Liberal Arts Study Guide for Rebecca Skloot’s *The Immortal Life of Henrietta Lacks*

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The following questions can be used for class discussion or writing assignments. Most would work as personal essay assignments, while some require extra research. All could benefit from extra research to expand the students’ understanding of these complex ideas.

Please ask the students to continually consider the process Rebecca Skloot went through to collect, organize, structure, and cite her work. They should be doing the same, albeit on a smaller scale. And they should keep in mind that she started this project when she was their age, after getting kicked out of high school and attending a community college.

Prologue:

- P. 2: Skloot first learned about Henrietta Lacks in a community college biology class. What have you learned about—even briefly—in your career as a student that piqued your interest in some particular way? Take a moment to consider where following your true interests may lead.
- P.7: Skloot writes, “Deborah and I came from very different cultures…” How does where you are from affect how you see the world?

Chapter 1:

- Have you ever known something was wrong with your body before the doctors did? Has someone in your life had that experience? How did you or s/he know? Explain.

Chapter 2:

- P. 23: Skloot writes, “People wouldn’t use words like *epilepsy, mental retardation,* or *neurosyphilis* to describe Elsie’s condition until years later. To the folks in Lacks Town, she was just simple. Touched.” How do we think about people with cognitive conditions today? Do we still think of them as “simple” or “touched” and just use different language, or do we think about them differently than we did in Elsie’s time. What does it mean to be “simple” or “touched?”
  - Research option: Investigate the history of the treatment of mental illness in the United States. Pay particular attention to the evolution of inpatient treatment. (Chapter 33 also deals with this subject.)
- P. 25: Sparrows Point and the steel mills play an important part in this story. Did anyone in your family ever work for Bethlehem Steel? What was that experience like?
  - Interview option: Speak with someone you know who worked in the Steel Mills. Ask him or her what it was like and about the circumstances of his/her retirement. Write a profile of the life of a Baltimore Steel Worker.
Research option: Bethlehem Steel played an enormous part in the economy of Baltimore, and when it began laying workers off and shutting down the mills, the city was profoundly affected and still is today. Research the history of the mills and its effect on the local community.

Chapter 3:

- Henrietta didn’t make a big deal of her illness to her family. She chose instead to deal with it privately. How does your family handle difficult issues like illness? Do they talk about it, or do they handle it quietly? What are the pros and cons of each approach?
- The medical establishment in the 1950s expected patients—particularly less educated patients like the Lacks family—to trust them completely (consent form on p. 31). We need to trust our medical professionals, but is there such thing as too much trust? When would you or should you question your doctor or a consent form s/he asks you to sign?
- To us today, Henrietta’s treatment for her cancer seems almost barbaric. But the same doctors and scientists who treated her often died of exposure to the radium (p. 32), and her treatment was described as standard practice for the day. Did Henrietta receive reasonable care for her cancer? Explain your position.
- It wasn’t standard practice or legally necessary to ask a patient before taking a tumor sample, like doctors did with Henrietta. Even so, was this an ethical violation on the doctors’ part? Should they have asked to take the sample even though they didn’t have to? Have you ever done something you didn’t have to do, something that maybe created some more work for you, because you thought it was the right thing to do? Explain.

Chapter 4:

- Mary Kubicek, Gey’s lab assistant, told Skloot that she thought “Why bother?” when Henrietta’s cells came into the lab (p. 35). She went through all the proper procedures anyway, and the cells grew. What does this tell you about persistence and preparedness as you pursue your work now as a student and later in the field for which you are training?
- According to Skloot, Margaret Gey, George Gey’s wife, may be the reason Gey was able to grow cells. Even though she often worked without pay (p. 193), she was trained as a surgical nurse and kept the lab sterile (p. 36). Why did Margaret work without pay or recognition? Would she have done this if she were a man? Would you be willing to help your spouse/partner achieve great things, even if it meant working without your own paycheck or formal recognition? Why or why not?
- George Gey had his own obstacles. He worked his way through school as a carpenter and mason because he came from a family without many resources. He went to medical school for eight years instead of four because he had to take every other year off to work construction and save for tuition (pp. 38-39). What
does Gey’s resourcefulness and work ethic show us about determination and perseverance? Can you relate to his situation? Explain.

