Appendix 1: Annotated Syllabus

Georgia State University (HON 4500; Spring 2020, 2021)

Through a Different Lens: Examining the Enduring Questions of Bioethics from Diverse Perspective

Courtney Anderson, Paul Lombardo, and Leslie Wolf*

COURSE OBJECTIVES

By the end of the course, students will:

- I. Identify bioethics issues in real-life cases of particular relevance to disadvantaged minority students
- II. Apply bioethics principles and methods to analyze critically these cases and evaluate potential solutions
- III. Study innovative examples of resolving bioethics issues in similar cases and identify why these examples were successful.
- IV. Identify potential career paths to working on such issues and the steps to attain them
- V. Reflect on the relevance of bioethics in their own lives and their communities
- VI. Recognize the applicability of bioethics principles and methods beyond traditional, explicitly bioethics cases.

In addition to the course objectives listed, please share what you hope to gain from this course.

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ASSESSMENT

Reflective Essay and Topical Essay:

During the course, you will be responsible for submitting two essays reflecting on and responding to class readings and discussions. You may relate the class readings and discussions in the context of current events or a news story that we have or have not discussed in class. You may also take an opposing view to one or more class readings and discuss why you disagree with the author's assertions based on class readings and discussion. If you choose to reference a news article or other information in your essay, please submit a copy of the article, or a working link to the article, with your reflection paper. The essay should be 500-700 words, double-spaced, and typed in Times New Roman 12-point font. There is freedom in this assignment to address topics raised in the course that are of interest to you. Do not hesitate to speak with the professors about your topic before it is finalized.

Your essay will be evaluated based upon your ability to identify a question raised by the readings, classroom discussion, or current events as they relate to the content of the course, and to address how current law and policy does or does not resolve the question. The essay should be well-written and edited. It will also be evaluated on your ability to express views or ideas in effective ways including organizing and communicating with precision and applying the mechanics of language effectively and with clarity, and attention to detail, grammar and punctuation. Students should use thesis sentences, paragraph structure and transitions. A grading guideline that supplements these instructions will be posted to TWEN.

Final Essay:

The final essay will be a piece suitable for publication in The Conversation. Additional details are forthcoming. The length will be 1000-2500 word, as required by The Conversation or as professors deem appropriate.

ASSIGNMENTS

Week 1: Introduction

Goal: To introduce students to key concepts and distinctions that are crucial to understanding the existing bioethics literature; to explore how such issues play out in concrete ways via the Serena Williams experience.

Read

- Rob Haskell, Serena Williams on Motherhood, Marriage and Making her Comeback, Vogue, January 10, 2018
 - a. We began the semester with an article that illustrates health disparities Black women experience in childbirth. Serena Williams' experience emphasizes how cultural difference and racial biases exist at every point on the socioeconomic spectrum. The counterstorytelling technique developed to illuminate diverse perspectives allowed students who were new to bioethics to understand the important impact the field can have on social justice.
- II. Paul Lombardo, Law and Ethics: An Ongoing Conversation, in Fletcher's Introduction to Clinical Ethics 3d Ed. (John C. Fletcher, Edward M. Spencer, and Paul A. Lombardo, eds.), Hagerstown, MD: University Publishing Group (2005), pp. 47-55

- III. Thomas R. McCormick, Principles of Bioethics, Ethics in Medicine, https://depts.washington.edu/bioethx/tools/princpl.html
- IV. Daniel Callahan, Bioethics, in Encyclopedia of Bioethics, Rev. Ed. (Warrant Thomas Reich, Ed), pp. 248-256
- V. Olivette R. Burton, Why Bioethics Cannot Figure Out What to Do with Race, The American Journal of Bioethics, 7:2, 6-12, DOI: 10.1080/15265160701193567

Watch

The Sad Life of The Caged Teen | Ota Benga

https://www.youtube.com/watch?v=klql6D3vN2c

Week 2: Doctor-Patient Relationship

Goal: The goal of this class is to introduce the basic bioethics principles and concepts relevant to the doctorpatient relationship, explore how historic and contemporary treatment of African-American patients differs from these norms and leads to distrust of the medical system, and identify mechanisms for altering this dynamic.

