

Questions of Race in Bioethics: Deceit, Disregard, Disparity, and the Work of Decentering

ABSTRACT

Philosophers working in bioethics often hope to identify abstract principles and universal values to guide professional practice, relying on ideals of objectivity and impartiality, and on the power of rational (individual, autonomous) deliberation. Such a focus has made it difficult to address issues arising from group-based, sociohistorical differences like race and ethnicity. This essay offers a survey of some of the major issues concerning race in the field of bioethics. These issues include a long history of racialized abuse in medical and scientific research, reproductive injustice and abuse against women of color, and persistent racial and ethnic disparities in U.S. health and healthcare. The essay also argues that the field of bioethics as a whole would be improved by taking the experience of racial minorities into account in all its theorizing. Philosophers can aid in this task by expanding their theoretical focus beyond questions of individual rights to questions of social justice, beyond informed consent to community collaboration, and beyond cultural competency to both structural competency and cultural humility.

Living as we did—on the edge—we developed a particular way of seeing reality. We looked both from the outside in and from the inside out. We focused our attention on the center as well as on the margin. We understood both. This mode of seeing reminded us of the existence of a whole universe, a main body made up of both margin and center.

- bell hooks, *Feminist Theory: from margin to center*

Racism, specifically, is the state-sanctioned or extralegal production and exploitation of group-differentiated vulnerability to premature death.

- Ruth Wilson Gilmore, *Golden Gulag*

Though a great deal of bioethical literature makes no mention of race, articles (and even books) that do consider race in some dimension with respect to bioethical issues of some sort are not so difficult to come by. The articles make admittedly token appearances in bioethics textbooks,¹ but can also be found gathered together in special issues of academic journals² and in edited volumes.³ Also available, and extremely valuable, are thorough and impressively researched book length treatments of particular sites, topics, or practices situated at the intersection of race and bioethics. In the first part of this essay, I hope to provide a brief (and necessarily limited) survey of some of the major injustices (historical and contemporary) around which much of this work has been focused (particularly in the U.S. context), including abuse in medical research, reproductive abuse, and health disparities. Awareness of

these injustices by people of color shapes what I call the *view from the margins* of U.S. healthcare and biomedicine.

As a field of inquiry, bioethics is both broad and highly interdisciplinary, admitting of a variety of methodologies and approaches. Between these many disciplines, one can discern a number of voices that are speaking up for the bodies and lives that have been marked (figuratively and literally) by racialization, discrimination, stigmatization and marginalization. Yet philosophers are underrepresented in this work at the intersection of race and bioethics.⁴ It's easy enough to speculate as to why. For one thing, the discipline of philosophy is overwhelmingly white and predominately male.⁵ For another, philosophy is often overly enamored of things like abstract principles, universal values, truth, objectivity, impartiality, and the power of rational (and often individual, autonomous) deliberation. Differences in thinking, knowing, desiring or needing that stem from differences in one's social, political or cultural situation (or from the world's inequalities and imperfections) have been difficult for philosophy to deal with, and often simply relegated to the social scientists. Yet, insofar as philosophy's obsessions with things like autonomous individuals and a rational "view from nowhere" have helped to form the "center" of bioethics, it's worth asking what kind of work philosophers of race might be able to do in service of the "margins." Thus, the second part of this essay will be dedicated suggesting the directions philosophers of race might take should they wish to enter the bioethical conversation in greater numbers. Pointing to insights from feminist standpoint theory, I suggest that the experiences of people of color be shifted *from margin to center*, engendering shifts in bioethics from rights to justice, from consent to collaboration, and from competence to humility.

The View from the Margins

When we speak of the view from the margins, as bell hooks does in the opening epigraph, we are speaking about reality as perceived by those people in society who experience less social recognition, command less political representation, have access to fewer resources, and are at greater

risk of violence and other hardship than those people who typically describe, define, theorize about, or otherwise represent that society. Here specifically, we are concerned with those whose marginalization is tied to the way they are racialized within U.S. society, and we are looking at how they experience things like health, healthcare, medical practice and medical research. As we shall see, the experience of racialized others in the United States is shaped by both histories of abuse and present inequalities. These have resulted in a persistent mistrust of biomedicine on the part of the marginalized that must be understood as far from irrational and addressed accordingly.

1. Abuse in the Name of Science/Medicine

The history of racialized abuse in medical/scientific research is long and sordid; I'll only highlight a few cases here.⁶ The most frequently discussed immoral experiment performed on black Americans is the U.S. Public Health Service's Study of Syphilis in the Untreated Negro Male – commonly known as the Tuskegee Syphilis Study.⁷ This study, which ran for 40 years in Macon County, Alabama, involved about four hundred poor black men with syphilis (along with 200 control subjects). The infected men – 61 percent of whom had congenital, non-venereal syphilis (despite stereotypes about black promiscuity) – were told they were receiving free treatment for “bad blood.” In reality, they received no treatment whatsoever. They did not receive treatment with arsenic compounds, which was the standard of care when the study began in 1932. Nor did they receive penicillin when it was discovered to be a safe and effective cure for syphilis in 1943. In fact, the Public Health Service worked hard to make sure that study subjects didn't receive treatment elsewhere, like in the military or at VD-treatment clinics, by exempting the men from the draft and distributing lists of their names to clinics. The ostensible aim of the study was to observe and record the “natural progression” of the disease (although ultimately the study yielded no valid or valuable data), and researchers strove to see the subjects through to their deaths, offering “free burials” as an enticement to get ahold of the bodies for autopsy – which practice was largely opposed by the black community.

