



playing god? A bioethics podcast

season 1 episode 1 lesson plan

I Would've Let You Die, Too

<https://bioethics.jhu.edu/research-and-outreach/the-dracopoulos-bloomberg-bioethics-ideas-lab/projects/playing-god/episode-1/>

Reviewers:

Dorothy Holley, PhD

Summary

While Andrea Rubin lay unconscious and severely burned after a car fire in 2014, her father told doctors to do everything they could to keep her alive. She would need many surgeries that 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. This disagreement 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 episode, we explore how families and doctors make medical decisions for patients who are 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 learn about different principles that are considered when patients are unable to make decisions for themselves. They will research policies relevant to surrogate decision making, learn about the role of clinical ethicists and ethics committees in difficult medical decisions, and articulate their own viewpoints on surrogate medical decision making.

Important Terms:

Capacity: the “determination that an individual is or is not capable of making a medical decision within a given situation.” Capacity can change over time, or depending on the situation at hand. Capacity is often determined by the healthcare team.

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

Consent (or 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."

→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.

Beneficence: Medical professionals have an ethical and legal duty to act in a way that benefits their patients. The flip side of this duty is to "do no harm." The healthcare team tries to work with patients and their families to decide what course of action will be most beneficial to the patient.

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.

Autonomy: Autonomy means "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. One way autonomy is respected is by working with patients to reach medical decisions through **informed consent**.

Paternalism: in the case of medical decision making, paternalism is the "intentional overriding" of a patients' preferences.

→In the case of Dax Cowart, doctors made a **paternalistic** decision to keep him alive and continue treatment, overriding his clearly expressed wishes for them to stop.

Quality of Life: This term is used to describe the general well being of a patient that considers their entire reality. This includes factors like "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."

Advance Directive: a legal document that provides guidance for medical decisions in the event that someone loses the capacity to make decisions for themselves

Surrogate Decision Maker: Someone who is designated to give **informed consent** for medical decisions on behalf of a patient who does not have the **capacity** to do it themselves. If the patient has not chosen their own surrogate decision maker, there are laws that determine who will serve in that role.

Substitute Judgment: If patients require a surrogate decision maker, we ask the surrogate to exercise **substitute judgment**. This means that, to the best of their ability, the surrogate should

make the decisions that the patients would have made for themselves. This requires that the surrogate know the values and preferences of the patient.

Ethics Committee: Every hospital has an ethics committee that can be called upon to help make difficult decisions or to try to resolve conflicts that arise in medical decision making. The committees often comprise ethicists, doctors, nurses, social workers, lawyers, and others. They give advice to medical decision makers to help inform their decisions.

Best Interest: Ideally, a patient's **surrogate decision maker** knows them well and can exercise **substitute judgment**. If they do not know what the patient's values and preferences are, then we ask them to resort to acting in the patient's **best interest**. This may mean choosing the option that results in the best medical outcome, but it can also consider other **quality of life** factors.

Discussion Questions:

- Articulate your standpoint on the issue. Do you agree with what happened? Why or why not?
- Who do you think should be involved in having these discussions and making decisions?
- Use this opportunity to further research the role of clinical ethicists and clinical **ethics committees**. What do these consults look and sound like? How can they help patients, families, and medical teams? What other types of cases do they often handle?
- Were you familiar with **advance directives** before listening to this episode?
 - What types of emotional reactions does this discussion generate, and how might those feelings contribute to society's willingness to talk about advance directives?
- Compare the cases of Andrea Rubin and Dax Cowart. What are the differences and similarities?

Suggested Activities

Partner Activity: Ice Breaker (5 minutes)

Description:

This activity acts as a lighter 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 knowing what someone else might want for themselves, and executing **substitute judgment**.

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 interest**. For example, Student A might want to order a meal that Student B deems unhealthy for them. Patients can make choices about their own healthcare that others might not want them to make. When we must act as a **surrogate decision maker** for someone, we respect their **autonomy** by

favoring what they would want and executing **substitute judgment**, even if we believe it is not the best choice.

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 (20 minutes)

Description:

This exercise gives students the opportunity to debate different viewpoints about Andrea’s case, and to try to reach a consensus as a group. It may be done before students have listened to the entire episode, so they aren’t as influenced by how the case actually went. Before this debate, students should be aware of the facts of the case, and should review and understand concepts like **autonomy**, **informed consent**, **substitute judgment**, and **best interest**. They should also understand the roles and responsibilities of **surrogate decision makers** and **hospital ethics committees**.

Instructions:

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 burnt and in a coma, the necessity for **surrogate medical decision making**, and the conflict between her father and her friends about what to do.

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

Divide the rest of the class into four groups. Each group will represent the stakeholders 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 interest** and **substitute judgment** come into play as the different groups need to consider the risks and benefits of either route and also what Andrea would want.

The ethics team acts as the moderator and calls on each group to share their opinion on Andrea's case. Students can engage by improvising and developing on the core stances that they have been assigned and rebutting or responding to other groups' opinions. The goal is to reach consensus, ideally by making the decision that Andrea would make for herself (**substitute judgment**). At the end of 15 minutes, the group playing Andrea's father makes a decision about what happens to Andrea.

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.

Individual: Research & Writing Assignments

1. If you could talk to one speaker in this episode, who would it be, and what would you ask them?

2. ELA writing assignment: Research your state's policy on surrogate medical decision making. Analyze the strengths and weaknesses of the policy (e.g., is it clear? How might it go wrong?). Take a position– do you agree with the policy as it's written? What changes would you make, if any? Why or why not?
 - a. Teachers could also assign a state to each student.
 - b. Additional Resources:
 - i. [Decisions by Surrogates: An Overview of Surrogate Consent Laws in the United States](#), Bifocal, 2014.

3. ELA Writing Assignment: Compare Andrea's case to the case of Dax Cowart in the 1970s. Summarize the details of each case, who was involved and how they ended. Articulate your view on why each case ended as they did. Identify any important differences and explain their importance.
 - a. A similar case to Andrea's happened in the 1970s. A man named Dax Cowart repeatedly asked doctors to let him die after suffering severe burns. But the doctors continued to treat him against his wishes. Below is a link to an interview with Mr. Cowart ten years after his accident, where he talks about his experience with the Washington Post. Dr. Gerrek, the clinical ethicist in the podcast, wrote a paper called "Getting Past Dax" comparing the two cases, and showing how medical decision making for severe burn patients has evolved over the past 50 years.
 - b. Additional Resources:

- i. Interview with Dax Cowart: [A Happy Life Afterward Doesn't Make Up for Torture](#), The Washington Post, 1983
- ii. Comparison by Dr. Gerrek: [Getting Past Dax](#), AMA Journal of Ethics, 2018

Careers Mentioned

- Firefighters
- Paramedics
- Doctors
- Bioethicists: Monica Gerrek (clinical ethics expert) and Jeffrey Kahn
- Social Workers
- Psychologists
- Psychiatrists
- Lawyers (hospital legal department)
- Nurse

Suggested Readings

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

[Ethics Talk: How Health Care Ethics Committees Engage Clinical Practice and Professionalization - An Interview with Joseph J. Fins](#), 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

[Decisions by Surrogates: An Overview of Surrogate Consent Laws in the United States](#), *Bifocal (ABA)*, 36(1), 2014.

[Who Makes Decisions for Incapacitated Patients Who Have No Surrogate or Advance Directive?](#) *AMA Journal of Ethics*, 2019

[Clinical Ethics and Law: Case 2 - Surrogate Decision Maker with Potential Conflict of Interest](#),
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

[When patients, families disagree on treatment: 6 ways forward](#), AMA News, 2018