

Graduate Studies Program

The Alden March Bioethics Institute

AMBI 624: Classic Cases in Bioethics

Fall 2023: September 6 – November 14 3 Credits

Instructor Contact Information

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Office Hours:	Wednesday, 2h-4h PM-or by special appointment			
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Delivery Method

This course is asynchronous. There are no required in-person meetings. All lectures and discussions for the course will be conducted asynchronously using the Sakai learning platform.

Course Description

Prerequisites: None

We will examine a range of moral issues in the context of classic cases that continue to shape bioethics. In so doing, we will also reflect on broader questions that lie at the heart of medical ethics. How, exactly, may physicians permissibly involve themselves in the termination of their patients' lives? What is the scope of a patient's authority to reject medical treatment, particularly if it is necessary for ensuring her basic rational functioning or even sustaining her life? How much discretion do parents and guardians have when making major medical decisions for their (minor or otherwise decisionally incapacitated) children? What general moral obligations do researchers—and ethics review committees—have toward the human subjects whom they study?

Our discussions will concern clinical practice and medical research in equal measure. Topics to be discussed will fall into four main categories. First, we will investigate the morality of physician-assisted suicide and the withdrawal of life-sustaining care for patients with a terminal physical illness or prolonged disorder of consciousness. Second, we will explore whether it is ever morally justified to force psychiatric treatment on people who are suicidal or who suffer from a psychiatric condition. Third, we will map out the 'gray zone' of parental discretion by considering whether parents have a right to pursue experimental treatments for their children and, if so, how broad that alleged right might be. Finally, we will think carefully about the

importance and complexity of consent to medical research—and how it may be (or may not be) problematically undermined by remuneration, conflicts of interest, riskiness, and biobanking.

Course Readings

There is no required textbook for this course. Course readings will consist of articles or book chapters, to be made available on Sakai (under the 'Readings' module).

Technology

Minimum Technology Skills

In this course, you will need access to AMC's Sakai site. Please submit all essays to me through Sakai. I will only accept essays submitted to me in .doc, .docx, and .pdf format.

You should conduct any email correspondence with me through your AMC email address rather than through Sakai's messenger system. Note that I strive to respond to your emails within <u>two</u> <u>business days</u>, where this excludes weekends and holidays. If I have not responded to your message within this time, please feel encouraged to (kindly) remind me to reply to you.

Course Outcomes

By the end of this course, you will be able to:

- **1:** Identify and critically engage with ethical issues raised by some of the classic cases in the biomedical ethics canon.
- **2:** Write an ethics paper in which you successfully defend a thesis with an argument of your own construction—including by responding to objections to your position/argument.
- **3:** Engage in respectful, constructive dialogue with your fellow classmates.

Course Schedule & Graded Activities

<u>Week 1</u> (September 6-12): Decisions at the End of Life I: Prolonged Disorders of Consciousness and Treatment Withdrawal

Case: Terri Schiavo

Required:

Josh Sanburn, 'How Terri Schiavo Shaped the Right-to-Die Movement'

Charles Foster, 'It is Never Lawful or Ethical to Withdraw Life-Sustaining Treatment from Patients with Prolonged Disorders of Consciousness'

Dominic Wilkinson et al, 'Functional Neuroimaging and Withdrawal of Life-Sustaining Treatment from Vegetative Patients'

Recommended:

AMA Code of Medical Ethics Opinions on Care at the End of Life

Optional Session:

Introduction to Course Content and Mechanics: Wednesday, September 6 (tentative)

<u>Week 2</u> (September 13–19): Decisions at the End of Life II: Terminal Physical Illness and Physician-Assisted Suicide

<u>Case</u>: Brittany Maynard

Required:

Brittany Maynard, 'My Right to Death with Dignity at 29' Ronald Dworkin et al, 'Assisted Suicide: The Philosophers' Brief' Frances Kamm, 'The Right to Choose Death?'