Researchers justified what should have been an obviously inhumane and unethical experiment, even by the standards of the time, by portraying black Alabamans as “resistant to health measures, intellectually inferior, impetuous, degenerate, and, above all, at the mercy of frighteningly powerful sexual drives” (H. Washington 160). In spite of regular publication of study “results” in medical journals, presentations of the study at American Medical Association meetings, and, ultimately, attempts by outside physicians and civil rights groups to end the study during the sixties, it was not actually terminated until 1972, after a journalist with the Associated Press exposed it to the public. While the Tuskegee Syphilis Study and its effects on the black community were undoubtedly traumatic, repeated mentions of the story *in isolation* can make it appear as an aberration, which risks casting African American’s wariness of the medical establishment as “an overreaction to a single event rather than an understandable, reasonable reaction to the persistent experimental abuse that has characterized American medicine’s interaction with African Americans” (H. Washington 181). Thus, it is important to acknowledge that Tuskegee was not the beginning, nor was it unique.

Consider doctor and slave-owner, Marion Sims, the so-called father of modern gynecology. Less remembered to history than Sims are Lucy, Anarcha, and Betsey, who, along with eight other unnamed enslaved black women, endured dozens of vaginal surgeries without anesthesia (though often dulled by and addicted to morphine afterwards) whilst Sims perfected his techniques. It is important both simply to remember these women and to reflect on what Sims’ treatment of them implies about the way he (and many though not all other doctors of the time) viewed them. Clearly, enslaved black women were enough like white women that techniques practiced on them could later be used on white patients. Yet they were not believed to experience pain the way white women did and were considered hardy enough to endure multiple procedures. Moreover, they were without modesty to be protected. There was nothing too untoward for Sims about asking his medical students to assist him in inserting a pewter spoon into Lucy’s vagina (forerunner to Sims’ speculum) to better view her fistula.⁸

Nor were black women the only victims of Sims' "noble" quest for knowledge. He also used black infants to conduct experiments on tetany, a neuromuscular disease more common in enslaved children due to malnutrition, but which Sims attributed to displacement of skull bones during birth. Believing a scientific myth that premature closing of the skull in black infants rendered them less intelligent and perpetually childlike, Sims cut open enslaved children's scalps and attempted to pry their skull bones into new positions using a cobbler's tool. Not surprisingly, these children died. Even Thomas Jefferson experimented on his family's and his neighbors' slaves, testing vaccinations against smallpox, before eventually inoculating his own white family members (H. Washington 59-63).

Moreover, during slavery, Southern medical schools established hospitals for blacks to which slave-owners were exhorted to send their slaves so that medical students could observe and practice procedures on them. Free blacks desperate enough to seek help at hospitals were also subject to experimental exploitation in the name of medical education (H. Washington 107). Indeed, even after death, black bodies were at risk for abuse. As the field of medicine and medical training became more scientific throughout the nineteenth century, the demand for cadavers for anatomical dissection far outpaced the legal supply. Thus, grave robbers known as "resurrectionists" or "night doctors" (many of whom were also black) could make a living plundering the graveyards reserved for African Americans and selling these stolen bodies to medical schools.⁹ As Harriet Washington points out, the predominance of black patients and black cadavers in medical education was likely sufficient to desensitize even sympathetic aspiring doctors to the humanity and suffering of black people, reducing blacks to mere objects of the white medical gaze rather than patients in need of care and healing (112-3, 136-8).

Another particularly troubling series of examples comes in the recounting of experiments performed on prisoners across the nation after World War II, most notably the work of Dr. Klingman in Philadelphia's Holmesburg Prison, where roughly three-quarters of the inmate population became experimental subjects.¹⁰ While the predominately black prisoners of Holmesburg earned very little

money for putting their health at risk (and lacked the information about the experiments to give meaningful informed consent), Klingman made a fortune and a career out of using their bodies to test anything from cosmetic products for companies like Johnson and Johnson to Cold War-era interrogation agents for U.S. intelligence agencies. As Hornblum describes it: “An uniformed and desperate group of prisoners met an unrestrained and ambitious doctor, and Holmesburg Prison became one of postwar America’s largest, non-therapeutic, human research factories” (1998, 233). By the time experimentation at Holmesburg came to an end in 1974 thousands of vulnerable men were left with physical and psychological scars.

