks of relying on the decisions of the following **surrogate decision makers**? *Examples of answers provided below.* 
    - Next of kin/closest adult family member

IDEAS

• We assume that, in many cases, close family members know the patient well and are most familiar with what they would want; but patients might be estranged from their family, or the family member's own interests (for example, not losing a child) might cloud the decision to make a true **substituted judgment** 



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- A friend or someone who insists they know what the patient would want
  - It's possible that a friend might have a closer relationship to the patient than a family member does. But, without proof, it is hard to verify the closeness of this person's relationship with the patient and the accuracy of their understanding of the patient.
- An advance directive written by the patient
  - This document is an expression of medical treatment wishes written by the patient. While it is helpful if it clearly addresses the specific medical situation, it may be outdated or may not cover the patient's exact circumstances.
- The patient's healthcare team
  - Healthcare providers understand the medical outcomes of different treatments and may be able to explain how these might change a person's **quality of life**. But they are unlikely to know what matters most to the patient or how the patient would feel about each outcome. Thus, they can only act based on what they believe is in the patient's **best interests**.
- The hospital ethics committee

IDEAS

• The committee, like the healthcare team, likely does not know the patients' values. But, discussing the case with diverse voices who are less emotionally connected may help minimize the potential for a biased outcome.



# **Sample Activities**

### Partner Activity: Ice Breaker

### Description:

This activity acts as a lower stakes version of the conversation at the heart of Episode 1– how best to make decisions on someone else's behalf. It can be used as a teaser, before students are introduced to the episode, to get them thinking about the challenges associated with applying **substituted judgment**, even in an everyday, low-risk scenario.

This context (ordering at a restaurant) can also be used to show the differences that might arise between what someone might want for themselves and what is in their **best interests**. For example, Student B might order a triple cheeseburger for Student A– acting with **substituted judgment**, knowing that Student A loves cheeseburgers. Or, Student B might order a salad for Student A, a healthier option, because eating healthy would be in Student A's **best interests**.

### Instructions:

*Before class*: Print menus from a local restaurant. Students will be divided into pairs, and each pair will need one menu.

*In class*: Divide students into pairs. Within each pair, identify which student is the oldest (Student A). The younger student (Student B) takes two minutes to ask Student A about food (e.g., what is your favorite food? Do you have any food allergies?). The instructions here should be purposefully vague (e.g., "talk about food") so that students come up with their own questions.

After one minute, hand out a restaurant menu to Student B. They now have one minute to order a meal for Student A, based on what they've learned during their discussion. Student B reviews the menu and tells Student A what they would order for them.

In the remaining two minutes, Student A can react to and assess the order that Student B placed for them. Is this a meal they would actually order for themselves? Why or why not? Did it align with the information that arose during their initial discussion about food? Student B can explain how they came to their decision. Why did they think Student A would eat this meal? Was there any information they were missing that would have helped them make a better decision?



### Large Group: Role Play

### Description:

This exercise allows students to debate different viewpoints about Andrea's case and try to reach a consensus as a group. It may be done before students have listened to the entire episode, so they aren't influenced by the resolution of her case. Before this debate, students should be aware of the facts of the case, and should review and understand concepts like **autonomy**, **informed consent**, **substituted judgment**, and **best interests** (see **Important Terms**). They should also understand the roles and responsibilities of **surrogate decision makers** and hospital **ethics committees**.

### Instructions:

*Before class:* Print out copies of **Handout 1.1** (One handout per role is sufficient; there are 5 different groups/roles).

*In class:* Listen to the beginning of the podcast, from 0:00 - 2:51. This segment introduces Andrea and the facts of her case—the accident that left her severely burned and in a coma, the necessity for surrogate medical decision making, and the conflict between her father and her friends about the appropriate decision.

Ask one student in the class to volunteer to play the role of Andrea. This student will sit outside the groups and observe the conversations.

Divide the rest of the class into four groups. Each group will represent the people in the episode who are in conflict about how to proceed with Andrea's treatment: Andrea's father, Andrea's friends, her healthcare team (doctors and nurses), and the hospital **ethics committee**.

Each group is given a written summary of their role to prepare for the role play (Handout 1.1). They can take a few minutes to prepare for their role. Themes of **best interests** and **substituted judgment** come into play as the different groups need to consider the risks and benefits of either route and what Andrea would want.

