

DIVERSITY READING LIST PRESENTS:

RACE, DISABILITY, AND GENDER IN BIOETHICS

A DRL READING GROUP BLUEPRINT BY CHRIS BLAKE-TURNER

LEVEL: EASY

INTRODUCTION

This blueprint is organized into three sections, each corresponding to an area that has been underdiscussed in the dominant bioethics literature. The first considers issues of race and bioethics. It focuses especially on bioethics and Black Americans, an intersection on which important work has recently been done. The second highlights new work on disability and bioethics. Topics include taking seriously the testimony of disabled people, and the triaging of care during the COVID-19 pandemic. The third section considers work on gender and bioethics. It begins with a paper that applies feminist ethics to moral distress, an important concept in nursing ethics that is often left out of physician-dominated mainstream bioethical discussion. The last two papers are on the care of transgender adults and children, respectively.

Together these papers can be used as the basis of an 8-week reading group. There are 9 papers, but both the Ray and Ashley papers are short, and either could be doubled up with the reading that comes after it. Despite being short, however, both papers are rich enough to furnish material for a week on their own.

These readings just scratch the surface of important and expanding areas of bioethics. But by the time you've worked through them, you should have a better grasp of some central concepts, and you should have a good idea of where to look to find further readings.

CATEGORIES

- Applied Ethics
- Biomedical Ethics
- Public Health
- Philosophy of Race, Gender and Sexuality
- Disability
- Feminist Bioethics

AVAILABLE ONLINE AT:

<https://diversityreadinglist.org/blueprint/race-disability-and-gender-in-bioethics/>

1. RACE AND BIOETHICS

RAY, KEISHA. *IT'S TIME FOR A BLACK BIOETHICS*

2021, *The American Journal of Bioethics*. 21(2): 38–40.

Difficulty: Easy

ABSTRACT:

There are some long-standing social issues that imperil Black Americans' relationship with health and healthcare. These issues include racial disparities in health outcomes (Barr 2014), provider bias and racism lessening their access to quality care (Sabin et al. 2009), disproportionate police killings (DeGue, Fowler, and Calkins 2016), and white supremacy and racism which encourage poor health (Williams and Mohammed 2013). Bioethics, comprised of humanities, legal, science, and medical scholars committed to ethical reasoning is prima facie well suited to address these problems and influence solutions in the form of policy and education. Bioethics, however, so far has shown only a minimal commitment to Black racial justice.

COMMENT:

In this short, seminal piece, Keisha Ray argues that bioethics needs to address issues of health and well-being of Black individuals. She applies Beauchamp and Childress's famous four principles of bioethics to a particular issue: the disproportionate maternal mortality rate of Black women in the United States. Ray argues bioethics must incorporate the lens of Black bioethics, if the discipline is to remain relevant.

DISCUSSION QUESTIONS:

1. Ray writes: "Bioethics, however, so far has shown only a minimal commitment to Black racial justice" (p. 38). Why do you think that is?
2. How does the lens of Black bioethics help us explain Black women's higher maternal mortality rates in the United States?
3. Ray deploys the principles of autonomy, beneficence and non-maleficence, and justice in a Black bioethics framework. But she is also explicit that "There are... other ways of doing bioethics" (p. 38). How might Black bioethics help us, if at all, understand other ways of approaching bioethical issues?
4. Ray raises the possibility of medical reparations for Black patients. What kind of reparations, if any, might be appropriate and why? Do you think they should be implemented?
5. Ray's discussion focuses on a particular case: Black women in the United States. To what extent does her argument about Black bioethics generalize to other contexts?
6. What, if anything, can we learn from Ray's paper about bioethics and non-Black marginalized groups?

ABSTRACT:

Intersectionality has become a significant intellectual approach for those thinking about the ways that race, gender, and other social identities converge in order to create unique forms of oppression. Although the initial work on intersectionality addressed the unique position of black women relative to both black men and white women, the concept has since been expanded to address a range of social identities. Here we consider how to apply some of the theoretical tools provided by intersectionality to the clinical context. We begin with a brief discussion of intersectionality and how it might be useful in a clinical context. We then discuss two clinical scenarios that highlight how we think considering intersectionality could lead to more successful patient–clinician interactions. Finally, we extrapolate general strategies for applying intersectionality to the clinical context before considering objections and replies.

