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Their Bodies, Our Conduct: How Society and Medicine Produce Persons Standing in Need of End-of-Life Care

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—*In Memoriam*, the victims of the Charleston Shooting, 2015

African Americans at the end of life challenge the normative boundary of this conversation. As much as medicine wants to focus on the geriatric patient, or a patient whose terminal disease has reached its final stages, end-of-life care for African Americans is an opportunistic occasion that spans the life cycle. Structural inequities and the social consequences of those inequities account for much of what end-of-life and palliative care specialists would have us regard as ''cultures'' that matter when we look at patient preferences. But culture is shaped by social circumstance and those events are mediated by direct practices, biases, and conduct that render African Americans into ''vulnerable populations.'' Being ''made'' vulnerable rather than being intrinsically vulnerable is a perspective that matters.[1]

This essay, excerpted from my 2002 book *Passed On: African-American Mourning Stories—A Memorial,* proffers a narrative of end-of-life care that reminds us of the opportunity, indeed the necessity, of shifting our cultural expectations away from an intrinsic characteristic to our medical and social practices.[2] With this perspective, we develop a patient population that is composed by our conduct and that reframes the needs of culturally sensitive practices to include how culturally selective experiences are produced. In this paradigm, race matters because we have made it matter. Our interest in culture must include our responsibility to the histories of conduct that have made aggregate populations out of individual persons, and rendered them vulnerable. This history has produced our contemporary landscape—one where mortality tables from the 20th century well into the 21st indicate excess mortality for black populations in every category from premature births to cancers to cardiac events. And as we learn more and more about epigenetics—the association of social circumstance to genetic propensity—the lie of racial indicators being identifiable within our genetics falls away to the reality of race being a social construct. In medicine and society, the most critical health indicator seems to be our zip code. And the histories of redlining, food deserts, liquor store licenses taking priority over fresh food markets, gun and drug regulations, and incarceration patterns are indeed neighborhood stories. The extent to which these represent culture is more a pattern of process and product rather than body and blood. But we have rendered these stories as the latter, and we have considered our bodies and blood to be the same despite our national habits of disparate treatment. It is worth our consideration why medicine would want to focus more on the outcome of our social conduct than on shifting the habits of inequities that produce the patterns. It may well be a matter of expediency. But if we want to disrupt the narratives that produce patterns of mortality in terms of race and identity, we must include the practitioner in the process.

Mortifications: How We Die

Black folk died in mournful collectives and in disconcerting circumstances. We died in riots and rebellions, as victims of lynching, from executions, murders, police violence, suicides, and untreated or undertreated diseases. In such deaths, being black selected the victim into a macabre fraternity. The story of how *we* died shaped a tragic community narrative.

"The only thing I have to do is stay black and die"

This aphorism is an old and familiar retort in the black community. Judged purely by its grammar, it is an odd phrase, for it identifies two ''only things'' that the speaker has to do. Yet, this tellingly simple and straightforward statement says exactly what it means. Over time, as the fact of a color line became absolutely distinguishable, and even predictable, staying black and being dead formed a singular relationship. What contributed to the persistence of that association between color and death? And what did it mean to the culture's collective sense of itself that mortality was associated with appearance?

After the Civil War, America's troubling response to its newly freed black citizenry was a constructed pattern of violence that confirmed the aphorism's saliency. The lynchings that laced this country made it perfectly clear that color was a danger in postbellum America. Many understood that law

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enforcement officials' benign neglect toward, and often participation in, lynchings placed the human rights of black folk out of bounds of the protections of the law. The extent to which lynching became associated with black presence, rather than black conduct, inculcated this sense of vulnerability. Some painful version of this history of lynching, either as literature or as factual record, constructs the stories of black deaths. Lynching is a pitiful example of how *we* die, and the evidence of our history continued to argue for some association between color and death, much as one might have wished it to be otherwise. The century's consistency seemed to be that black folk, especially and specifically black males, were likely to die before their time in America.

Again and again statistics from agencies like the National Institutes of Health and the Centers for Disease Control clarified that, when it came to death rates, race was a consistently predictable factor in patient mortality. This was true in every decade of the century, for urban as well as rural areas, and for northern as well as southern regions. Maternal death rates from childbirth, for example, formed one of the most distinctive gaps in public health. Black women in the United States were four times as likely to die during childbirth or in the period immediately following childbirth than white women. Whether the numbers cited infant morality, adult death from heart disease, young adult death from violence, or children's deaths from diseases about which medical knowledge had made tremendous strides (asthma, for instance), the death rates for black folk were dramatically higher, black-white disparities in health status persist, and black-white mortality differences involve mainly preventable deaths.

But relatively little public attention has been devoted to other well-documented problems in black health care: the attention, respect, and intervention given by medical personnel to their black patients. When research shifted from looking at medical causes for the disparities in black and white mortality rates to ethnography and psychology, doctors' approaches and attitudes toward their black patients began to come under appropriate and revealing scrutiny. The Tuskegee episode, in which patients were viewed as experimental subjects, characterized the significant bias and dangerous psychological distance that health care workers often displayed in their care of black patients. As a result of such attitudes, black people in general and black women in particular were less likely to receive aggressive, costly care—whether diagnostic or palliative—than their white counterparts.[2]

Coda

The point must be made that as we appropriately consider culture as having necessary standing in our end-of-life care conversations, we need not simplify the task by aggregating a collage of cultural information that seems identificatory, but that actually elides the complex cultural landscapes that most Americans navigate. Culture is a complex of conduct and this nation's multicultural practices are not easily disaggregated—especially not by skin color. The critical ethic of individualized care must guide our practice and this means we must ask each patient what matters—and listen for the answer without our own cultural biases as the interpretive agent.

But further than that, for a population so marked by histories of civic conduct that this history has produced structural differences, we must look for ways to disrupt differences that harm and acknowledge our role in differences that sustain. Our end-of-life care might be delivered in an emergency room rather than a hospice facility. It might need to anticipate that a patient population has had direct experiences with inequity, disrespect, and disregard. (Please, let's encourage and allow the narrative of Tuskegee to take its place in history without displacing our contemporary agency in ongoing patterns of discrimination.) When we speak of palliative care we must understand how our own interpretations of someone's pain has a cultural valence and has expressed results in unequal treatment.[3] When we see children in crisis situations our judgment regarding their culpability cannot predict our conduct regarding their care. End of life might be an everyday ritual in some families and communities. Our respect and understanding for that tragic familiarity and medicine's role in its production would go a long way in expanding the ways in which we think about which persons are our patient populations at the end of life. We can all learn a good deal from those whose histories have prepared them for this task and the familiarity of this aphorism, *The only thing I have to do is stay black and die*. Some of us come to medicine with far too much experience with grief.

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