- Why did Gey give away the HeLa cells to anyone who asked? (p. 41) What were the pros and cons of his generosity?

Chapter 5:

- Henrietta didn’t understand that her cancer treatment would leave her unable to have more children (pp. 47-48). The doctors say that they explained this to her, but she didn’t understand until it was too late. The standard of “informed consent” requires that patients understand the risks and consequences of medical treatment, but what should doctors do when speaking to patients whose education and background may make it difficult for them to understand?

Chapter 6:

- The Lacks family had been used and abused by people investigating Henrietta’s story, and they didn’t want to speak with Rebecca Skloot, another educated white journalist looking to possibly make money from their story. Should she have respected their wishes and left them alone? If not, why was it okay for her to make a career and a living off their story?

Chapter 7:

- Gey sent Henrietta’s cells to anyone who asked. Compare his approach to what we today call “Creative Commons.” From the Wikipedia page on Creative Commons: “Creative Commons works to counter what the organization considers to be a dominant and increasingly restrictive permission culture. According to Lawrence Lessig, founder of Creative Commons, it is ‘a culture in which creators get to create only with the permission of the powerful, or of creators from the past.’ Lessig maintains that modern culture is dominated by traditional content distributors in order to maintain and strengthen their monopolies on cultural products such as popular music and popular cinema, and that Creative Commons can provide alternatives to these restrictions.” Why might it make sense to share ideas and work instead of owning them and protecting individual rights? (This could become a research project.)
- On page 62, Skloot writes, “Tissue culture was the stuff of racism, creepy science fiction, Nazis, and snake oil.” Is that still true today about genetic advances (designer babies and cloning) and research into immortality? If immortality became an option, to whom would it be made available? How would you react if the wealthy could live forever, but you and your family could not afford that technology?

Chapter 8:
• On page 63, Skloot writes, “This was a time when ‘benevolent deception’ was a common practice—doctors often withheld even the most fundamental information from their patients, sometimes not giving them any diagnosis at all. They believed it was best not to confuse or upset patients with frightening terms they might not understand, like cancer.” Is it ever kinder not to tell someone the truth about his/her medical condition? Should families have the right to request that doctors not tell their loved ones frightening news?

• The description of Henrietta’s suffering (p. 66) is heartbreaking. Should patients in Henrietta’s condition be given the right to physician-assisted suicide? Why or why not?

Chapter 9:

• While waiting in vain for Sonny to call back, Skloot decided to start calling every Lacks in the phone book to see if they knew Henrietta. Consider the possibility that Skloot was successful in this project because of her willingness to look silly in the pursuit of the story. What do you care enough about that you’re willing to look a little bit silly in order to pursue it? Have you ever put yourself out in an uncomfortable way because you really wanted something? What happened?

• What does Skloot’s description of Turner Station (pp. 70-71) tell us about the culture of low-income neighborhoods? Is her description accurate, based on your experience?

Chapter 10:

• On page 81, Cootie says to Skloot, “Nobody round here never understood how she dead and that thing still livin. That’s where the mystery’s at.” If you had to explain to the family that Henrietta was in fact dead, but her cells were very much alive, how would you do it?

• Cootie and the rest of the Lacks family used spiritual explanations as a way to understand the natural world. Unless you are an atheist, you probably do, too. In what ways does your spirituality help you understand the world around you? When do you look to science for explanations, and when do you look to the supernatural? If you are an atheist, what questions has science yet to answer for you completely?

Chapter 11:

• What does this chapter teach us about community? Does community like the one described in this chapter exist today? Are you a part of one? If not, why not?