COMMENT:

Wilson et al. argue that intersectionality is an important concept in clinical practice. They clarify the concept and distinguish their call for intersectionality from nearby claims. For instance, they argue that intersectionality goes beyond mere cultural competence that healthcare providers are already trained in, at least to some degree. Their paper is anchored around two fictionalized case studies, which they use to make vivid and explain their central claims. They end by responding to objections, including the very idea of intersectionality itself.

DISCUSSION QUESTIONS:

1. How do you understand intersectionality? How, if at all, does that differ from Wilson et al.’s understanding?
2. What are we supposed to learn about intersectionality in clinical medicine from the two cases, i.e. History of Trauma and Chronic Pain? What are the similarities and differences between the two cases when it comes to applying intersectionality in clinical contexts?
3. Why do Wilson et al. say that “an intersectional framework to clinical practice does not call for simple concordance of physician-patient race and gender” (p. 12)?
4. Wilson et al. argue that “clinicians can be as knowledgeable about the impact of social policies on their patients as they are about [medical issues]” (p. 14). Is it feasible to expect physicians and other healthcare providers to be knowledgeable about socio-historical contexts and structures, in addition to having medical expertise?
5. Which of the three objections that Wilson et al. consider do you find most compelling? Do they address it adequately?
6. How might you put Wilson et al.’s paper in conversation with Ray’s? Are Black bioethics and intersectionality in clinical medicine compatible? If so, how? If not, under which circumstances is each approach to be preferred?

ABSTRACT:

The genome between socially constructed racial groups is 99.5%-99.9% identical; the 0.1%-0.5% variation between any two unrelated individuals is greatest between individuals in the same racial group; and there are no identifiable racial genomic clusters. Nevertheless, race continues to be used as a biological reality in health disparities research, medical guidelines, and standards of care reinforcing the notion that racial and ethnic minorities are inferior, while ignoring the health problems of Whites. This article discusses how the continued misuse of race in medicine and the identification of Whites as the control group, which reinforces this racial hierarchy, are examples of racism in medicine that harm all us. To address this problem, race should only be used as a factor in medicine when explicitly connected to racism or to fulfill diversity and inclusion efforts.

COMMENT:

Yearby argues that appeals to racial categories—social, but especially biological—in medicine harm people from all races, including those from dominant racial groups, like Whites. Yearby first gives evidence for the claim that there is no biological reality to race. She then argues that the continued use of racial categorization in medicine—for instance, as a basis for different standards of care—leads to worse outcomes for all. For example, because Whites are often the de facto standard group in healthcare, their worse health outcomes are sometimes overlooked. Yearby ends by making suggestions for improving the categorization of people in healthcare.

DISCUSSION QUESTIONS:

1. How does Yearby distinguish between biological and social race?
2. How does Yearby argue that using racial categories in medicine leads to racial health disparities?
3. Do you agree with Yearby that “the root cause of poor health outcomes for all groups... is racism” (p. 21)?
4. How, if at all, does Yearby’s discussion of morality in childbirth affect your understanding of Ray’s argument?
5. What does Yearby mean by “the corruption of knowledge production” (pp. 22–23)? How does she argue that racism plays a role in this process?
6. Yearby argues that race-based medicine with respect to breast cancer “not only reifies the racist belief that Whites are superior, but also prevents women of all races from equal to treatment” (p. 24). Is her argument a good one? How might it extend beyond breast cancer?
7. Like the other authors in this section, Yearby focuses on the medical system in the U.S. To what extent do Yearby’s arguments apply to other medical systems, for instance those with state-provided medical access as in the U.K.?

2. DISABILITY AND BIOETHICS

TAYLOR, SUNAURA. *BEASTS OF BURDEN: ANIMAL AND DISABILITY LIBERATION*

2017, The New Press.

Difficulty: Easy

Fragment: “On Ableism and Animals”, excerpt published by *The New Inquiry*.

ABSTRACT:

How much of what we understand of ourselves as “human” depends on our physical and mental abilities—how we move (or cannot move) in and interact with the world? And how much of our definition of “human” depends on its difference from “animal”?

Drawing on her own experiences as a disabled person, a disability activist, and an animal advocate, author Sunaura Taylor persuades us to think deeply, and sometimes uncomfortably, about what divides the human from the animal, the disabled from the nondisabled—and what it might mean to break down those divisions, to claim the animal and the vulnerable in ourselves, in a process she calls “cripping animal ethics.”