Recommended:

Sacred Congregation for the Doctrine of the Faith, 'Declaration on Euthanasia' David Velleman, 'A Right of Self-Termination?', pp. 606–20

Graded Assignment:

Quiz 1 Due: Tuesday, September 19 by 11h59 PM

<u>Week 3</u> (September 20–26): The Ethics of Forced Treatment I: Suicide Intervention

Case: Elizabeth Bouvia

Required:

Francis Kane, 'Keeping Elizabeth Bouvia Alive for the Public Good' Julian Savulescu, 'The Problem with Do-Gooders'

Recommended:

Mark Cherry, 'Non-Consensual Treatment is (Nearly Always) Morally Impermissible'

Dieneke Hubbeling, 'Decision Making Capacity Should Not Be Decisive in Emergencies'

<u>Week 4</u> (September 27–October 3): The Ethics of Forced Treatment II: The Force-Feeding of Patients with Eating Disorders

Case: "E"

Required:

Simona Giordano, 'Anorexia Nervosa: A Case for Exceptionalism in Medical Decision-Making' Jennifer Radden, 'Food Refusal, Anorexia and Soft Paternalism: What's at Stake?'

Recommended:

Jacinta Tan et al, 'Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values'

Optional Session: How to Write an Ethics Paper: Monday, October 2 (tentative)

Graded Assignment: Quiz 2 Due: Tuesday, October 3 by 11h59 PM

<u>Week 5</u> (October 4–10): Experimental Treatment and Parental Discretion I: The Care of Minor Patients

Case: Charlie Gard

Required:

Lynn Gillam, 'The Zone of Parental Discretion' Giles Birchley, 'Charlie Gard and the Weight of Parental Rights to Seek Experimental Treatment'

Recommended: Lainie Friedman Ross, 'Better Than Best (Interest Standard) in Pediatric Decision Making'

Graded Assignment: Paper 1 Due: Tuesday, October 10 by 11h59 PM

Week 6 (October 11–17): Experimental Treatment and Parental Discretion II:

The Care of Severely Cognitively Disabled Patients

Case: Ashley X

Required:

Douglas Diekema & Norman Fost, 'Ashley Revisited: A Response to the Critics' Matthew Liao et al, 'The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making'

Recommended:

Peter Singer, 'A Convenient Truth' Eva Feder Kittay, *Learning from My Daughter*, ch. 9 ('Forever Small: The Strange Case of Ashley X')

Graded Assignment:

Quiz 3 Due: Tuesday, October 17 by 11h59 PM

<u>Week 7</u> (October 18–24): Consent to Medical Research I: Research on Patients Incapable of Giving Consent

Case: The Residents of Willowbrook State School

Required:

Walter Robinson and Brandon Unruh, 'The Hepatitis Experiments at the Willowbrook State School'

Gregory Pence, *Medical Ethics: Accounts of Ground-Breaking Cases*, ch. 9 ('Medical Research on Vulnerable Populations')

<u>Week 8</u> (October 25–31): Consent to Medical Research II: Risky Research and Paternalism

Case: Jesse Gelsinger

Required:

S.J.L. Edwards et al, 'Research Ethics Committees and Paternalism' Lynn Jansen and Steven Wall, 'Paternalism and Fairness in Clinical Research'

Graded Assignment:

Quiz 4 Due: Tuesday, October 31 by 11h59 PM

Week 9 (November 1–7): Consent to Medical Research III:

Payment for Research Participation

Case: The Belmont Report

Required:

Alan Wertheimer and Frank Miller, 'Payment for Research Participation: A Coercive Offer?'

Joseph Millum and Michael Garnett, 'How Payment for Research Participation Can Be Coercive'

Recommended:

The Belmont Report (1976), pp. 2-20

Week 10 (November 8–14): Consent to Medical Research IV:

Lack of Consent, Broad Consent

Cases: Tuskegee Syphilis Study, Henrietta Lacks, the Havasupai Tribe

Required:

Mark Sheehan, 'Can Broad Consent Be Informed Consent?'