Read

- I. Patricia A. King & Leslie E. Wolf, Empowering and Protecting Patients: Lessons for Physician-Assisted Suicide from the African-American Experience, *Minnesota Law Review* 82: 1015-1043 (1998).
- II. Jessica Nutik Zitter, The Never-Ending Mistreatment of Black Patients, *The New York Times*, June 29, 2019.
- III. Katie E. Raffel, Anna P. Goddu, Monica E. Peek, "I Kept Coming for the Love," Enhancing the Retention of Urban African Americans in Diabetes Education, *Diabetes Educ.* 2014 40(3): 351-60.
- IV. Anna P. Goddu, Tonya S. Roberson, Katie E. Raffel, Marshall H. Chin, and Monica E. Peek, Food Rx: A Community-University Partnership to Prescribe Health Eating on the South Side of Chicago, *J. Prev. Interv. Community* 2015; 43(2): 148-162.

Watch [in class]

- I. Monica Peek, Clinical Medical Ethics at the University of Chicago: Applying Medical Humanism in Patient Care (Jan. 10, 2017) https://www.youtube.com/watch?v=ZpppqHJU5Gs&feature=youtu.be
- II. Monica Peek, https://www.youtube.com/watch?v=OydhbkcMU g

Week 3: Setting Priorities for Rationing

Goal: The Seattle dialysis case exemplifies the kinds of decisions that are made in the medical context when first access to novel technologies must be determined, and social values are embedded in choosing who will benefit from them. The setting of priorities among potential recipients of medical benefits is a feature of every health care system; understanding the Seattle Committee process provides the backdrop for discussion and analysis of current and/or future systems, and makes transparent the rationing decisions that are submerged in existing programs, such as the ACA.

Read

Trial of Peculiar Interest, Wisconsin Enquirer, May 21, 1842, http://www.newspapers.com/image/37082481.

- II. Kristina Cooke, David Rhode, and Ryan McNeil, The Undeserving Poor, *The Atlantic*, December 20, 2012.
- III. They Decide, Who Lives, Who Dies http://www.nephjc.com/news/godpanel (original written by Shana Alexander and published in Life Magazine Nov. 1962).

Watch:

I. Who Shall Live? Seattle God Committee, https://www.youtube.com/watch?v=FMay5zw1loA

Week 4: The Primacy of Consent

Goal: This class should introduce students to the primacy of bodily autonomy, both as a legal expectation and ethical principle critical to medical practice. The first two readings will force them to realize that this concept is ancient, not novel, and has been a feature of US law for centuries. The Childress reading puts the principle in the context of biomedical ethics, pitting physicians and patients as candidates for decision making. The case of Sarah Baartman—the woman displayed in public exhibitions as the "Hottentot Venus"—provides an early 19th century example of the objectification of an African woman by Europeans.

Read

- I. John Franklin Shields, As to the Necessity of Consent to Rend Surgical Operations Lawful (1900).
- II. Pratt v. Davis, 118 III. App. 161 (1905).
- III. Justin Parkinson, The significance of Sarah Baartman, *BBC News Magazine*, 7 January 2016 https://www.bbc.com/news/magazine-35240987.
- IV. James F. Childress, Consents, in *Who Should Decide? Paternalism in Health Care*, New York: Oxford University Press (1982), pp. 77-101.
- V. Claire Cain Miller, Why Mothers' Choices about Work and Family Often Feel Like No Choice at All, *The New York Times*, January 17, 2020.
- VI. Wyman v. James, 91 S.Ct. 381 (1971) [discussed in class]
 - a. This is a landmark welfare case that established the rule that home visits related to eligibility confirmation for social services are not "searches" under the fourth amendment. One line of reasoning emphasized by the court is that these home visits are voluntary, because the visit can be refused. The result of the refusal is ineligibility for cash benefits, but this does not mean that the visit is mandatory, because receiving benefits is a choice. We challenged the students to define consent, informed consent and voluntary actions, and how context can affect these definitions. Reading this case in conjunction with classic bioethics articles and cases on consent allow the students to apply bioethics principles to areas of public policy, constitutional law and public benefits.