Beasts of Burden suggests that issues of disability and animal justice—which have heretofore primarily been presented in opposition—are in fact deeply entangled. Fusing philosophy, memoir, science, and the radical truths these disciplines can bring—whether about factory farming, disability oppression, or our assumptions of human superiority over animals—Taylor draws attention to new worlds of experience and empathy that can open up important avenues of solidarity across species and ability. *Beasts of Burden* is a wonderfully engaging and elegantly written work, both philosophical and personal, by a brilliant new voice.

COMMENT:

In this excerpt from her book, *Beasts of Burden*, Taylor resists the way that animals and intellectual disabled people are often framed in terms of one another. She argues that this does a disservice to both groups. Animals are not voiceless, as they are often constructed. And their comparison to disabled people in the (in)famous argument from marginal cases should not be accepted. Perhaps most importantly, the argument opens for discussion the worth of disabled people’s lives. But this is not something that should be open for discussion, especially given the marginalization of disabled people.

DISCUSSION QUESTIONS:

1. How does Taylor cast doubt on the idea of animal advocacy as giving “voice to the voiceless”? Do you agree with her?
2. What is the argument from marginal cases?
3. Why, according to Taylor, is there a “danger” in the argument from marginal cases?
4. How does Taylor argue for the conclusion that to “compare animals to intellectually disabled people... harms both populations”?
5. What does Taylor mean when, in the final paragraph, she claims that “We need to crip animal ethics”? Do you agree?
6. How might Taylor’s article have implications for bioethical issues beyond animal ethics?

ABSTRACT:

Disabled people face obstacles to participation in epistemic communities that would be beneficial for making sense of our experiences and are susceptible to epistemic oppression. Knowledge and skills grounded in disabled people's experiences are treated as unintelligible within an ableist hermeneutic, specifically, the dominant conception of disability as lack. My discussion will focus on a few types of epistemic oppression—willful hermeneutical ignorance, epistemic exploitation, and epistemic imperialism—as they manifest in some bioethicists' claims about and interactions with disabled people. One of the problems with the epistemic phenomena with which I am concerned is that they direct our skepticism regarding claims and justifications in the wrong direction. When we ought to be asking dominantly situated epistemic agents to justify their knowledge claims, our attention is instead directed toward skepticism regarding the accounts of marginally situated agents who are actually in a better position to know. I conclude by discussing disabled knowers' responses to epistemic oppression, including articulating the epistemic harm they have undergone as well as ways of creating resistant ways of knowing.

COMMENT:

Wieseler draws on resources developed by feminists and disability theorists to critique the practice of philosophical bioethics (bioethics done by philosophers). In particular, she argues that philosophical bioethics involves and perpetuates ableism. Among its many problems, this ableism is epistemically fraught. It interferes with disabled people's ability to participate in various kinds of knowledge production. Wieseler uses a lot of technical terms—like epistemic exploitation, epistemic imperialism, and willful hermeneutical ignorance—but she explains everything clearly and the payoff is worthwhile. Wieseler uses these concepts to develop a powerful and thought-provoking critique of bioethical practice with respect to disability. The concepts are also useful in broader contexts, as we'll see in section 3.

DISCUSSION QUESTIONS:

1. How does willful hermeneutical ignorance differ from hermeneutical injustice?
2. What is the "double bind" of epistemic exploitation (p. 717)?
3. What is the "standard view of disability" and why is not a "value-free starting assumption", according to Wieseler (pp. 719–720)?
4. How does Wieseler draw on the notions of epistemic exploitation, epistemic imperialism, and willful hermeneutical ignorance to critique Singer (a stand in for philosophical bioethicists more generally) on his approach to disability?
5. What are "crip skills" and what is their significance for bioethics and epistemic resistance (p. 726)?
6. As well as arguing that assuming that disabled people have a low quality of life is ableist, Wieseler claims that quality of life should not be conflated with value of life. What is valuable about lives other than their subjective quality?
7. What points of harmony and friction are there between Wieseler's piece and Taylor's?

