

## Racism and the Textures of Visibility

Melissa S. Creary

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## Racism and the Textures of Visibility

Melissa S. Creary 

University of Michigan

I gave remarks at the Third International Summit on Human Genome Editing in London, UK on the first day for the section titled, “Sickle Cell Disease: A Case Study Affecting Millions.” It did not escape me that the only African and African-diasporic people in the overflowing auditorium that day were there to discuss the state of science and the success of the curative gene technology as embodied via a Black woman—Victoria Gray. At 33, Victoria received a CRISPR-based therapy to cure her sickle cell and was invited to tell us her story. Her natural hair in twists, and wearing pink and tan, she was visibly nervous. Right before she gave her remarks, I did what I could to try to put her at ease. I told her that she had even more important things to say than the scientists, that she belonged in this space just as much. When she took to the dais, she did so confidently, her husband recording her on his phone. She began by telling us what her life was like before treatment and then how her life was changed forever. We were riveted. All other Black people in the space of the Crick Institute who did not have the privilege of speaking that day, were part of the staff serving meals or cleaning up after the participants.

If sickle cell—the first disease that will receive approval for the breakthrough therapy—was not the exemplar, I wonder if this exciting scientific innovation and its ecosystem of players would otherwise engage our Black bodies at all. Outside of the example of SCD, the pondering still stands. We should interrogate how racism operates as a throughline for this event even in the excitement (perhaps, especially because of the excitement) of attending to the neglect associated with those living with SCD. Ferryman (2023) guides us in a situation like this where bounded justice, “through its orientation to erasures

of oppressive histories and structural inequities, brings to the fore the dialectical processes of racialization that create both hyper-visibility and invisibility for racialized people” (29).

Bounded justice is a critical tool in the bioethical toolkit to help us understand the continued need to provide deeper societal texture to the ways we respond to the complex problems that arise from biomedical and scientific endeavors. One such problem is the way that racialization—how socially constructed racial and ethnic categories are used to order groups in society—operates in biomedical research (Omi and Winant 2014). Ferryman applies bounded justice with sharp specificity to the concern of the scientific apparatus’ ability to render Black bodies both invisible and hyper-visible, and what that means for inclusion in precision medicine. Like other biomedical initiatives, precision medicine has had challenges engaging with and responsibly including the Black population. Ferryman (re)introduces us to the important analyses of social scientists whose work helps us understand some of the experiences of a racialized person. To the social scientists highlighted in Ferryman’s article, I’d like to add social epidemiologists Ford and Airhihenbuwa (2010) who tell us that “to understand the causes of racial health inequities requires solid understandings of the salience of racialization in society and in one’s personal life,” (1391). Ford uses critical race theory as the foundation of the public health critical race praxis in which Contemporary Racialization is one of four principles. This critical principle of understanding is one that will help us make sense of *all* bioethical quandaries, but helps us be especially critical of the processes of inclusion of Black bodies that are required for successful scientific endeavors. As we consider what justice—as delivered

by science—looks like, especially in the practices we build around inclusion, those producing the knowledge must have a *deeper* understanding of exclusion.

On that day in London, the biotech and pharmaceutical industries held the spotlight for Ms. Gray, but in the wake of the promise of innovation, these industries have also turned their keen attention to the clinical expertise of hematologists. The lure is strong. Clinicians working primarily with sickle cell have all navigated what neglect looks like and while normalizing neglect may be a coping mechanism, what industry offers is stark in comparison and a compelling draw. Not only do sickle cell clinicians get to work on the promise of therapeutic advancement, they do so in a much more resourced space. The unintended consequence, however, is the gap in care for an already sparse and fragile network of providers. The promise of tomorrow's advancements sometimes means we are left with the peril of the present. This, too, is another configuration of hypervisibility and invisibility and begs us to ask a number of ethical questions. How do we interpret justice in this scenario? How does the inclusion of particular biomedical expertise help or hinder justice processes, particularly for those living with sickle cell disease?

The concept of bounded justice is created in situated knowledge of well-established schemas such as structural violence, ecological frameworks of health, intersectionality, embodiment, and biocultural citizenship. Each of these concepts offers distinct ways to help conceptualize how deployed justice tactics fall short while also working together to explain larger societal phenomena (Creary 2021). In this vein, bounded justice when used as an analytic should be deployed alongside emerging models of bioethics such as Black bioethics as developed by Ray (2021), an intersectional bioethics as refined by Martschenko, and an abolition ethics as envisioned by James (Ray et al. 2023). Each of these formations pushes us to think beyond “protecting institutions and maintaining equilibrium within unjust systems,” (Ray et al. 2023, 14) and to better center community. We cannot consider the ways in which we engage with and attempt to include Black bodies in precision medicine or any other biomedical project without centering the Black voices, needs, wants, fears, and joys at that project. This requires a paradigm shift in how we conceptualize and operationalize science. No longer can we lead with empty gestures and we cannot

begin to understand how to pivot until we take note that “to be racialized as Black, means being subject to both processes of hyper-visibility and invisibility, spotlighting and erasure” (Ferryman 2023, 29).

Victoria ended her remarks to thunderous applause and a standing ovation. Journalists live tweeted her speech and remarked on how powerful her words were. She was the darling of the press room and as part of an exclusive agreement, NPR followed and documented her whole trip throughout London. She will be clinically followed for at least 15 years to track the unknown variables and potential adverse events that might be unforeseen. In the same ways that many are concerned about the unforeseen ethical questions that may be answered, I want the biomedical ecosystem of players who are imbricated in the production of this technology to be just as concerned about the non-clinical sociological and economical textures of her life too—all of which will still be roughened by racism.

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## ORCID

Melissa S. Creary  <http://orcid.org/0000-0001-7904-3377>

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