



Erasing Blackness From Bioethics

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OPEN PEER COMMENTARIES



Erasing Blackness From Bioethics

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February is Black History Month and so healthcare practitioners will soon rummage history books for information about famous African Americans, like Onesimus (fl. 1709–1720), the African slave who taught his erudite master, Cotton Mather, BA, MA, (1662–1728), about inoculation. Onesimus’s tutelage of Mather did more than suggest the idea of smallpox inoculation to the American colonists, it challenged their conception of “savage” black slaves becoming enlightened by their “civilized” white Christian masters (Koo 2007). If bioethicists turn to standard histories of their field (Evans 2012; Jonsen 1998; Rothman 1991) for information about influential Blacks, like Onesimus, they will find tales of white whistleblowers ending white researchers’ exploitation of functionally illiterate Blacks, but nothing challenging this narrative of white men saving black and female victims; nothing about female heroines or black whistleblowers; nothing about the African Americans who created foundational documents protecting patients’ rights. A more complete history would recognize that bioethics originated as a moral insurrection initiated by female bureaucrats and black civil rights activists protesting the derogation and exploitation of patients and research subjects by scientific paternalist physicians, medical researchers, and healthcare institutions (Baker 2002, 2019).

Female white FDA bureaucrat Frances Kelsey, PhD, MD (1914–2015) is famous for saving American newborns from a thalidomide tragedy, but her role in successfully inserting an informed consent requirement into the 1962 Kefauver-Harris Act is barely mentioned

in standard histories of bioethics. As Kelsey recalls this feat,

We never imagined we could have gotten away with anything [like requiring informed consent], however much we thought the doctor should do [it], because at that time the doctors felt they were the Lord Almighty. That the patient should take what the doctor gives them because doctor knows best. And if the doctor thinks it is important that this drug be studied in a fashion that the patient does not know he is getting an unproven drug—not to worry. Big Daddy will take care of you (Kelsey, undated).

Although the specialist literature credits Kelsey with pioneering an informed consent requirement in pharmaceutical research (e.g., Ley 1969), standard histories of bioethics only credit her with rescuing American babies from thalidomide. They barely mention her bioethical triumph over “Lord Almighty” doctors (see, e.g., Jonsen 1998, 140–142). Why would they laud Kelsey for saving babies but not for championing patients’ rights? Because babies are a properly feminine interest; telling male doctors not to act as “Lord Almighty” is “uppity” and unfeminine. Moreover, no good deed going unpunished, the “Lords Almighty” struck back: Kelsey “lost formal control over investigational drugs and suffered what one reporter would later describe as a ‘humiliating *bare desk* treatment, she was generally ignored and given little to do of consequence” (Carpenter 2010, 421): an embarrassing origin story for bioethicists who earn their living by advising physicians and researchers.

Standard histories also ignore William Jenkins (1945–2019), the African American coeditor of the

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*This commentary draws on research for R. Baker’s manuscript in process whose working title is: “Making Modern Medical Ethics: A History of How African Americans, Anti-Nazism, Committees, Feminists, Institutes, and Whistleblowing Moralists Created Bioethics.”

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Student Nonviolent Coordinating Committee's newsletter *Drum*. In 1968 his newsletter published an exposé of the Tuskegee Syphilis Study. Copies were sent to the *New York Times* and *Washington Post*—which ignored them (Stanley 2017). Four years later, a white law school student, Peter Buxtun, gave similar information to the Associated Press. White's narratives being deemed more trustworthy than Black's narratives, Buxtun's made front page headlines in the same newspapers. As reported in standard histories, these headlines led to Senator Kennedy's hearings and to a national bioethics commission that issued The Belmont Report; notably absent from these accounts is the media's failure to act on Jenkin's exposé.

In 1969, as Daniel Callahan (1930–2019) and Willard Gaylin were founding the Hastings Center, the Joint Commission for Accrediting Hospitals required that a patients' bill of rights be posted in all hospitals seeking accreditation to receive Medicare or Medicaid funding. In 1972 the American Hospital Association (AHA) affirmed a version of A Patient's Bill of Rights. These documents "raise[d] radical questions about the prerogatives of the doctor's role. Implicit was the belief that the interests of doctors and patients frequently diverged and hence that patients needed protection" (Starr 1982, 390). These patients' rights statements were deemed so important that the AHA version was included in the first edition of *Principles of Biomedical Ethics* alongside the Nuremberg Code and the Declaration of Helsinki (Beauchamp and Childress 1979, 285–287); it is also the sole document reproduced in the first editions of the feminist best seller, *Our Bodies, Our Selves* (Boston Women's Health Book Collective 1971).

