“Vulnerable” Populations—Medicine, Race, and Presumptions of Identity

Karla F.C. Holloway, PhD, MLS

At the beginning of the twentieth century, renowned sociologist William E. B. Du Bois warned that “the problem of the twentieth century” would be “the problem of the color line” [1]. I suspect that Du Bois would not have imagined that this color line would be as enigmatic and troubling in the twenty-first century. But the fact is that today’s issues of race and identity reveal an arguably more complicated terrain. To illustrate this point, consider the background of the following patients [2].

Ms. A’s father is Nigerian and her mother is British.
Ms. B’s mother and father are both from Jamaica. She has lived in the United States since birth.
Ms. C’s parents were both born in the United States. Her father is from Detroit’s inner-city and her mother is white.
Ms. D’s parents were born in Ghana and South Africa.
Ms. E, who has curly blond hair, fair skin and green eyes, has checked the box for “black or African-American” on her medical history form. She was adopted at birth.

In fact, each of these patients has checked that same box—“black or African American”—on their patient history forms. What does this tell us?

The quick answer is that it tells us not much at all about the patient—but a whole lot about whomever provided the box. Just the quick background sketch I provided for patients 1-5 indicates how different they are. In fact, the receptionist who made the appointment for the woman with Jamaican parents was surprised to see a woman with brown skin report at the scheduled time. “On the phone, you sounded like you were British,” she told her as she gave her a clipboard with the new patient information form attached to it. In the receptionist’s racial imaginary, being (or sounding) British is a stand-in for being white.

The receptionist is not alone. When you read about the first woman (the one with the Nigerian father and the British mother) did you make a presumption about the race of the British mother that would coincide with the receptionist’s? Did the third patient’s “inner-city Detroit” father signal a particular race for you? If so, you’re not alone. For the majority of Americans, “urban” (or “inner-city”) is a synonym for black or African American. “Suburban” is a synonym for white. Geography matters. Before we leave this example, did it occur to you that the fourth woman’s South African parent might be white (something we tend to ignore when we imagine “African” ancestry)?
These examples indicate the ways in which U.S. residents are primed to make certain presumptions regarding race. We’ve given race its substance and assured its viability despite its growing complication as a coherent category of identity. There’s little doubt of medicine’s interest in sustaining these racial designations. Patient history questionnaires betray this preoccupation. But what is it that we learn from a patient’s response? Is it worth the sustained stereotyping that comes from some people being assigned to a community and others not?

Our research and our practices both confuse and conflate the many social referents of the word “race.” We commit this error most frequently when we tolerate the notion that prompts our assigning someone membership in an “African American community.” It is an affiliation that suggests that being “black or African American” places you into immediate and reasonable consonance with any other black person in this country. Our habit of assigning community also suggests that phenotype reveals something about biology in a reliable and consistent enough manner to make that categorical assessment have standing equal to other factors like weight, dietary habits, smoking history, and whether or not you had rheumatic fever as a child.

The black folk whose souls Du Bois worried over in 1903 had a peculiar history of visibility and vulnerability. It is a history replete with narratives about medical care of lesser quality and exploitation sutured to institutionalized racial biases and stereotypes. When contemporary medicine takes up the category of race as a biologic rather than a social indicator, it ignores the complexity that is resident in “African American communities.” A community-based medicine or research ethic cannot escape this history of identity and vulnerability and the significant variables that accompany the experience of race. This is not an occasion when new and good intentions erase the impact of past bad acts. Language has a habit of entanglement. “Vulnerable” patient populations are not an invention of bioethicists in search of a subject. When bioethicists refer to vulnerable populations these persons might be minorities, women, children, the elderly, the imprisoned or other institutionalized persons. We sometimes forget that the source of their vulnerability is not intrinsic. It is decidedly extrinsic. They are, as the title of this essay indicates, vulnerable to patterns of institutionalized bias. Categorical vulnerability is a consequence of medical research and medical practices that have exposed persons to bad acts because of a guiding presumption about the value of their identities [3]. The labeling does not develop a neutrality simply because we bring it to a different setting and a new era. We take ourselves wherever we go. The assignation of community and color began as a way to distinguish rights and assign moral value. That history is not dissoluble simply because a contemporary society accepts this labeling as benign—just one among several options. There is a lived history in our words.

The simplest way to make this plain is to ask someone to point you in the direction of the white community. It is a reasonable bet that your request will be met with some degree of puzzlement. But if you asked to be directed to the black or Latino
communities, your chances are pretty good that you’ll get an easy answer to the inquiry.

The ability or the inability to locate the “white community” precisely underscores the social construction of the inquiry and its answer. Black and brown folks are visible in ways that renders whiteness both invisible and inconsequential. In fact, the privilege of whiteness has made the contemporary complexity of race and ethnicity in the United States persistently vulnerable to the practices of history [4]. Social and biopolitical circumstances are the substance from which determinations about biologies of body and blood are determined. We forget the association of society to science and recall the science. This is a flawed way in which to make determinations about patient outcomes and patient profiles. In an age where we still hope there are genomic indicators that can point us toward individualized patient care, there is little reason to depend on a racially categorized community (that includes only some of us) before making health-related decisions about anybody. But the social is a powerful motivator, and the language with which we have come to designate certain populations is a familiarity that is difficult to disregard.

Given the opening example of five patients, what other than a professional’s ease and want of efficiency makes the “African American community” a viable category? Perhaps a more useful question is how physicians might deliver better patient care and develop and practice more attentive listening strategies if the artifice of a community membership didn’t begin writing a patient’s narrative before any questions had been asked or answered. This perspective constructs a research ethic that begins with an affirmation of the body biologic. It returns a professional authority to the physician, and abjures practices that elevate race in ways that might obscure critical differences. It is a perspective that restores a patient’s autonomous standing as a person rather than a racial representative—a member of someone’s idea(l) of a community.

A final example might be helpful. When the head of an administrative search committee was asked how her committee was assuring a diverse candidate pool, she pointed out that there were two black faculty representatives on the committee for the “African American community.” This kind of nonsense needs a blunt and unambiguous response. Diversity should be the responsibility of the entire committee, not something turned over to the black folks in the room. The categorical presumptions of a coherent and even an insular “African American community” encourage this kind of simple-mindedness and lack of accountability. It illustrates the harm in producing a community as a commodity.

It is antithetical to reach toward a science that will bring us closer to the goal of individualized medicine with a research paradigm that begins with “community”-based categories. Certainly and without argument there are occasions when ethnicity and race will matter. Discrimination produces stress. Stress can contribute to hypertensive disease. Black folks are vulnerable to discrimination. However, in an ideal research paradigm, this relational outcome would be the product of research
and investigation that discovers the relationship rather than with a hypothesis that instantiates the difference. With this kind of shift in perspective, we might end up with research practices that bring us closer to the achievement of individualized medicine where rigorous science and credible social science drive the questions. This seems a goal worthy of a professional community’s collective effort.

References
2. The patients and the incident are composite sketches of real persons and an actual event.

Karla F.C. Holloway, PhD, MLS, is James B. Duke Professor of English and professor of law at Duke University in Durham, North Carolina. She is on the advisory board of the Greenwall Foundation’s Faculty Scholars in Bioethics and a core faculty member in the Trent Center for Bioethics, Humanities & History of Medicine at Duke. Her recent books include Passed On: African American Mourning Stories (2002) and Public Bodies, Private Texts: Race, Gender and a Cultural Bioethics (2011).

Related in VM
Dissecting Health Disparities in Cardiology Patients, October 2010

Race, Genomics, and Health Care, June 2003

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.