

Fate or Free Will: My Passage to Bioethics

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I remember applying for the master's in bioethics program at the University of Pennsylvania and thinking very carefully about what I wanted any reader to know about my childhood and its impact on shaping my career path to this point. At the time, I was nearly three years removed from electing to take a semester off from my study of sociology at the University of Virginia to have major reconstructive surgery on my left mandible. This procedure stemmed from an earlier childhood benign tumor, initially diagnosed when I was six years old and then removed once a year, each time it recurred. The tumor did not recur after the age of nine, at which point the mandible could not be preserved. I grew up with an asymmetrical face and a scar on my chin. By age 19, never mind restoration of eating functioning, my "disease" was the absence of sameness to other faces. After many skin and bone grafts, jaw wirings, and all the auxiliary procedures that followed, I am now partially cured, and my face is mostly "the same," both as its own reflection and in its likeness to other faces. Admittedly, it has taken some time for me to process what I mean by conceding to only a partial cure. I recognize now that even the best surgery cannot repair the subjective or objective omnipresence of difference.

Even though more than a decade has passed between that first reconstructive procedure and today, it is still important for me to articulate the authenticity and magnitude of these experiences in catalyzing my untiring professional interest

in bioethics. At a young age I was forced to ask myself metaphysical questions related to aesthetics and normality, which generated other, broader questions about the influence of socioeconomic status, race, and gender on the provision of healthcare and the problem of finite resources and infinite needs. Given time and education, the questions I have now are perhaps more sophisticated, but they remain thematically the same: why did my African American mother (having grown up in the Jim Crow South and having migrated to a housing project in the suburbs following the Civil Rights movement) not look these (white, male, well-educated, presumably all-knowing) doctors in their eyes, or even ask them questions? Why did she/we just do what these doctors told us to do? By extension, how informed was any consent process if all she did was sign and defer? These impressions of autonomy and patient rights in practice still linger in my mind.

I recall an instance when I "refused" treatment (I was nearly 20 years old) and expressed that I was tired of being poked and prodded for one vial of blood every four hours and, in this case, of being pierced several times during one encounter, because my veins were "too small." Although I felt increasingly empowered each minute that passed after I said no, my recalcitrance lasted all of an hour, until my favorite fellow from my maxillofacial surgical team came in and asked if he could have a turn. I quietly relented, feeling somewhat ashamed that I had allowed the

situation to escalate to the point at which a fellow was required to intervene. Were the tactics used by the staff coercive, manipulative, or necessarily paternalistic? Although this was years ago, I still wonder, considering the claim of a “postracial” America, whether dominant models of autonomy, consent, and assent adequately reflect nondominant cultural belief systems regarding what constitutes a right, humility, vulnerability, and respect for, as well as deference to and defiance of, authority. At the time, I certainly did not recognize my observations or suppositions as ethical ones. Yet my contextual environment set the stage for my inquisition about matters of justice, systemic oppression by healthcare clinicians and institutions, patient-physician communication, African American distrust of the healthcare environment, and, tangentially, how certain attitudes and behaviors about healthcare are transmitted to future generations. Ultimately, my preparation in bioethics is deeply connected to where I am coming from and who I am.

My extensive personal experiences with the healthcare system coupled with exposure to courses and participatory learning experiences at the University of Virginia strengthened my resolve to grow in my understanding of bioethical inquiry. Overall, I have been immersed in bioethics for much of my postcollege training and work, and fortunately, the culmination of these work experiences allowed me to become more astute in both research and teaching practices.

Out of necessity I have always had to work, but it was curiosity that led me to pursue a doctorate in public health. I wanted to understand the ivory tower, because I was working in the trenches of the community, but “they”—public health academics—were the people who were writing about these places and people. I thought, somewhat naïvely, that I would have the freedom to flu-

idly exist between my dual communities (the African American community and academia) if I had a Ph.D., and I thus began my next rite of passage.

At many points in this journey I rationalized remaining A.B.D. These initials are used to denote “all but dissertation,” but at my lowest points, I likened the acronym to “all but dead.” Different mentors had their own words of wisdom to encourage me to finish. Two statements left lasting impressions on me: “You have to finish or they will continue to exploit you” (said by a white male who has a higher degree) and, “You have to finish because we need you” (said by an older black female without a higher degree). There is an indescribable heaviness to both these statements, yet I am appreciative that this same heaviness drove me to stay the course.

My dissertation investigated the relationship between current household food insecurity, select prenatal and current maternal and child factors, and child weight outcomes in an inner-city, preschool- and school-aged population. Identifying potential participants was a significant challenge, particularly given the six-year time lapse between my study and the original study, movement in and out of the healthcare system, challenges with coordinating in-home visits, and the skepticism of African Americans about participation in research studies. Beyond these well-known challenges was the fact that many of my study participants lived in abject poverty and in neighborhoods that were unsafe for me to travel into to conduct the required in-home visits.

Because my safety had to be balanced against achieving my educational goals, most painfully eye opening as I did my research was my simultaneous proximity to and distance from “the” (African American) community. Intellectually I knew that it was more precise to say African American *communities*, acknowledging that there is no single African

American community. Yet what does it mean to be in any community? Did my role as a researcher somehow make me less a part of the African American community? Did I fall somewhere in the middle of a continuum of African American-ness? How would I really fit in as someone with a Ph.D. and someone who is also African American? Why did I treat the two as mutually exclusive? I continue to grapple with these questions and intend to explore how race plays out at individual as well as systemic levels.

It was during my doctorate training that I realized that I missed bioethics, and that it was important for me to integrate my bioethics background with the expertise I was developing in the area of public health. Beyond my academic training, I also realized that it was important for my professional life to have some personal significance, particularly given my experiences as a child. I have engaged in many research projects, using several different methods of scientific inquiry across a range of populations, and have had many defining moments along the way. I firmly believe that bioethics has provided the appropriate foundation for me to pull from my collective experiences.

As a newly minted bioethicist, my biggest challenge is to advance a discussion about race in a way that is both intelligent and provocative while avoiding the appearance of being either too angry or too polite. Discussion of race often becomes so circular that, pun

intended, the issue then re-fades to black. Although I want to move beyond black, I do not want to pretend that as a society we have achieved that goal. Tackling race is a daunting topic for bioethics. Yet in accord with what bioethics forces us to do, I am unwavering in my commitment to inspire others and compel individuals to challenge their own convictions and biases.

In this short narrative I have considered the ways that my personal, educational, and professional experiences have shaped, refined, and focused my career direction. Being on the receiving end of an unequal and often ambivalent healthcare system gave me a continuing passion to understand and effect change in the provision of health services to vulnerable populations. My bioethics and doctoral training have taught me to think deeply and systematically about questions that have both personal and professional significance. My ongoing experience with multiple methods of empirical inquiry provides me with a particular set of skills required to produce the knowledge needed to help answer these questions. My different life situations and career choices have been chronologically appropriate, deliberate, and purposeful. At this moment, I am confident that these experiences have brought me to this exact space in bioethics and allowed me to share my journey with those who seem to be different but are, paradoxically, just the same.