

Some Study Questions for Skloot, The Immortal Life of Henrietta Lacks

Part One

1. Have you or a close family member ever had a major illness requiring extensive hospitalization? If so, how did the treatment you got from your doctors compare with the treatment that Henrietta got? If you got the kind of medical care that Henrietta did at Johns Hopkins, would you be satisfied? Have things changed since the 1950's?
2. What are the facts behind the Tuskegee syphilis study described on pages 50 and 51? (You may want to look into this in more detail in other sources.) What was the real ethical issue here? Was it the mere fact of doing a study like this at all? Was it the fact that an effective treatment for syphilis became available after the study started, but the study went on unchanged? What effects do you think the revelations of the way the study was carried out had on the level of trust African-Americans had in medicine and government agencies? What other studies like this are mentioned in the book?
3. Neither Henrietta nor her family ever had much education and they spoke (still speak in some cases) what amounts to a Southern country dialect of English. Rebecca Skloot's choice to portray their patterns of speech as she does has been perceived as offensive by some people. Why do you suppose this is true? Do you agree with that point of view? (How do people judge others by their accents or speech patterns?)
4. What do you make of George Gey? Do you think he was an admirable person? Do you believe the story on page 66 about his supposed conversation with Henrietta before her death?

Part Two

5. What are the currently accepted basic ethical principles for studies involving living human subjects? What are some of the documents or statements embodying these principles? (Again, you may want to look at other sources.) What do you think about the studies described in Chapter 17? Why is genetic research on human subjects especially sensitive? Should studies conducted using tissues collected from no-longer-living humans be subject to the same kind of restrictions as those involving living human subjects?
6. What is the point of the anecdote that starts at the bottom of page 90 and goes over to the top of page 91?
7. Why do you suppose that George Gey was so deceptive about the identity of the subject that HeLa cells came from? (See p. 108-109.)

8. This is bound to be a sensitive subject, but here goes: What do you think of Henrietta's family? What does it mean when one of them says that Henrietta's sister Lillian "converted to Puerto Rican?" What does this tell us about their view of themselves?
9. HeLa cells have been both essential tools in medical research and huge problems in that research. Why have they sometimes been such a problem?

Part Three

10. What were the major issues for Henrietta's family with the way her cells were used? Was it that she had not given her consent for that use? Was it that others were profiting monetarily and they felt they were entitled to some part of that? Was it that they wanted Henrietta to be properly recognized? Was it different for different family members? Has it changed now?
11. Another sensitive question – what does it mean to get informed consent for a medical study if the person involved does not understand any of the basic science involved? Does the researcher have the obligation to educate them so that they can understand?
12. Who was John Moore? Why is his story relevant here? What was the ultimate outcome of his lawsuit?
13. What actually caused the "immortality" of the HeLa cell line?
14. What do you think about Henrietta's daughter Deborah? Why was she so set on finding the records about her mother and her older sister Elsie? Why was she so suspicious of Rebecca Skloot at first, and intermittently throughout their relationship? Do you think Deborah found any peace after learning what she did?