The hospital **ethics committee** acts as the moderator and calls on each group to share its opinion on Andrea's case. Students can engage by improvising and developing on the core stances for their assigned role described in **Handout 1.1**), and rebutting or responding to other groups' opinions. The goal is to reach consensus, ideally by arriving at the decision that Andrea would make for herself (**substituted judgment**). At the end of 15 minutes, the group assigned to the role of Andrea's father decides what happens to Andrea and gives an explanation of their decision.

Finally, the student playing Andrea, who has observed this process, shares whether they are satisfied with the decision made by the rest of the class and expresses their thoughts.

*After the activity:* Use the **Discussion Guide** to debrief with the class and assess how their views and reasoning have changed as a result of the activity.





### Individual Activity: Research & Writing

- ELA writing assignment: Research your state's law on surrogate medical decision making. Analyze the strengths and weaknesses of the policy (for example, is it clear? How might it go wrong?). How does the policy consider ethics principles like patient autonomy, best interests, and minimizing harm? Take a position—do you agree with the policy as it's written? What changes would you make, if any? Why or why not?
  - Teachers could also assign a state to each student.
  - o Additional Resource
    - <u>Decisions by Surrogates: An Overview of Surrogate Consent Laws in</u> <u>the United States</u>, Bifocal (American Bar Association), 2014.
- 2. *ELA Writing Assignment:* Compare Andrea's case to the well-known historical case of Dax Cowart from the 1970s. Summarize the details of each case, who was involved, their viewpoints and values, and the outcome. Articulate your view on why each case ended as it did. Identify any important differences and explain their significance.
  - Additional Resources

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- Interview with Dax Cowart: <u>A Happy Life Afterward Doesn't Make Up</u> for Torture, The Washington Post, 1983.
- Comparison by Dr. Gerrek: <u>Getting Past Dax</u>, AMA Journal of Ethics, 2018.



# **Additional Resources**

### An Interview with Andrea Rubin

The Story of Andrea Hope Rubin, MetroHealth News, 2018.

### More About Clinical Ethics Committees

Ethics Committees in Healthcare Institutions, Opinion of the American Medical Association.

<u>Ethics Talk: How Health Care Ethics Committees Engage Clinical Practice and</u> <u>Professionalization - An Interview with Joseph J. Fins</u>, AMA Journal of Ethics - Podcast, 2016.

### Ethics: Autonomy & Informed Consent

What's the Role of Autonomy in Patient- and Family-Centered Care When Patients and Family Members Don't Agree? AMA Journal of Ethics, 2016.

# Law: Surrogate Decision Makers & Advance Directives

<u>Decisions by Surrogates: An Overview</u> of Surrogate Consent Laws in the <u>United States</u>, Bifocal (ABA), 36(1), 2014.

# **Careers Mentioned**

**Bioethicist**:

Monica Gerrek, PhD (clinical ethicist) Jeffrey Kahn, PhD, MPH (philosopher)

### Patient Advocate: Andrea Rubin

FirefighterParamedicDoctorSocial WorkerPsychologistPsychiatristLawyerNurse

<u>Who Makes Decisions for Incapacitated Patients Who Have No Surrogate or Advance</u> <u>Directive?</u> AMA Journal of Ethics, 2019.

<u>Clinical Ethics and Law: Case 2 - Surrogate Decision Maker with Potential Conflict of</u> <u>Interest</u>, University of Washington.

### Medicine: Decision Making & Beneficence

Advance Care Planning: Advance Directives for Health Care, National Institute on Aging.

Advance Care Planning, Opinion of the American Medical Association.

IDEAS

When patients, families disagree on treatment: 6 ways forward, AMA News, 2018.



# **About This Lesson Plan**

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The Podcast Episode and this lesson plan are not designed to answer patient-specific clinical, professional, legal, or ethical questions. Information contained herein is not intended as a substitute for professional consultation.

<sup>&</sup>lt;sup>3</sup> Teoli D, Bhardwaj A. "Quality Of Life." 2023 Mar 27. In: StatPearls. Treasure Island (FL): StatPearls Publishing.





<sup>&</sup>lt;sup>1</sup> Shah P, Thornton I, Turrin D, Hipskind JE. "Informed Consent." 2023 Jun 5. In: StatPearls. Treasure Island (FL): StatPearls Publishing.

<sup>&</sup>lt;sup>2</sup> Dworkin G. "Paternalism", In: The Stanford Encyclopedia of Philosophy (Fall 2020 Edition). Edward N. Zalta (ed.).