Week 5: Criminal Justice and Capacity

Goal: This class will explore conflicts between caregivers and patients surrounding whether we expect patients -- as a condition of consent--to appreciate and understand the reasons for and effects of the treatments offered to them. Patients who suffer from mental disabilities, temporary or permanent, pose special cases, and particular rules apply to those who are allowed to decide for them. Students will also read about the private prison and probation industry. Students will draw parallels to an accused's competency to accept a plea deal or probation. Students will revisit the principles of bioethics and engage in a dialog on the applicability of these principles to the right of counsel, mandatory minimums, health care standards in prison and the collateral consequences of incarceration. Students will learn of one group

working to alleviate collateral consequences and will work in small groups to discuss others, based on principles of bioethics.

Read

- I. Paul S. Appelbaum, Assessment of Patients' Competence to Consent to Treatment, *New Engl. J. Medicine*, 357: 1834-40 (2007)
- II. Benjamin Weiser, Kalief Browder's Suicide Brought Changes to Rikers. Now It Has Led to a \$3 Million Settlement, *The New York Times*, Jan. 24, 2019
 - a. We use this story to ask the students to think about the consequences when personal autonomy is removed, and to think about racism and mental health. We discuss this in the traditional bioethics context, but want to underscore the principles and logical reasoning can also be applied in the criminal justice context. Kalief Browder was on Rikers Island jail for three years as he awaited trial for allegedly stealing a backpack and spent two of those years in solitary confinement. Upon release he suffered from mental health issues and ultimately committed suicide.
- III. Nicole Goodkind, Top 5 Secrets of the Private Prison Industry, *yahoo! Finance*, August 6, 2013, https://finance.yahoo.com/blogs/daily-ticker/top-5-secrets-private-prison-industry-163005314.html
 - a. Classroom discussion includes incentives for healthcare professionals to adhere to bioethics principles, and to examine if there are situations in which scarcity of resources, personal interests, or other professional conflicts would take precedence over such principles. This same tension exists in the criminal justice system. Outsourcing carceral activities to private parties exemplifies this issue.
- IV. Andrew Cohen, How Americans Lost the Right to Counsel, 50 Years After 'Gideon', *The Atlantic*, March 13, 2013
 - a. With respect to the concept of informed consent in bioethics, we discuss how power dynamics and cultural differences between the doctor and the patient. In order to show the prevalence of bioethics principles in other fields, we read about the right to legal counsel, and the power imbalance between lawyers and clients, and also between the prosecution and public defenders.
- V. Corinne A. Carey, No Second Chance: People with Criminal Records Denied Access to Public Housing, 36 *University of Toledo Law Review* 545 (2005).
 - a. The ramifications of a criminal record extend far beyond the incarcerated period. Similarly, the consequences of patients falling victim to a dearth of bioethics principles extend beyond the healthcare system. Often times, patients who are marginalized or oppressed in other ways are most harmed by a failed healthcare system. We use the example of formerly incarcerated people being among the most at risk for homelessness, yet prohibited from public housing, to draw a parallel to fields of study outside of bioethics.

Week 6: Guest Speaker [(virtual), re COVID]

Goal: To provide an opportunity for students to see how bioethics issues are embedded in the decisions that are being made daily with respect to COVID testing, treatment, and vaccines and, tapping into their own experiences, identify ways to alleviate the stark disparities and structural injustice revealed through the pandemic.

Read

I. Lindsey R. Baden, Eric J. Rubin et al., We Can Do Better – Improving Outcomes in the Midst of an Emergency, *New Engl. J. Med*, 377(15): 1482-1485 (2017)

Week 7: Research Ethics

Goal: The Tuskegee Study of STD is the most infamous 20th Century US example of research malfeasance, and its public revelation launched the modern era of government regulation of biomedical research. The goal of this class is to introduce the students to the facts and the consequences of that event, develop an appreciation for the lingering shadow of the study over attitudes concerning research and medical care delivery in minority communities, and highlight ways researchers are working to overcome this history and ensure diverse communities benefit from research.