Mark Sheehan et al, 'Authority and the Future of Consent in Population-Level Biomedical Research'

Graded Assignments: <u>Quiz 5 Due, Paper 2 Due</u>: Tuesday, November 14 by 11h59 PM

Grading

Graduate Letter Grades

Course Average	Grade	Points
95–100	А	4.0

90–94	A-	3.667
87–89	B+	3.334
83–86	В	3.0
80–82	B-	2.667
77–79	C+	2.334
73–76	С	2.0
70–72	C-	0
60–69	D	N/A
1–59	F	N/A

Grade Breakdown

Activity	% of Final Grade	Due Dates:
Discussion Posts	25%	Every Tuesday
Weekly Quizzes	25%	Every other Tuesday
Papers (x 2)	50%	October 10, November 14

Criteria for Assessment

Required Assignments

Reading Quizzes: You will complete five quizzes. The aim of these quizzes is to ensure that you are reading regularly by testing your comprehension of the material. You will typically have a week to complete online quizzes. While you may use the readings, your notes, or the instructor's handouts in taking the quizzes, I strongly recommend that you study for the quizzes as you would for an in-person, closed-book/-notes exam.

Reading quizzes will be due every other Tuesday by 11h59 PM.

<u>Note</u>: I do not generally allow students to take a quiz once the deadline for that quiz has passed, unless the student also has a valid excuse for failing to complete it.

Discussion Posts: I will post two to three discussion questions per week on the forum for that week. Every week you are expected to contribute four discussion posts to these fora, at least one of which must be a response to a post produced by one of your classmates.

Guidelines beyond the discussion board participation criteria set by the program:

• Posts should consist in a substantive attempt to critically engage both with (1) the

question(s) posed in that week's discussion board and (2) the readings referenced.

- To obtain credit, posts should consist of at least a long paragraph, ideally two or more. To make reading the discussion boards manageable for everyone, however, please generally avoid posting elaborate, essay-length contributions.
- To obtain credit, response posts should not simply signal agreement with, or praise for, the content of the post to which you are responding. Rather, they should advance the discussion by raising a question/worry about, an objection to, the post in question.

All four discussion posts are due *every Tuesday by 11h59 PM*. However, to spread discussion out throughout the week, please do not post all your contributions on Tuesday. I will try to respond to discussion board posts within <u>one business day</u>. However, depending on the number of students enrolled, I may not be able to respond to everyone.

Papers: You will write and submit two papers no shorter than 3,000 words each. The goal of these papers is to defend an ethical claim—a claim about right and wrong—on some issue raised by the readings. You will be expected to give an argument for this claim and to anticipate potential objections to your position/argument.

You may write papers either on assigned topics or—by request and subject to instructor approval—on topics of your own design. Note that if you decide to write on a topic of your own design, you must request approval no less than two weeks before the deadline.

Papers will be graded according to how well they exemplify the virtues of an ethics paper: clarity of expression, organization, cogency of argument, accuracy of interpretation, efficiency of communication, and charity.

Paper 1 is due Tuesday, October 10, and Paper 2 is due Tuesday, November 14.

I will grade your papers and return them to you, with comments, within one week.

Grading Criteria	Α	A-/B+	В/В-	С	F
Posts are clearly written,	Excellent:	Very good:	Meets some	Below	Unsatisfactory;
demonstrate reflective thinking, and show effort.	Exceeds	Meets	expectations;	expectations;	Contact instructor
tilliking, and show errort.	expectations	expectations	Room for	Contact	(<3 points)
Writer uses reading	(5 points)	(4.5 points)	improvement	instructor	
strategies to make sense			(4 points)	(3.5 points)	
of texts, and/or to ask					

General Discussion Board Participation Criteria:

thoughtful clarifying questions when struggling with an assigned text.			
Writer uses evidence from assigned materials to support their points.			
Posts are timely (at least 4 of 7 days), concise, and respectful of others in tone and language.			