Also notable is the case of Henrietta Lacks, an African American woman who died of cervical cancer in Johns Hopkins Hospital in 1951 at age thirty-one. Though it was not common practice at that time to inform patients that tissue samples were being taken or to ask for their consent, Lacks’ case was uncommon in that the cells taken from her tumor became the first immortal human cells ever grown in a laboratory – the HeLa cell line. These cells have been sent up in space missions and have contributed to medical breakthroughs like the polio vaccine, chemotherapy, cloning, gene mapping, and in vitro fertilization (Skloot 2). HeLa cells have been grown on an industrial scale and distributed for profit; the medical advances made by using the cells have also been profitable. Yet, like many African Americans, many of Henrietta Lacks’ descendants (some of whom have themselves been tested by researchers hoping to learn more about the HeLa cell line) are poor and lack access to health care. As Henrietta’s youngest son Zakariyya puts it,

Them doctors say her cells is so important and did all this and that to help people. But it didn’t do no good for her, and it don’t do no good for us. If me and my sister need something, we can’t even go see a doctor cause we can’t afford it. Only people that can get any good from my mother cells is the people that got money, and whoever sellin them cells – they get rich off our mother and we got nothing. (Skloot 246-7)

Her daughter Deborah wrote a poem to similar effect:

cancer

check up

can't afford

white and rich get it

my mother was black

black poor people don't have the money to pay for it

mad yes I am mad

we were used by taking our blood and lied to

We had to pay for our own medical, can you relieve that.

John Hopkin Hospital and all other places, that has my mother cells don't give her

Nothing. (Skloot 280)

The objectification and commodification of Lacks' cells was not malicious and it was of great scientific value, but was it morally wrong? Though the story may disturb, as Wald points out, it has been "difficult to identify and name the specific malfeasance" (187). A more appropriate question may be to ask about the injustices reflected in Lacks' story. For whose benefit has medical science acted? And at whose expense?

Nor were African Americans the only racialized group subject to decidedly non-therapeutic research programs in North America. Mosby documents a series of nutrition experiments performed in aboriginal/First Nations communities and residential schools in Canada between 1942 and 1952.¹¹ In these studies, aboriginal children and adults who were severely malnourished were given a variety of experimental nutritional supplements whose value was unknown – rather than foods that would certainly have helped them – so that nutritional scientists could improve their understanding of nutrition and further their field. At the same time, some residential school students were designated as controls and left to what were known to be inadequate diets. Further, many students involved in the studies were denied dental care so the effect of their diet on their dental health could be measured.

Meanwhile, in the first decades of U.S. colonialism in Puerto Rico, a network of maternal and reproductive health clinics were established that did little to improve the reproductive health of Puerto Rican women at that time. Instead, the clinics saw their greatest “achievements” in providing access to clinical trial subjects for “population activists, researchers, and physicians who implemented a ‘wild west’ standard of medical research on the island,” using Puerto Rican women to test various forms of birth control, including the pill, Depo Provera, contraceptive foam and the intrauterine device (Gutiérrez and Fuentes 87).

2. *(Reproductive) Abuse in the Name of the Public Good*

Puerto Ricans were also a significant target for sterilization abuse. Over 34 percent of Puerto Rican mothers aged 20-49 had been sterilized by 1965, and by 1980, the county had the highest rate of female sterilization in the world (Gutiérrez and Fuentes 86-7). Though most of these women could be said to have “chosen” sterilization, it would be naïve to characterize that choice as free or just. As Gutiérrez and Fuentes describe, in the colonial context, “coercion, a lack of proper informed consent, the lack of birth spacing or pregnancy prevention methods, a political economy that created poverty and joblessness, and a state interest in promoting population control” colluded to make sterilization “desirable” (88). Meanwhile, not even this level of constrained choice is to be found in the American history of forced and coerced domestic sterilizations. Sterilization laws and policies originally aimed at poor, rural whites like Carrie Buck,¹² came to be used against a variety of women of color, including Mexican-origin, black, and Native American women.

Discourses that portray women of color as hypersexual, weak willed, and excessively fertile, and as corrupting influences on their own children, have been used to blame poor people of color for perpetuating a “culture of poverty” (Ortiz and Briggs 42-4) and to convince the broader society that poor people of color overburden state resources by bearing too many (illegitimate) children. Such discourses have supported not only eugenic sterilizations, but also coercive birth control policies tied to welfare

and other forms of public assistance.¹³ They have also been reflected in the racially disparate application of hospital policies that screened women for drugs when those women were giving birth – policies which resulted in women losing their newborn children or being sent to jail (Ortiz and Briggs 47). These discourses continue to affect both the treatment pregnant women of color receive from physicians and other health care workers¹⁴ and the likelihood of prosecution of such women under a growing number of fetal protection laws.¹⁵