Read

- I. Allan M. Brandt, Racism and research: The case of the Tuskegee Syphilis study," *The Hastings Center Report* 8(6): 21-29 (1978).
- II. Arthur L. Caplan, When Evil Intrudes, The Hastings Center Report, 22(6): 29-32 (1992).
- III. Brynn Holland, The 'Father of Modern Gynecology' Performed Shocking Experiments on Slaves, *History.com*, August 29, 2017 (updated December 4, 2018) https://www.history.com/news/the-father-of-modern-gynecology-performed-shocking-experiments-on-slaves.
- IV. Paul Adepoju, Africa's first biobank start-up receives seed funding, The Lancet, 394: 108 (2019).
- V. Wendy Brown White, Asoka Srinivasan et al., Capacity-Building for Career Paths in Public Health and Biomedical Research for Undergraduate Minority Students: A Jackson Heart Study Success Model, *Ethnicity & Disease* 26(3): 399-406 (2016)

Watch [in class]

Deadly Deception

Week 8: Housing

Goal: The purpose of this class is for students to understand how law, development decisions and policies adversely affect the impoverished population, and to explore the connection (or lack thereof) between the policies that created our current welfare system and the principles of bioethics. The students will also reflect on the prevalence of stigmatization in their own lives and communities, and how this stigma influences the use of bioethics to address involuntary displacement and equitable social service structures.

Read

I. Community Involvement, in Institute of Medicine, Committee on Ethical Issues in Housing-Related Health Hazard Research Involving Children, Youth, and Families, *Ethical Considerations for Housing-*

Related Health Hazards Involving Children, Bernard Lo and Mary Ellen O'Connell, Eds., National Academies Press (2005), pp. 76-98.

- a. Connecting the principle of beneficence to the moral obligation that community members have to ensure the safety of families in the neighborhood is a theme that we discuss as we read this article about environmental hazards in housing, and the impact on children.
- II. Austin Sarat, "... The Law Is All Over": Power, Resistance and the Legal Consciousness of the Welfare Poor, 2 Yale J.L. & Human. 343 (1990)
 - a. Marginalized individuals are constrained by legal, social and political systems, and this article shows how laws designed to create opportunities for some result in the oppression of others. We discuss how the application of bioethics principles to the legal system can address this problem.
- III. Aid to Families with Dependent Children (AFDC) and Temporary Assistance for Needy Families (TANF), Overview, http://aspe.hhs.gov/hsp/abbrev/afdc-tanf.htm
 - a. These laws provide cash assistance to qualifying individuals, and we discuss how the eligibility criteria has elements of moral judgments. We discuss if the criteria is "ethical" as defined in bioethics.
- IV. Center on Budget and Policy Priorities, TANF Should Reach Many More Families in Georgia, https://www.cbpp.org/sites/default/files/atoms/files/tanf trends ga.pdf
 - a. This report illustrates the decline of TANF's reach to families who are eligible for and in need of cash assistance. We discuss how declining TANF caseloads are a priority for policymakers, though declining caseloads in times of rising poverty are not critically analyzed. Students view these political decisions through a bioethics lens to understand how people living below the poverty line are affected by this approach.
- V. Williams v. Martin, 283 F.Supp.2d 1286 (2003)
 - a. This case upheld the ability for TANF to cap the amount of children for which a family can receive benefits. We discuss the stereotypes of people who allegedly abuse benefits, such as Medicaid, Medicare and TANF, and how laws and policies taken into potential abuse of these programs compared with programs designed to provide monetary benefits to people with higher incomes.
- VI. Ron Haskins, The myth of the disappearing middle class, The Washington Post, March 29, 2012
 - a. This article is written from a perspective that places the onus of being impoverished on the person living in poverty. We examine the concept of personal autonomy as a justification for laws and policies that prohibit those deemed as undeserving from receiving public benefits.
- VII. James Tracy, Hope VI Mixed-Income Housing Projects Displace Poor People, from RP&E Journal 15(1): Who Owns Our Cities
 - $\frac{\text{https://www.reimaginerpe.org/node/1811\#:} \sim :\text{text=In\%20reality\%2C\%20what\%20often\%20happens,subsidies\%E2\%80\%94to\%20lose\%20their\%20homes.}$

- a. We discuss how and if the principles of bioethics should be applied when making urban planning and development decisions. This article illustrates gentrification and its effects, as well as the effects of replacing public housing with mixed-income housing.
- VIII. David K. Shipler, A Poor Cousin of the Middle Class, *The New York Times Magazine*, January 18, 2004.
 - a. This article uses storytelling to show how poverty is the result of a number of external factors, and how stigma and shame can perpetuate inhuman treatment. The subject of this story is a woman who has worked minimum wage jobs her whole life, been the victim of domestic violence, suffers from health issues, and who struggles with financial literacy.
 - b. Students discuss how the concept of non-malfeasance given the prevalence of abject poverty.