Since these rights statements are foundational for bioethics, some standard histories credit the National Welfare Rights Organization (NWRO, 1966–1975) with their creation (Jonsen 1998, 368, 369; Rothman, 145). Absent from their narratives, however, is any indication that the NWRO was an African American civil rights organization or that it was founded and led by George A Wiley, PhD (1931–1973), a well-known afro-wearing black civil rights leader (Whitman 1973) who led the negotiations culminating in each of these patients' rights statements (D'oronzio 2001 288–289; Tsuchia 1973). Yet Jonsen derides *A Patient's Bill of Rights* as

hardly a revolutionary document. It was, in fact, something of a moral fraud, for the rights contained therein were not wrest from a tyrant by an aroused and offended people but were defined and granted by *nobles oblige*, with a content, extent, and duration at the will of the grantor. Dr. Willard Gaylin ... harshly

criticized the Patient's Bill of Rights, describing it as "the thief lecturing its victims on self-protection ... [It] was nothing more than hospitals returning to patients the legal rights that hospitals had previously stolen from them" (Curran 1974, 32–33; Jonsen 1998, 369).

Gaylin and Jonsen invert the history of *A Patient's Bill of Rights*. It was everything they claimed it was not. It was a statement of "rights ... wrest from a tyrant [i.e., the hospitals represented by the AHA and the Joint Commission] by an aroused and offended people." To quote one NWRO member, "We get whatever doctors are at the clinic and the clinic is crowded, and we are waiting in line a long time, and then we are pushed through. There's no time to ask questions. WE ... need services. That's what my group expects" (Pollner 1973). Speaking on behalf of such women Wiley protested that welfare recipients have "been required to wait interminable lengths of time for the most meager and inadequate and most stingily given out medical treatment ... the poor [have] been on the short end of the medical facilities" (D'oronzio 2001, 294, Note 23).¹

It seems that the authors of standard histories are embarrassed to admit that *A Patient's Bill of Rights* was negotiated by a black civil rights leader heading an organized uprising by unmarried black women with dependent children against a healthcare system that perpetuated systemic classism, misogyny, and racism in innumerable ways, large and small. For example, unlike respectable white people with employer-supplied insurance benefits, welfare recipients were not permitted to make advance appointments. To see a doctor, they had to stand for interminable lengths of time in hospital corridors. This arrangement structurally communicated to hospital staff, to other patients—and to these women—that the healthcare system believed that their time, and they themselves, were of little or no importance. As Wiley put this point, the poor "had access to sophisticated miracle treatment only as the guinea pigs. ... the medical establishment have run a colonial empire on the poor, on the black, on the minorities in this country" (D'oronzio 2001, 294, Note 23). Thus, the first right Wiley negotiated with both the Joint Commission and AHA is a patients' "right to considerate and respectful care." In negotiating with the AHA Wiley also managed to include as Right 10, a patient's "right to know in advance what

¹This is the only recorded speech by George Wiley on this topic. It was delivered at the 17th annual meeting of the National Health Council (D'oronzio 2001, Note 23, 294).

appointment times and physicians are available and where,” (Beauchamp and Childress 1979, 285–287). Implementing this requirement would eliminate any need for mainly black welfare recipients and their children to stand on lines for interminably long times.

Jonsen dismisses these insurrectional achievements. He insists that “Bioethics moved with a certain tranquility through the tempestuous moral turmoil of racism and warfare that was contemporaneous with its origins... the work of revising the commandments of medical morality ... was done in a relatively quiet way” (Jonsen 1998, 397) This may represent Jonsen’s experience in think tanks and government commissions, but it fails to recognize that before these commissions and institutes became operational Kelsey and Wiley were challenging the scientific paternalist exploitation of patients, especially Blacks and the poor; so too were Jews motivated by Holocaust memories, like Buxton, and a repentant sinner turned whistleblower named Henry Beecher (1904–1976). As should be evident from this commentary, Professor Russell’s carefully considered proposals for continued bioethical engagement with structural racism is our field’s birthright, and bioethicists should seriously consider integrating her suggestions into their research plans and other professional activities.

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