3. *Health Disparities*

Among the most frequent subjects of work at the intersection of race and bioethics are the significant and ongoing racial and ethnic disparities in American health, healthcare, and health outcomes. As compared to white Americans, African Americans in particular experience poorer health, earlier death, reduced access to health care, inferior treatment when accessing health care, and a decreased likelihood of recovery from various illnesses.¹⁶ LaVeist sorts the various theories posited to explain racial/ethnic health disparities into three categories: socioenvironmental, psychosocial/behavioral, and biophysiological. The reality of substantial racial/ethnic segregation in the U.S. lends credence to socioenvironmental explanations because living grouped together in very different neighborhoods means that members of different racial/ethnic groups experience substantially different levels of exposure to both social health risks and environmental toxins (LaVeist 2005, 136). Neighborhoods also differ greatly in the resources available for health, like grocery stores and pharmacies. Psychosocial or behavioral theories include the “weathering hypothesis,” which attributes deteriorating health to premature aging caused by “long-term exposure to social and financial stress and prolonged active coping with stressful circumstances,” and “John Henryism,” which attributes increased rates of hypertension among African Americans to the considerable energy that must be exerted on a daily basis to “manage the psychological consequences generated by chronic exposure to stress” (LaVeist 2005, 143-5). Also disturbing are studies that show that foreign-born non-whites have better

health outcomes than their U.S.-born counterparts – outcomes which decline the longer the non-white person lives in the U.S. (LaVeist 2005, 147-8). Meanwhile, suggests LaVeist, biogenetic theories of racial health disparity have been losing ground, in part because of the difficulty of defining racial categories biogenetically (2005, 154).

When faced with evidence of disparities and with the above theories (and especially if one dismisses race as a biogenetic category), it is natural to ask if race/ethnicity in this case is actually reducible to socioeconomic status (SES). While there is no doubt that SES dramatically affects health and health care access, race itself, as a sociohistorical designation, still matters. For one thing, some studies suggest racism itself (rather than merely the difficult socioeconomic conditions in which many members of U.S. minorities find themselves) is a stressor that negatively impacts health (LaVeist 150-3). For another, as mentioned above, histories of medical abuse continue to affect various minorities' perception of and reliance upon the medical establishment. Moreover, as also mentioned, pervasive racial stereotypes in the American social imaginary continue to affect how members of racial minorities are perceived and treated by physicians and other medical staff. For example, as compared to white patients, physicians perceive their black patients as more likely to use drugs and alcohol, less likely to comply with medical advice, less likely to desire a physically active lifestyle, less intelligent, less educated, less pleasant, and less rational. Indeed, physicians are less likely to see black patients as the kind of person with whom they could see themselves being friends (LaViest 119). These differences in perception can and do translate into differences in medical treatment.¹⁷ Ultimately, when researchers control for SES, they find racial minorities are still worse off in terms of their health than white people in the U.S.

In a significant sense, however, even if SES and race could be neatly disentangled – which they cannot – it would not matter. If we were to conclude that the black Holmesburg prisoners were subjected to medical experimentation because they were prisoners and not because they were black,

that would not mean we should stop talking about Holmesburg and only talk about Tuskegee instead. Work on race and bioethics often takes up health issues that might affect people with any racial designation but that currently affect people of color disproportionately. Thus a collection of essays dedicated to the ethics of health care for African Americans features pieces on homelessness, HIV/AIDS, treatment of the poor and uninsured, and even an essay explicitly concerned with poor rural whites in Appalachia (demonstrating that concern with “race” in bioethics is often concern over healthcare justice in a broader sense).¹⁸ It is also crucial, I would argue, to interrogate the ways in which these forms of socioeconomic marginalization are accompanied by stigmatization, which may be significantly racialized. In considering the issue of obesity among people of color, for example, it would be important to consider not only how mounting concern over a so-called “obesity epidemic” takes on a moralizing and stigmatizing tone, blaming individuals rather than addressing structural causes,¹⁹ but *also* how such discourses intersect with discourses that stigmatize members of certain minorities as lazy, weak-willed, and undeserving of either empathy or assistance.

From Margin to Center

If we return again to the first epigraph with which I began this piece, we recall that bell hooks does not describe the view from the margins as simply a different one with personal significance for the people or groups who hold it. Instead, she claims that it is a more complete view of the world than the one from the center. This idea that marginalization yields epistemic privilege, associated with *feminist standpoint theory*, has not gone unchallenged.²⁰ However, as Sandra Harding and others argue, even if it is not the case that any single marginalized viewer sees the full or most complete picture, it is undoubtedly the case that the fullest possible picture cannot be seen *without* incorporating a wide variety of views from a variety of marginalized positions. A variety of *situated knowledges* must be brought together in any effort to pursue a critical (and ultimately liberatory) form of objectivity (Haraway 89).

In the case of bioethics, then, I would argue that philosophers of race must insist upon not only the necessity, but the *centrality*, of discussions of race to the broader field. They must show that there are vital lessons to be drawn from the experiences of racial minorities for bioethics *as a whole*. It is not simply a matter of applying bioethical analysis to the problems of marginalized people (to “help them out” or “be more fair”). Rather, it is a matter of making bioethics more genuinely universal in its scope by gathering more perspectives, not merely as a collection of incommensurable experiences, but as a means of obtaining a more comprehensive (and more just) view of the world. It is a matter of recognizing real deficiencies in current bioethical knowledge and correcting those deficiencies in order to develop better practices for everybody (including even those privileged persons who most closely approximate the rational, autonomous individual at which much of bioethics thus far has been aimed). We must go beyond simply adding some attention to the problems lying at the margins of bioethics; we must look from the margins of bioethics toward the center in order to critique and ultimately to displace that center in favor of something more expansive, more responsible, more responsive, and much more flexible in terms of its worldview.