Listen to

- I. Ira Glass, House Rules, This American Life, November 22, 2013 https://www.thisamericanlife.org/512/house-rules.
 - a. This podcast gives a historical overview of private and public housing discrimination. We discuss how historical racism can and should be addressed by racial justice laws and policies in present day. Bioethics principles are, in part, a response to historical racism by healthcare providers and the healthcare system. Our goal is for students to understand that the study of bioethics is transferrable to different professions.

Week 9: Peer Evaluation, Writing and Editing

Goal: Student develop skills in giving and receiving feedback through a structure process of peer evaluation.

Week 10: Guest Speaker

Goal: Provide an opportunity to learn from community-engaged researcher and provide positive role model.

Week 11: Confidentiality in Medicine

Goal: The goal of this class is to explore the concept of confidentiality, its role in medicine, and exceptions to it. Case examples will illustrate how facially neutral policies can have disproportionate impact on underrepresented minorities.

Learning objectives:

At the end of this session, students will be able to:

- i. Explain why confidentiality is an important norm for medicine
- ii. Identify and give the rationale for common confidentiality exceptions
- iii. Describe the risks those exceptions can have to underrepresented minorities

Read

- Mark Siegler, Confidentiality in Medicine A Decrepit Concept, New Engl. J. Med. 307(24): 1518-1521 (1982).
- II. Evan G. DeRenzo, Privacy and Confidentiality, in Fletcher's Introduction to Clinical Ethics, University Publishing Group, pp. 87-97.
- III. Tarasoff v. Regents of the University of California, 17 Cal.3d 425 (1976).
- IV. Ferguson v. City of Charleston, 121 S.Ct. 1281 (2001).
- V. Jessica Horan-Block, A Child Bumps Her Head. What Happens Next Depends on Race, *The New York Times*, August 24, 2019.

Week 12: Eugenics

Goal: To provide students with background for understanding the impact of eugenic thinking on governmental reproductive interventions involving minority populations, including the massive sterilization programs among Native Americans, Puerto Ricans and African Americans unearthed as a result of the Relf case and its aftermath.

Read

- I. Reif v. Weinberger, 372 F.Supp. 1196 (D.D.C. 1974).
- II. John A. Robertson, Norplant and Irresponsible Reproduction, *The Hastings Center Report*, 25(1): S23-S26 (1995) https://www.jstor.org/stable/3562508.
- III. Gregory Michel Door, Protection or Control? Women's Health, Sterilization Abuse, and *Reif v. Weinberger*, in *A Century of Eugenics in America: From the Indiana Experiment to the Human Genome Era*, Paul A. Lombardo, Ed., Bloomington & Indianapolis: Indiana University Press (2011), pp. 161-190.

Week 13: Access to Family Planning

Goal: To expose students to the controversies and dilemmas that are embedded in contemporary debates over access to reproductive health interventions, including birth control and abortion.

Read

- I. Judith Jarvis Thomson, A Defense of Abortion, *Philosophy & Public Affairs*, 1(1): 47-66 (1971).
- II. Harry J. Gensler, A Kantian Argument Against Abortion, Philosophical Studies, 48: 57-72 1985).
- III. Michael J. Sandel, Embryo Ethics The Moral Logic of Stem-Cell Research, New Engl. J. Med. 351(3): 207-209 (2004) and Paul R. McHugh, Zygote and "Clonote" The Ethical Use of Embryonic Stem Cells, New Engl. J. Med. 351(3): 209-211 (2004).
- IV. William Neaves, The status of the human embryo in various religions, *Development*, 144: 2541-2543 (2017).