ABSTRACT:

In this paper, I make three arguments regarding Crisis Standards of Care developed during the COVID-19 pandemic. First, I argue against the consideration of third person quality of life judgments that deprioritize disabled or chronically ill people on a basis other than their survival, even if protocols use the language of health to justify maintaining the supposedly higher well-being of non-disabled people. Second, while it may be unavoidable that some disabled people are deprioritized by triage protocols that must consider the likelihood that someone will survive intensive treatment, Crisis Standards of Care should not consider the amount or duration of treatment someone may need to survive. Finally, I argue that, rather than parsing who should be denied treatment to maximize lives saved, professional bioethicists should have put our energy into reducing the need for such choices at all by resisting the systemic injustices that drive the need for triage.

COMMENT:

Stramondo critiques triage protocols that were put into place, or at least proposed, during the COVID-19 pandemic. Stramondo argues that protocols that prioritize quality of life involve ableist commitments. While chance-of-survival protocols might do better here, he argues that they are also vulnerable to creeping ableism. Stramondo's paper is valuable not only for its perspective on triage protocols, but also for highlighting some crucial theoretical contributions by philosophers of disability and by bioethicists. Stramondo also argues not to cede too much ground to fatalism in thinking about triage protocols; bioethicists should also, and perhaps primarily, resist the framing of triage as inevitable, rather than a product of various privileged interests.

DISCUSSION QUESTIONS:

1. What is the so-called "disability paradox" and what are Stramondo's reservations about that term (p. 202)?
2. What is wrong, according to Stramondo, with the University of Washington's invocation of "health" in their triage protocol?
3. Stramondo writes: "I would argue that any triage protocol is unjustly discriminatory against disabled people insofar as it deprioritizes them due to a belief that their lives are of less value because they are of less quality" (p. 204). How is Stramondo's argument affected, if at all, by Wieseler's injunction to separate quality of life from value of life?
4. Why is individual assessment, rather than assessment based on group membership, of likelihood of survival important?
5. What is the distinction that Stramondo draws between inefficiency and waste? How does the distinction allow him to argue for accepting the likelihood-of-survival criterion while rejecting the level-of-resource intensity criterion? How does the distinction play a role in bioethical issues beyond triage?
6. What is the "powerful paradigm shift" Stramondo interprets Shelley Tremain as calling for (p. 206)? What does Stramondo suggest that bioethicists do in response? Is he right?
7. Taking Stramondo's points into consideration, what do you think a just, and in particular an anti-ableist, triage protocol would involve?

3. GENDER AND BIOETHICS

PETER, ELIZABETH AND LIASCHENKO, JOAN. *MORAL DISTRESS REEXAMINED: A FEMINIST INTERPRETATION OF NURSES' IDENTITIES, RELATIONSHIPS, AND RESPONSIBILITIES*

2013, *The Journal of Bioethical Inquiry*. 10: –345.

Difficulty: Easy-Intermediate

ABSTRACT:

Moral distress has been written about extensively in nursing and other fields. Often, however, it has not been used with much theoretical depth. This paper focuses on theorizing moral distress using feminist ethics, particularly the work of Margaret Urban Walker and Hilde Lindemann. Incorporating empirical findings, we argue that moral distress is the response to constraints experienced by nurses to their moral identities, responsibilities, and relationships. We recommend that health professionals get assistance in accounting for and communicating their values and responsibilities in situations of moral distress. We also discuss the importance of nurses creating “counterstories” of their work as knowledgeable and trustworthy professionals to repair their damaged moral identities, and, finally, we recommend that efforts toward shifting the goal of health care away from the prolongation of life at all costs to the relief of suffering to diminish the moral distress that is a common response to aggressive care at end-of-life.

COMMENT:

Moral distress is, roughly, when a healthcare worker is institutionally constrained to act against their best moral judgement. A typical example is a nurse being prevented from giving care they deem morally required because they are hierarchically constrained by the orders of a physician. Moral distress has been much discussed in nursing ethics, but is almost entirely absent from broader bioethics syllabi and conversations. This paper examines moral distress through a lens of feminist care ethics. In doing so, it draws lessons that apply very broadly throughout professional ethics.

DISCUSSION QUESTIONS:

1. How do Peter and Liaschenko define moral distress? Is their definition a good one? Why or why not?
2. What is a moral identity and why is it important in thinking about moral distress?
3. Peter and Liaschenko write that “the identity of ‘nurse’ is a social construction” (p. 339). What do they mean by that? Are they right?
4. How does foregrounding relationships shed light on moral distress?
5. How does gender play a role in the moral distress of hospital nurses?
6. What recommendations do Peter and Liaschenko make for alleviating the problem of moral distress? Are likely to work? What other recommendations might be implemented?
7. Peter and Liaschenko focus on the moral distress of hospital nurses, but recognize that moral distress is a broader issue. What are some examples of moral distress beyond hospital nursing, or even beyond the context of healthcare?