1. *From Rights to Justice*

When mainstream bioethical approaches seek primarily to justify or condemn particular actions by particular individuals operating in biomedical contexts, such attempts risk creating a separation between what we might call the ethical and the political. The ethical, where it is centered on autonomy conceived in terms of personal freedom, comes to be concerned only with what is or is not permissible in biomedical practice in terms of individually-conceived ethical rights, duties, obligations or prohibitions. With ethical rules in place, much of patient and physician decision-making is taken to be a private matter, with little relevance to politics or social justice.²¹ By contrast, the view from the margins suggests that bioethics ought to be at least as concerned with what we might label the *political* – that is,

social responsibility, collective life, the power dynamics and inequalities of social orders, and the role that concepts like race have played in creating and maintaining such inequalities.

Take, for example, the coalitions that women of color have formed around the concept of *reproductive justice*.²² The reproductive justice framework uses the experiences of women of color to oppose any ethical discourses on reproduction that focus primarily or exclusively on a (white, middle-class) woman's *privacy right* to make a *choice* about whether or not to have an abortion. A narrowly individual "right to chose" is inadequate to addressing the histories and present-day cases of racialized reproductive inequalities described above. By contrast, the reproductive justice framework insists not only on a human right *not* to have children, but also on both the right to *have* children *and* the right to parent the children one has in safe and healthy environments. It also sees these rights as entailing "the obligation of government and society to ensure that the conditions are suitable for implementing one's [reproductive] decisions," requiring, at a minimum that all reproductive choices be safe, affordable and accessible to women (SisterSong). I think it is clear in this example that centering the issues of women of color does not mean ignoring the individual rights of white women, but aims, in fact, at improving reproductive conditions for all women. Taking this example, philosophers of race could use the view from the margins to argue for more just and expansive approaches to other bioethical issues where the conversation has begun and remained focused around a particular set of raced, classed, and/or gendered experiences. Ideally, such a move would require even the mainstream participants in those conversations to expand their approaches as well.

2. *From Consent to Collaboration*

Members of marginalized groups also use the language of *justice* in their efforts to transform research practices. While a lack of disclosure by researchers and their failure to seek or achieve the genuine informed consent of their subjects were significant aspects of the harms described above, calls for research justice do not see informed consent as sufficient to create or maintain *just* research

practices. The larger problem that must be addressed is the carving up of the world into researchers and subjects (or knowledge production communities and subject communities). Sharp lines between these two categories are both produced by and productive of sociohistorical inequalities in power and resources. Indeed, Tuhiwai Smith argues that the belief that research is for “the good of mankind” is a Western ideology. By contrast, the attitude of many indigenous people toward the research of which they have been the subject (or to which they have been subjected) may be much more cynical: “It told us things already known, suggested things that would not work, and made careers for people who already had jobs” (3).

In order to “decolonize” research, Tuhiwai Smith suggests researchers ask several questions *in collaboration with* members of the community in which the research would take place:

Whose research is it? Who owns it? Whose interests does it serve? Who will benefit from it? Who has designed its questions and framed its scope? Who will carry it out? Who will write it up? How will its results be disseminated? (10)

If the answer to each of those questions points back to the researchers themselves, their research practice can be understood as exploitative and colonizing in nature, no matter what the “goodness” of their intentions. Goering et al. advocate for what they call *responsive justice* when conducting research with marginalized communities, a conception that includes three elements – (re)distribution, recognition, and responsibility – each of which is necessary to justice, but all of which must exist for justice to be sufficient. *(Re)distribution* goes beyond simply making sure that communities receive “benefits” from research to making sure that communities have a say in defining what is considered beneficial (44-6). *Recognition* is defined as “a reciprocal relation of respectful engagement and attentive concern that allows for shared power and parity of participation,” where researchers do not simply make concessions or compromises for the communities, but are actually called upon “to consider alternative world views and values when developing a research protocol and plan” (Goering et al. 46-7).

Responsibility involves awareness of past and current power differentials and an acknowledgement that the position of the privileged is partly built on the backs of the marginalized, making researchers responsible not simply to their own careers but to the communities in which they work (Goering et al. 49-50). Finally, Goering et al. emphasize that the goal is not just better treatment of communities targeted for research, but better knowledge as a product of that research. When all these dimensions are considered, the many injustices of the research programs described in the first half of the essay come into much greater relief. In the Henrietta Lacks case, for example, it is not simply that no one sought her permission to use her cells, but that their use, while of great benefit to biomedicine at large, did little to improve the lot of her descendants or of the communities of which she was a part. Indeed, once brought to light, the case often served to heighten those people's distrust of biomedicine as a whole.