Week 14: Advance Care Planning

Goal: The purpose of this class is to explore how inequities in the healthcare system may impact willingness to engage in advance care planning and to highlight the work of diverse scholars to affect change.

Read

- I. Katharine Q. Seelye and Jess Bidgood, Guilty Verdict for Young Woman Who Urged Friend to Kill Himself, *The New York Times*, June 16, 2017.
 - a. We return to the concept of autonomy with discussion of a current story that requires students to examine mental health, and power dynamics in the context of consent.
- II. Kimberly S. Johnson, Maragatha Kuchibhatla, and James Tulsky, Racial Differences in Self-Reported Exposure to Information about Hospice Care, *Journal of Palliative Medicine*, 12(10): 921-927 (2009).
- III. Julia Craven, How Racial Health Disparities Will Play Out in the Pandemic, *Slate*, March 30, 2020 https://slate.com/news-and-politics/2020/03/how-racial-health-disparities-will-play-out-in-the-coronavirus-pandemic.html
 - a. This article provided background for our classroom discussion on how to decide which people should receive the vaccine first, and how to appropriately address the adverse impacts of the pandemic that were exacerbated in communities of color due to systemic issues.

Appendix 2: Additional Resources

We used multiple resources to identify materials for use in our course, and there are many more high-quality articles, videos, and other resources than we could include. Other teachers may focus on different topics. Recognizing that any list will invariably leave off excellent options, and that more resources become available each day, we want to highlight some resources that we found helpful.

Websites

A particularly helpful resource for identifying diverse scholars on particular topics, whether for course materials or speakers, is diversebioethics.org, maintained by Holly Fernandez Lynch from the University of Pennsylvania. The purpose of the list is "to **amplify the voices** of diverse, underrepresented scholars at all stages of their careers doing work related to bioethics and to **increase awareness** of their expertise." It can be used "as a starting point for: faculty recruiting, identifying project/grant collaborators, identifying working group/committee members, inviting lecturers/panelists, identifying media sources, diversifying course syllabi." The website acknowledges that most LatinX entries were initially created by https://latinxbioethics.com. It also acknowledges the List of Bioethicists of Color available at https://drive.google.com/file/d/1nhi3U6ARfEahmBjqza9NX6T4Kzt0vaPT/view.

<u>Videos</u>

The internet is a tremendous resource for videos that can be used to introduce concepts and stimulate conversation. As remote conferences and talks become the norm during the COVID-19 pandemic, the number of videos available for use in teaching has expanded. However, many of these are longer than ideal for use in the classroom. We have developed a collection of short videos that highlight the work and careers of diverse scholars that we are available on the Georgia State University College of Law website (https://readingroom.law.gsu.edu/bioethics/) for use in teaching. We also highly recommend Monica Peek's video "Segregation is Bad for Your Health" (youtube.com/watch?v=hkHXOYMa4ck).

Ted Talks and their progeny (e.g., TedMed, Ted[Institution]) are a potentially rich source of material, as they are designed to be short, engaging, and informative. Some examples we considered include:

- o Camara Jones, M.D., M.P.H., Ph.D., Morehouse College of Medicine, "Allegories on race and racism" TedxEmory, available at https://www.youtube.com/watch?v=GNhcY6fTyBM (approximately 20 minutes). (Dr. Jones's storytelling approach illuminates different ways to approach race and racism and inspires action to improve health equity.)
- Denisse Rojas Marquez, M.D., "No longer afraid: an undocumented immigrant's experience in American health care," https://www.youtube.com/watch?v=X7m3FUSeXCE (approximately 12.5 minutes)(Dr. Marquez describes her mother's experience in the US health care system and how it inspired her to pursue her medical degree.)

Useful videos may surface in other ways. Our searches uncovered the work of Malone Mukwende, a medical student in the United Kingdom, who was disturbed by the failure of his medical textbooks to talk about how some conditions may present differently in brown or black skin. His conversations with his teachers led to a collaboration that resulted in a book, "Mind the Gap," to remedy this omission. (see https://www.blackandbrownskin.co.uk/) The video (https://youtu.be/4L7HgDZFXJs) describing the book and the motivation for it is short and provides some background that can effectively introduce the topic of bias in medicine, as well as provide inspiration to students about how they can make a difference.