ABSTRACT:

Although informed consent models for prescribing hormone replacement therapy are becoming increasingly prevalent, many physicians continue to require an assessment and referral letter from a mental health professional prior to prescription. Drawing on personal and communal experience, the author argues that assessment and referral requirements are dehumanising and unethical, foregrounding the ways in which these requirements evidence a mistrust of trans people, suppress the diversity of their experiences and sustain an unjustified double standard in contrast to other forms of clinical care. Physicians should abandon this unethical requirement in favour of an informed consent approach to transgender care.

COMMENT:

Ashley draws on their own experiences as a trans person, as well as that of the trans community more broadly, to argue against assessment and referral requirements for hormone-replacement therapy (HRT). Ashley argues instead for an informed consent model, on which providers of HRT are not gatekeepers of transness, but facilitators of thoughtful decision-making.

DISCUSSION QUESTIONS:

1. An important part of Ashley's argument is their own experience in accessing HRT and other transition-related healthcare, as well the experiences of the trans community. Appeals to anecdotal, and especially personal, evidence mark a departure from the how bioethics is normally practised. What are the advantages and disadvantages of Ashley's approach?
2. How can the concepts of epistemic exploitation, epistemic imperialism and willful hermeneutical ignorance (explained in Wieseler's paper) augment Ashley's argument that trans people are subject to injustice when "physicians deny the authority trans people have over their own mental experiences" (p. 481)?
3. "Medically transitioning is not all about gender dysphoria", Ashley writes (p. 481). What do they mean? How do they argue that gender dysphoria assessments problematize and pathologize trans experience?
4. How does Ashley argue that assessment and referral requirements either assume that trans people are mentally ill or involve double standards?
5. In general, how should we think about the limits of informed consent? That is, what are the circumstances in which someone requesting medical treatment is not sufficient for providing that treatment? It might be helpful to think both about the circumstances of the person making the request and about the thing they're requesting.

ABSTRACT:

In this article, I argue that (1) transgender adolescents should have the legal right to access puberty-blocking treatment (PBT) without parental approval, and (2) the state has a role to play in publicizing information about gender dysphoria. Not only are transgender children harmed psychologically and physically via lack of access to PBT, but PBT is the established standard of care. Given that we generally think that parental authority should not go so far as to (1) severely and permanently harm a child and (2) prevent a child from access to standard physical care, then it follows that parental authority should not encompass denying gender-dysphoric children access to PBT. Moreover, transgender children without supportive parents cannot be helped without access to health care clinics and counseling to facilitate the transition. Hence there is an additional duty of the state to help facilitate sharing this information with vulnerable teens.

COMMENT:

Priest argues that the state should provide puberty-blocking treatment (PBT) for trans youth, even if their parents are not supportive. Priest's argument is important partly because it avoids the issue of whether adolescents and children can give properly informed consent. This is a point that some of Priest's critics seem to have missed (see, for example, Laidlaw et al. 2019. "The Right to Best Care for Children Does Not Include the Right to Medical Transition", and Harris et al. 2019. "Decision Making and the Long-Term Impact of Puberty Blockade in Transgender Children"). Priest's conclusion is founded instead on a principle of harm avoidance.

DISCUSSION QUESTIONS:

1. Priest argues that psychological harm is not less important than physical harm. How does she argue for this claim? Is she correct?
2. Priest argues that the state should intervene and offer PBT to trans youth with unsupportive parents. What is her argument exactly? Is it a good one?
3. How does Priest address the objection that some studies suggest "many transgender children do not go on to become transgender adults" and so shouldn't be given PBT (p. 49)?
4. Why does Priest not base her argument on the "mature minor doctrine" (p. 52)?
5. What is the special role of schools in providing PBT, according to Priest?
6. Priest considers several objections to her argument, especially in the section beginning on p 54. Are her replies convincing? Are there any other objections that she doesn't address? How might you reply on her behalf?
7. Although Priest is not committed to the idea that PBT should only be provided to trans youth when they give properly informed consent, it's worth considering informed consent in children and adolescents as an issue in itself. If children can't give properly informed consent to PBT, why not? Are there things they can give properly informed consent to? If so, why is PBT different?