3. *From Competence to Humility*

Finally, a popular suggestion for addressing racial health disparities, particularly at the physician or clinical level, is to train health care professionals in cultural competency. The idea is to make physicians aware of the different cultural beliefs and values their diverse patients might hold and how those beliefs and values may affect their interactions with the mainstream American healthcare system. While cultural competency is not a bad goal, it is problematic if the approach is one that portrays *only* non-white or non-Western patients as the possessors "culture" or if it portrays such "culture" as an irrational obstacle to be overcome so that the proper delivery of "real" medicine can be achieved (Ikemoto 92). By contrast, a just approach to cultural competency should involve self-reflection on the part of medical practitioners and a healthy dose of cultural humility.

Doctors and other health care workers must recognize that, even if they occupy a privileged social position, they, too, have cultures – they have morals, hold values, and make judgments that are not universal. Moreover, health care itself has an institutional culture, which reflects the dominant

culture in which it evolved – one which Ikemoto describes as racist, ethnocentric and nativist (80). Indeed, even science, which is typically presented in contrast to religion or culture, has its own set of assumptions and articles of faith, and sees the world through a particular lens which filters out a good deal of “subjective” information in favor of data it regards as “objective.” The scientific worldview produces what Ikemoto calls the *medical gaze*, a way of assessing patients that prizes time and efficiency, effectively stripping patients of much of their social and lived experience (79). Even bioethics, in its critical examination of clinical practice and other biomedical issues, reflects the culture of its first and most dominant practitioners, selecting which issues are most critical, which values should be protected and promoted, and which sort of interventions are most valid and useful.²³ Unless those in privileged positions take account of their own biases and operating assumptions, they will never be “competent” to take into account those of marginalized others. Furthermore, physicians must learn what is called *structural competency*:

the ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases...also represent the downstream implications of upstream decisions about such matters as health care and food delivery systems, zoning laws, urban and rural infrastructure, medicalization, or even about the very definitions of illness and health (Metzl 2012, 216).

In fact, it is structural competency that generates awareness of the very existence of the “margins” and “center” around which this essay has been organized.

This, then, is the task I set to philosophers of race as they venture into the realms of bioethics: (1) to take the views from the margins of health, biomedical research, and healthcare, and (2) to use those perspectives, along with other critical, philosophical resources, to interrogate both biomedicine and bioethics about their most fundamental assumptions and practices, (3) not simply as an intellectual exercise, but always with an eye toward justice.

¹ In Jecker, Jonsen, and Pearlman (2007), for example, the final (and shortest) section of each of its three parts is dedicated to “Cultural Assumptions,” a designation which seems to encompass issues of race, class and

global inequality, as well as culture; such issues are thus set apart from mainstream bioethics. In Vaughn (2010), the term “race” does not appear at all in the index, though there is a page each dedicated to Tuskegee and to unequal health care for minorities; there is also one article on multiculturalism and two on the ethics of research in the developing world. By contrast, Parks and Wike (2010) not only dedicate full chapters to “Justice and Health Care” and “Experimentation and Research on Human Subjects,” topics in which race is already heavily implicated, but they also take up matters of race and other forms of difference in every other chapter.

² Some of the special issues used in this article include the *Journal of Urban Health* (2001) issue on urban bioethics, the *Journal of Law, Medicine and Ethics* (2006) symposium on the use of racial and ethnic categories in research, and the *Saint Louis University Public Law Review's* (1996) Bioethics and Law Symposium on “Deconstructing Traditional Paradigms in Bioethics: Race, Gender, Class, and Culture.”

³ See, for example, Dula and Goering (1994), Prograis and Pellegrino (2007), Satcher and Pamies (2006), and Wallace (2008).

⁴ In the four volumes cited in the previous note, philosophers make up eight of 45 contributors, three of eleven contributors, none of the contributors, and none of the contributors, respectively.

⁵ See, for example, Paxton, Figdor and Tiberius (2012) on women in philosophy; Minorities and Philosophy (MAP) as also compiled statistics on both women and racial/ethnic minorities in the profession, which are available on their website: <http://www.mapforthegap.com>.

⁶ For a detailed exploration of the medical abuses against black Americans, see Harriet Washington (2006).

⁷ The study is only sketched here. More detailed descriptions are available from multiple sources, but Chapter 7 of Harriet Washington (2006) offers a reasonably concise, but thorough and nuanced account, from which my sketch here is drawn.

⁸ For more on Sims, see Harriet Washington (2006), pp. 61-68, and Deleso Alford Washington (2009), pp. 976-84.

⁹ See Harriet Washington (2006), Chapter 5.

¹⁰ Details of these experiments can be found in Hornblum (1998) and Hornblum (2007).

¹¹ See Mosby (2013) for details on these studies.

¹² For a brief description of what would become the U.S. Supreme Court Case *Buck v. Bell* (1927), see Brunius (2006), pp. 3-8.