Course Success

You should expect to devote 12 hours a week to fully engage in all the learning activities and to successfully complete all the required assignments.

Course Policies

Course Conduct and Respect for Diversity

Albany Medical College is committed to diversity, equity, and inclusion. Diverse backgrounds, embodiments and experiences are essential to the critical thinking endeavor at the heart of higher education. We will work together to foster a supportive, non-discriminatory learning environment for everyone. Please be mindful of each other's feelings, and respectful during forum debates and discussions. Remember that the tone of online communication can sometimes be more difficult to interpret than in-person discussion. In this course and at AMC, students and faculty are expected to respect individual differences (which may include but are not limited to age, cultural background, disability, ethnicity, family status, gender presentation, immigration status, national origin, race, religion, sex, sexual orientation, socioeconomic status, and veteran status). We are also expected to engage respectfully in discussion of diverse worldviews and ideologies embedded in course materials, including those that may be at odds with our personal beliefs and values. Students seeking support around these issues can find more information and resources at The Division of Community Outreach and Medical Education, <u>https://www.amc.edu/academic/Undergraduate_Admissions/backgrounds.cfm</u>

Late Work

No late discussion posts will be accepted. Late quizzes will be accepted only in unusual circumstances, with a valid excuse approved by the instructor. Late papers will be penalized 1/3 of a letter grade per day (so, e.g., from A to A-, A- to B+, etc.) except in unusual circumstances or with an approved request for an extension. *Requests for an extension must be submitted to the instructor no later than 24 hours before the deadline*.

Institutional Policies

Academic Integrity

When you use words or ideas published by others (including online) without citing them as the source, this is <u>plagiarism</u>. When you use work done by someone else and submit it as your own, this is <u>cheating</u>. Both plagiarism and cheating are forms of academic misconduct and will be dealt with according to college policies, which require the reporting of all suspected violations to the Honor Committee. In addition, <u>any</u> assignment that is the product of plagiarism or cheating will be given a zero.

You are responsible for knowing what constitutes a violation of the Albany Medical College Honor Code, which is described here:

https://www.amc.edu/academic/graduatestudies/Rules-and-Regulations.cfm.

Note that the use of ChatGPT or comparable programs to write any portion of either your papers for this course or your discussion board posts also constitutes a violation of academic integrity. I reserve the right to use any and all software to verify my suspicion that a paper has been plagiarized. If you are confused or uncertain about what constitutes plagiarism, please contact the instructor for help. I also recommend this helpful site from the University of Washington library system: <u>http://libguides.uwb.edu/ai</u>.

Students with Disabilities Requesting Accommodations

Albany Medical College is committed to the academic, social, and cultural integration of individuals with disabilities. Reasonable accommodations will be provided for students with documented physical, sensory, systemic, cognitive, learning, and psychiatric disabilities. If you believe you have a disability requiring accommodation in this class, please contact Monica Minor, Director of Student Affairs (minorm@amc.edu, The Commons ME-7, 518-262-6354).

Other Policies of Note:

Library Resources

The Schaffer library staff are the campus experts on research resources. Do not be reluctant to consult them about helpful sources for your research proposal. All library resources should be accessible to you remotely. If you are looking for an article and hit a paywall, **do not pay!** Make sure you are logged in and try again or consult the library for help. Please also see the AMBI Library Orientation Sakai Site (listed below) for guidance on how to conduct searches for scholarly sources.

• AMC Library web site: <u>https://www.amc.edu/academic/Schaffer/forstudents.cfm</u>

- AMBI Library Orientation Sakai site: <u>https://sakai.amc.edu/portal/site/63a5fb0b-</u> b571-4e1a-b8cb-dda47f098a9a
- Email: <u>Library@amc.edu</u>
 Phone: 518-262-5532