

## Skloot, R. (2010). *The Immortal Life of Henrietta Lacks*. New York, NY: Crown Publishers

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Respected science writer Rebecca Skloot unearths the story of the African American woman from Baltimore, Maryland, whose virulent strain of cervical cancer cells were harvested and grown for medical research. Black history, health disparities, and bench science converge in this entertaining, sociopolitical, anthropological account that relates how one poor African American woman changed the field of cancer research, and nobody knew it for 60 years.

Skloot's ten-year quest to research and write this award-winning book began when she was a sixteen-year-old student in an alternative public school biology class. Her instructor explained the process of mitosis to the class and wrote the name Henrietta Lacks on the board. She told the class that her cells "were one of the most important things that happened to medicine in the last 100 years and that she was a black woman." According to Skloot, her quest challenged everything she knows about "faith, science, journalism, and race." To this reader, her book is a gentle but damning exposé of how grand scientific advances sometimes come at a psychological cost for the individuals or their families who made them possible.

Henrietta Lacks's important story is told in a disjointed, nonchronological manner. We learn that she was like many other women of her time: the poor off-spring of rural Virginia slave owners. She migrated to Baltimore in search of a job during World War II and in January 1951, sought treatment at Johns Hopkins Hospital for what she called a "knot on her womb." What is extraordinary about her knot, a cervical tumor, is that her cells, termed

HeLa, were harvested without her consent. This fundamental social injustice perpetrated for the greater good of medical science affected both cancer research and the cancer “industry.” While the sliver of her immortal tumor cells was innocently shared among scientists to create a uniform cell tissue culture that would ultimately launch the field of virology, *the gap between scientific advancement and the process of science* created havoc in the lives of her family. This epitomizes the meaning of health disparities and the quest for health equity.

Health disparity and equity raise questions at both the individual and institutional levels. Informed consent has a historical context, and tissue rights have present and future implications.

According to Skloot’s investigation, “no law or code of ethics required doctors to ask permission before taking tissue from a living person.” However, the law clearly stated that to perform an autopsy and remove tissue without permission was illegal. The family gave permission for the autopsy that allowed the tissue removal. The ethical concern stems from the fact that her cancerous tissues were used for not only the benefit of science but private business gain. Both profited, while the Lacks family did not. At the institutional level, the method for producing cell lines was perfected at Tuskegee University, a historically black college/university (HBCU). Once the process was perfected, the lab was shut down, and the process became the possession of private investors. Like the Lacks family, the university did not profit.

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The second ethical question involves tissue rights. We are told that now, “there is no law requiring informed consent for storing tissues for research; there is no clear requirement for telling donors when their tissues might result in profits.” Activists advocate disclosing the potential for financial gain from their tissues to patients but believe that the fundamental problem “isn’t the money but that the people from whom the tissue came do not matter.” We are several generations from Mrs. Lacks and far more technologically oriented and educated, but the question remains: how much does the individual matter to the research enterprise and the science industry?

Henrietta Lacks left us more than an important story. Her legacy includes an evolving discussion of the relationship between science and people and whom primarily science serves. Skloot’s literary achievement is an exquisite example for graduate students, clinicians, and behavioral social scientists that “the data have faces”.

Hopefully, any health professional reading this book will face three challenges. The first is seeing the world through the lens of the clients or project participants. Although diversity in academe was successfully addressed a decade ago by Dr. Henry Louis Gates, Jr. and colleagues (Baez, 2000), professional practice does not seem to demonstrate this competence.

The second challenge is using a multifaceted, multidimensional, non-Western interpretation of data, rather than an upper-class, heterosexual male interpretation. The Office of Institutional Research and Assessment ([OIRA], n.d.) defines data analysis as a process of making

meaning and drawing conclusions, postulating significance, and examining the implications. Making meaning of data is a subjective process (Blumer, 1969), and the classic example of diversity in meaning is the controversy that surrounded the famous Moynihan Report, *The Negro Family: The Case for National Action* (1965). It held that slavery caused contemporary African American families to become a “tangle of pathology”, best represented by data indicating increasing percentages of unemployed, female-headed, single-parent households; other indicators were high crime, lower educational levels, and absentee fathers. Dominating mothers were the exemplars of this dysfunction. African American families would be labeled dysfunctional today if African American researchers like Dr. Andrew Billingsley (1968) had not argued that “the extended, matriarchal black family was an effective adaptation to the socioeconomic difficulties that African Americans confronted in racially divided society. The black family was in fact an appropriate structural response rather than a social pathology” (Moynihan Report, 2008).

The third challenge concerns ethical practices of health professionals. As we endure this new normal milieu of economic downturn and workplace pressures and increased toxicity in beliefs, values, and practices, higher ethical standards are sorely needed. Dr. Martin Luther King, Jr. (1966) said, “Of all the forms of inequality, injustice in health care is the most shocking and inhumane.” Health professionals function in this environment of injustice.

The best outcome of Skloot’s treatise will be a diverse body of scientific professionals who enhance the knowledge base because of their collective breadth of interpretation and meaning. Ultimately, this approach will protect both participants and the public. To quote Albert Einstein (1938, p. 95), “To raise new questions, new possibilities, to regard old problems from a new angle, requires creative imagination and marks real advance in science.” This openness may be Henrietta Lacks’s legacy to us.

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