Chapter 12:

• On page 91, Henrietta’s toenails shock Mary into the realization that Henrietta was a real woman. Why did this move her so much?
• Again, the Lacks family sees tremendous spiritual significance in the storm that happened after Henrietta’s burial. What did they think Henrietta was trying to convey by ripping the roof off buildings and tearing a house from its foundation, killing a cousin. Do you believe Henrietta could have been behind the storm? Explain.

Chapter 13:

• Which distinction do you think is more important in Tuskegee’s history: The syphilis studies that oversaw the preventable suffering and death of many black men, or the polio project that Charles Bynum used to provide valuable training to many young black scientists? Explain.
• Research option: On page 98, Skloot writes about the technology developed to freeze a cell, which not only preserved them but also allowed scientists to stop cells in various stages of reaction/development. This technology led people to believe they could freeze themselves if diagnosed with an incurable disease, and then be thawed when a cure was discovered (cryogenics). This hasn’t worked. Why? Write a paper explaining.

Chapter 14:

• Henrietta Lacks was known as Helen Lane and several other names for many years. Why were scientists hesitant to reveal her real name? Who did changing her name protect? Who did it hurt? Explain.

Chapter 15:

• Some in the Lacks family thought that Ethel abused Sonny, Deborah, and especially Joe “just to get out all the hate she had for Henrietta by torturing her children” (p.111). How does this theory compare to what we know about child abuse?
  o Discussion or research option: Why does anyone hurt someone (a child or vulnerable adult) or something (an animal) weaker than he or she?
• On page 112, Skloot writes about Joe during his abuse, “He stopped feeling pain; he felt only rage.” Is it possible to stop feeling pain in a painful situation? Explain.
• Deborah’s older cousin Galen sexually abused her. But on page 114, Skloot writes, “Despite the beating and molesting, Deborah felt closer to Galen than she ever had to [her father] Day.” How could that be?
  o Research option: Is it uncommon for the victims of abuse to develop an attachment to their abusers? Why does that happen?
• Deborah’s father, Day, knew about the abuse and ignored it. On page 115, Skloot writes, Galen “grabbed Deborah by the arm, threw her in the car, and punched her hard in the face. Her father didn’t say a word, just stared through the windshield.” Try to explain Day’s reaction. To whatever degree you can, put yourself in his
shoes and try to think about why he might not protect his daughter (understanding that this is not a defense of his actions).

- Research option: Is it uncommon for a parent to allow his/her child to be abused? Why does that happen?

Chapter 16:

- On page 122, Skloot writes that Henrietta’s cousin Cliff thought, “there was something beautiful about the idea of slave-owning white Lackses being buried under their black kin.” Why does Cliff love this idea?
- The black Lackses don’t seem to resent that the white Lackses slept with their slaves and how the offspring were treated and continue to live today. Think about why this might be. Why and how do people forgive terrible injustices?

Chapter 17:

- Dr. Chester Southam injected people, without their knowledge or consent, with cancer cells to see if they would get cancer. When he was challenged, his lawyer argued, “If the whole profession is doing it, how can you call it ‘unprofessional conduct’?” (p. 134). Consider this argument as it applies to the modern day banking industry: If everyone was offering predatory sub-prime mortgages to people they knew couldn’t afford the houses, can you call it unprofessional? If everyone was bundling these risky loans and then selling them as safe investments, can you call it unprofessional? If everyone was taking out huge insurance policies on investments they knew were going to crash, investments they wanted to crash so they could cash in on the insurance, can you call it unprofessional? What is the relationship between common behavior and ethical, professional behavior?

Chapter 18:

- Cutting-edge science is often frightening for the general population. The explanation for pursuing ethically difficult research is that it should be done with the greatest transparency, and if ethical scientists stop, it leaves the work to unethical scientists. When and how should scientific exploration ever be stopped in the name of ethics or human decency and dignity? What are the pros and cons to attempting to control scientific research?

