

## *The Immortal Life of Henrietta Lacks* Reconsidered

BY VANESSA NORTINGTON GAMBLE

Rebecca Skloot's *The Immortal Life of Henrietta Lacks* received renewed attention in August after the National Institutes for Health reached an agreement with the Lacks family over the use of the HeLa genome. The book details how researchers took cancerous cervical cells from a poor black woman, without even telling Lacks or her family, and how the cells evolved into the scientifically significant and commercially lucrative HeLa cell line while the family continued their hardscrabble existence after her 1951 death. As an expert on race and bioethics, I am frequently asked about the book. I have mixed feelings. By bringing the family's story to a wide audience, the book has prompted necessary discussion about bioethical issues such as informed consent and tissue ownership. But I am not a huge fan.

How can I not love a book that has received stellar reviews and become mandatory reading at many colleges? One problem is that it views the history of African Americans in medicine and bioethics exclusively through the lens of exploitation, powerlessness, and victimization. Undeniably, racism is inextricably linked to the development of American medicine and adversely affects African Americans' health and lives. The history of medicine demonstrates that the Lacks family's experience is just one among innumerable examples of what happened when a black person entered the health care system—and what often still happens. In Newport News, Virginia, black patients were housed in the local jail until the 1914 establishment of a black hospital. In November 1931, Juliette Derricotte, a prominent educator, died after being denied hospital care following an automobile accident in Georgia. Unconscious bias plays a role in racial and ethnic inequities in contemporary health care. And yes, there was the United States Public Health Service Syphilis Study at Tuskegee.

The Henrietta Lacks and syphilis study stories are the most widely known episodes in the history of African Americans and American medicine and biomedical research; however, focusing on them exclusively obscures

countless instances of accomplishments, agency, and activism. African Americans have protested poor health conditions and established institutions to provide health care and professional opportunities. A young black woman's rejection by every Chicago nurse training school solely because of her race prompted Dr. Daniel Hale Williams to open the nation's first black-controlled hospital in 1891. At Johns Hopkins—the same institution where those “immortal” cells were removed—Vivien Thomas, an African American surgical technician, contributed to advancements in cardiac surgery and taught surgical techniques for thirty years. As a teacher of medical humanities and bioethics, I have an

obligation to use Skloot's book, but I discuss Lacks's story within the broader context of the history of race and American medicine, something the book does not succeed in doing.

Beyond that failing, the book at times depicts a stereotypically dysfunctional black family. Skloot spotlights

promiscuity, mental illness, and incarceration without any explanation for why these are vital to her larger narrative. And her transcription of family conversations in what she calls “native dialects” contributes to a mistaken picture of an uneducated family unable to make complicated decisions.

I encourage my students to think about the Lacks family beyond the prism of exploitation and stereotype. I ask them to do the same for the syphilis study victims, to understand how the unexamined use of the description “poor, uneducated sharecroppers” obscures the men's individuality and resilience. In class, we recognize that the Lacks family survived harsh racism in Virginia, that several members migrated to Maryland in pursuit of better lives, and that some have entered college. The family's objections to a German laboratory's publication last spring of the genome of a HeLa cell line without their permission led to their agreement with the NIH. Their actions make plain that their history should be viewed as one that moves beyond victimization to accomplishment. Now, when considering the family's strengths, my students need look no further than their successful negotiations with the NIH to be granted some control as to how the HeLa genome is used in research.

■  
*A history of agency  
and accomplishment*  
■