

The Immortal Life of Henrietta Lacks by Rebecca Skloot *Broadway Books, 2011*

Summary¹

Her name was Henrietta Lacks, but scientists know her as HeLa. She was a poor black tobacco farmer whose cells- taken without her knowledge in 1951- became one of the most important tools in medicine, vital for developing the polio vaccine, cloning, gene mapping, in vitro fertilization, and more. Henrietta's cells have been bought and sold by the billions, yet she remains virtually unknown, and her family can't afford health insurance.

This book takes readers on an extraordinary journey, from the "colored" ward of Johns Hopkins Hospital in the 1950s to stark white laboratories with freezers filled with HeLa cells, from Henrietta's small, dying hometown of Clover, Virginia, to East Baltimore today, where her children and grandchildren live and struggle with the legacy of her cells. It is a riveting story of the collision between ethics, race, and medicine; of scientific discovery and faith healing; and of a daughter consumed with questions about the mother she never knew. It's a story inextricably connected to the dark history of experimentation on African Americans, the birth of bioethics, and the legal battles over whether we control the stuff we're made of.

Ethics Issues

- Research ethics
- Culture and ethnicity
- Informed consent
- Faith and spirituality
- Patient-family relationships
- Privacy and confidentiality
- Honesty and truth-telling
- Business ethics and health care industry

Discussion Questions

1. Based on the consent form that Henrietta signed (the text is on page 31), did TeLinde and Gey have the right to obtain a sample to use in their research? If not, what additional information would they have had to provide in order for Henrietta to give informed consent?
2. Do you think Henrietta's experience with the health care system and medical research would have been different if she was a white woman? If she was a patient in our current health care system?
3. Discuss the Supreme Court of California ruling that states when tissues are removed from your body, with or without your consent, any claim you might have had to owning them vanishes.
4. Discuss the role of faith in Henrietta's family as it relates to their understanding of and reaction to Henrietta's experience. Are science, faith and ethics at odds in this story or do they align?
5. Should Henrietta's family be financially compensated for the cells? Why or why not? Where should those funds come from? What are the ethics issues involved in this decision?
6. Is ethics relative? Do our values change over time? If it was ethical and standard practice at the time to take Henrietta's cells without her knowledge, can we say today that it was unethical?
7. Discuss the argument that the good that came out of the research using Henrietta's cells outweighs the bad of taking them without her knowledge.

¹ Adapted from the publisher's summary

8. George Gey gave Henrietta's cells away for free and never profited directly from them, however, they were later commercialized by others. When considering the ethics issues involved, would this story be different if no one had profited financially from the cells?
9. What effect did Henrietta's experience have on her daughter Deborah? Do you think about the generational legacy of health care decisions in your practice?
10. What ethics issues related to privacy and medical information are discussed in this book? Should Henrietta's medical records been published without her family's consent?
11. Discuss the relationship between Henrietta's family and Rebecca Skloot, the author of the book. What role does storytelling play in the field of health ethics?
12. Discuss the following passages in the book:
 - "Everybody in the world got her cells, only thing we got of our mother is just them records and her Bible." (p. 284)
 - "Like I'm always telling my brothers, if you gonna go into history, you can't do it with a hate attitude. You got to remember, times was different." (p. 276)
 - "But I always have thought it was strange, if our mother cells done so much for medicine, how come her family can't afford to see no doctors? Don't make no sense" (p. 9)

Resources

Author Rebecca Skloot's website has a wealth of resources related to this book, including more discussion questions, teachers' and readers' guides, videos and photos, author interviews and more-
<http://rebeccaskloot.com/the-immortal-life/>