¹³ See Roberts (1999), Chapter 5.

¹⁴ See Bridges (2011), Chapters 4 and 6.

¹⁵ See Goodwin (2008).

¹⁶ For a thorough (if decidedly quantitative) introductory text on a variety of racial health disparities, see LaVeist (2005). For a survey of more in-depth work by a variety of authors, see LaVeist (2002), Satcher and Pamies (2006), or Wallace (2008).

¹⁷ See Smedley, Stith, and Nelson (2003), Chapter 4.

¹⁸ Dula and Goering (1994).

¹⁹ See Lebesco (2010) and the larger argument of Metzl and Kirkland's (2010) edited volume on health as an ideological concept and moralizing norm.

²⁰ For a concise overview of various iterations of feminist standpoint theory and the challenges to it, see the “Introduction” of Harding (2004). For more detailed discussions, see the other essays in the same volume.

²¹ For one description of how bioethics traveled along a straight and narrow road primarily concerned with “the place inhabited by the very intimate contacts between individual physicians and individual patients” (21), see Jonsen (2001).

²² For a history of organizing for reproductive justice that includes African American, Native American, Latina, and Asian and Pacific Islander women, see Silliman et al. (2004).

²³ See, for example, Myser (2003).

Works Cited

- Blustein, Jeffrey. "Setting the Agenda for Urban Bioethics." *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 78.1 (2001): 7-20. Web.
- Bridges, Khiara M. *Reproducing Race: An Ethnography of Pregnancy as a Site of Racialization*. Berkeley: U of California, 2011. Print.
- Bruinius, Harry. *Better for All the World: The Secret History of Forced Sterilization and America's Quest for Racial Purity*. New York: Knopf, 2006. Print.
- Dula, Annette, and Sara Goering, eds. *"It Just Ain't Fair": The Ethics of Health Care for African Americans*. Westport, CT: Praeger, 1994. Print.
- Fleischman, Alan, ed. *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 78.1 (2001): 1-211. Web.
- Fleischman, Alan R., Betty Wolder Levin, and Sharon Abele Meekin. "Bioethics in the Urban Context." *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 78.1 (2001): 2-6. Web.
- Gilmore, Ruth Wilson. *Golden Gulag: Prisons, Surplus, Crisis, and Opposition in Globalizing California*. Berkeley: U of California, 2007. Print.
- Goering, Sara., Suzanne. Holland, and Kelly Fryer-Edwards. "Transforming Genetic Research Practices with Marginalized Communities: A Case for Responsive Justice." *Hastings Center Report* 38.2 (2008): 43-53. Web.
- Goodwin, Michele. "Prosecuting the Womb." *The George Washington Law Review* 76.6 (2008): 1657-746. Web.
- Gutiérrez, Elena R., and Liza Fuentes. "Population Control by Sterilization: The Cases of Puerto Rican and Mexican-Origin Women in the United States." *Latino(a) Research Review* 7.3 (2009-10): 85-100. Web.
- Haraway, Donna. "Situated Knowledge: The Science Question in Feminism and the Privilege of Partial Perspective." 1987. *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. Ed. Sandra G. Harding. New York: Routledge, 2004. 81-101. Print.
- Harding, Sandra G., ed. *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. New York: Routledge, 2004. Print.
- . *Is Science Multicultural?: Postcolonialisms, Feminisms, and Epistemologies*. Bloomington, IN: Indiana UP, 1998. Print.
- Holloway, Karla FC. *Private Bodies, Public Texts: Race, Gender, and a Cultural Bioethics*. Durham, NC: Duke UP, 2011. Print.
- hooks, bell. *Feminist Theory: From Margin to Center*. Boston, MA: South End, 1984. Print.
- Hornblum, Allen M. *Acres of Skin: Human Experiments at Holmesburg Prison: A True Story of Abuse and Exploitation of Medical Science*. New York: Routledge, 1998. Print.
- . *Sentenced to Science: One Black Man's Story of Imprisonment in America*. University Park, PA: Pennsylvania State UP, 2007. Print.

- Hutchinson, Ted, ed. *The Journal of Law, Medicine & Ethics* 34.3 (2006): 483-558. Web.
- Ikemoto, Lisa C. "Racial Disparities in Health Care and Cultural Competency." *Saint Louis University Law Journal* 48 (2003): 75-130. Web.
- Jecker, Nancy S., Albert R. Jonsen, and Robert A. Pearlman, eds. *Bioethics: An Introduction to the History, Methods, and Practice*. 2nd ed. Sudbury, MA: Jones and Bartlett, 2007. Print.
- Jonsen, Albert R. "Social Responsibilities of Bioethics." *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 78.1 (2001): 21-28. Web.
- LaVeist, Thomas A., ed. *Race, Ethnicity, and Health: A Public Health Reader*. San Francisco: Jossey-Bass, 2002. Print.
- . *Minority Populations and Health: An Introduction to Health Disparities in the United States*. San Francisco: Jossey-Bass, 2005. Print.
- Lebesco, Kathleen. "Fat Panic and the New Morality." *Against Health: How Health Became the New Morality*. Ed. Jonathan Metzl and Anna Kirkland. New York: New York UP, 2010. 72-82. Print.
- MAP. "Statistics Compiled by MAP." *Minorities and Philosophy*. N.p., n.d. Web. 27 May 2014.
<http://www.mapforthe-gap.com/uploads/2/2/3/2/22328318/statistics_compiled_by_map.docx>.
- Metzl, Jonathan M., and Anna Kirkland, eds. *Against Health: How Health Became the New Morality*. New York: New York UP, 2010. Print.
- Metzl, Jonathan M. "Structural Competency." *American Quarterly* 64.2 (2012): 213-18. Web.
- Mills, Charles W. "Philosophy Raced, Philosophy Erased." *Reframing the Practice of Philosophy: Bodies of Color, Bodies of Knowledge*. Ed. George Yancy. Albany: State U of New York, 2012. 45-70. Print.
- Mosby, Ian. "Administering Colonial Science: Nutrition Research and Human Biomedical Experimentation in Aboriginal Communities and Residential Schools, 1942-1952." *Histoire Sociale/Social History* 46.91 (2013): 145-72. Web.
- Myser, Catherine. "Differences from Somewhere: The Normativity of Whiteness in Bioethics in the United States." *The American Journal of Bioethics* 3.2 (2003): 1-11. Web.
- Ortiz, Ana Teresa, and Laura Briggs. "The Culture of Poverty, Crack Babies, and Welfare Cheats: The Making of the 'Healthy White Baby Crisis.'" *Social Text* 76 21.3 (2003): 39-57. Web.
- Parks, Jennifer A., and Victoria S. Wike, eds. *Bioethics in a Changing World*. Upper Saddle River, NJ: Prentice Hall, 2010. Print.
- Paxton, Molly, Carrie Figdor, and Valerie Tiberius. "Quantifying the Gender Gap: An Empirical Study of the Underrepresentation of Women in Philosophy." *Hypatia* 27.4 (2012): 949-57. Web.
- Prograis, Lawrence, Jr., and Edmund D. Pellegrino, eds. *African American Bioethics: Culture, Race, and Identity*. Washington, D.C.: Georgetown UP, 2007. Print.
- Randall, Vernellia R. "Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy!: An African American Perspective on Bioethics." *Saint Louis University Public Law Review* 15.2 (1996): 191-235. Web.
- Reverby, Susan M. "Invoking 'Tuskegee': Problems in Health Disparities, Genetic Assumptions, and History." *Journal of Health Care for the Poor and Underserved* 21.3 (2010): 26-34. Web.

- Roberts, Dorothy E. *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century*. New York: New, 2011. Print.
- . *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*. New York: Vintage, 1999. Print.
- Satcher, David, and Rubens J. Pamies, eds. *Multicultural Medicine and Health Disparities*. New York: McGraw-Hill, 2006. Print.
- Schulz, Amy J., and Leith Mullings, eds. *Gender, Race, Class, and Health: Intersectional Approaches*. San Francisco, CA: Jossey-Bass, 2006. Print.
- Silliman, Jael, Marlene Gerber Fried, Loretta Ross, and Elena R. Gutiérrez. *Undivided Rights: Women of Color Organize for Reproductive Justice*. Cambridge, MA: South End, 2004. Print.
- SisterSong. "What Is RJ." *Sister Song: Women of Color Reproductive Justice Collective*. N.p., n.d. Web. 07 June 2014. <http://sistersong.net/index.php?option=com_content&view=article&id=141&Itemid=81>.
- Skloot, Rebecca. *The Immortal Life of Henrietta Lacks*. New York: Crown, 2010. Print.
- Smedley, Brian D., Adrienne Y. Stith, and Alan R. Nelson, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, D.C.: National Academy, 2003. Print.
- Tuhiwai Smith, Linda. *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed, 1999. Print.
- Vaughn, Lewis, ed. *Bioethics: Principles, Issues, and Cases*. New York: Oxford UP, 2010. Print.
- Wald, Priscilla. "American Studies and the Politics of Life." *American Quarterly* 64.2 (2012): 185-204. Web.
- Wallace, Barbara C., ed. *Toward Equity in Health: A New Global Approach to Health Disparities*. New York: Springer, 2008. Print.
- Wallerstein, Nina B., and Bonnie Duran. "Using Community-Based Participatory Research to Address Health Disparities." *Health Promotion Practice* 7.3 (2006): 312-23. Web.
- Washington, Deleso Alford. "Critical Race Feminist Bioethics: Telling Stories in Law School and Medical School in Pursuit of 'Cultural Competency.'" *Albany Law Review* 72.4 (2009): 961-98. Web.
- Washington, Harriet A. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial times to the Present*. New York: Doubleday, 2006. Print.
- Wolf, Susan M., ed. *Saint Louis University Public Law Review* 15.2 (1996): 183-432. Web.