Chapter 19:

- Consider having the class read the May 9, 2011 New Yorker article, “The Mitigator: A new way of looking at the death penalty” by Jeffrey Toobin and discussing it in terms of Joe Lacks’s crime and sentencing. Toobin writes: “The idea was to use the mitigation process to tell the life story of the defendant in a way that explained the conduct that brought him into court. The work was closer to biography than criminal investigation, and it led to the creation of a new
position in the legal world: mitigation specialist.” I have a hard copy of the article. Here is the abstract:
http://www.newyorker.com/reporting/2011/05/09/110509fa_fact_toobin#ixzz1TQG3QCK5

Chapter 20:

- HeLa cells were so robust that they contaminated experiments with other cell lines, compromising the results and causing major problems for scientists. Initially, even after they were presented with evidence, scientists refused to admit there was a problem. Humans often see what they are hoping will be there and don’t see things they don’t want or don’t expect to see. This is true even if a person is trying to be unbiased. Discuss this phenomenon in terms of its effects on scientists and scientific discovery.

Chapter 21:

- Did you ever hear rumors of “Night Doctors” growing up? Did you ever hear rumors about Johns Hopkins Hospital? What do you think of those rumors today?
- On page 160, why did it matter that Skloot ate Lawrence’s cooking?
- What is the difference between talking to someone and talking down to someone? Is it possible to explain something to someone, something difficult for that person to understand, without talking down to him/her? Explain. Use examples from your own life if you have them.
- The family resented that they kept “givin out information and not getting nuthin” (p. 164). To what do you think the family is/was entitled?
- It seems like a tragic irony that the Lacks family doesn’t have health insurance. Should someone/some company simply give them healthcare for the contribution Henrietta made? Who should do that? Who should pay for it?
- Why did the Lacks family ultimately talk to Skloot?
- Did George Gey make a mistake, perhaps not legally, but morally or ethically?

Chapter 22:

- On page 171, Skloot describes Gey’s selflessness as he dealt with his cancer. Does this prove that his motives were pure regarding HeLa? Explain.

Chapter 23:

- Discuss the Lacks family’s confusion over the HeLa cells, ways they were and were not Henrietta, and the things science had accomplished with them. Why did the family’s misunderstandings about the cells seem so profound and persistent? Was it more than a matter of education?
- Susan Hsu thought she explained what she was doing and why to the family. What else could/should she and/or Dr. McKusick have done?
- On page 187, Skloot writes that the risk of medical testing was now “about
violation of privacy” because of all the information contained in our genes. Do you think about protecting your privacy with respect to your genetic information? What are the potential consequences if a boss, potential employer, potential insurer, etc. learned the information encoded in your genes?

Chapter 24:

- Skloot and Michael Rogers are both only partly kidding when they talk about Henrietta’s presence as they both investigated her story, in spite of the fact that neither is particularly spiritual. Do you believe that Henrietta influenced the discovery of her story after her death? Why or why not?
- Skloot writes on page 197 about the Black Panthers protesting a “racist health-care system” back in 1976. Is our modern-day health-care system still racist? If not, what changed? If so, what needs to be done?
- Johns Hopkins Hospital did not make money on the HeLa cells. Do they, or anyone else, owe the Lackses money?

Chapter 25:

- What are the ethical and practical issues in the Moore versus Golde case? Was Moore entitled to tissue that he gave away freely? Was Golde entitled to compensation for the work he did on the Moore cells to turn them into the commercially viable Mo line?
- What are the consequences of the Supreme Court’s decision that life can be patented? What difference does it make if a for-profit company owns each gene that is decoded in the human body? (See also the Afterword and p. 323 specifically.)
  - This question could also be a research project, since students are unlikely to know the answer without further research.
- The Slavin case is ideal. Could this case apply to the HeLa cells and the Lacks’s situation?
- Respond to Skloot’s statement on page 205: “When tissues are removed from your body, with or without your consent, any claim you might have had to owning them vanishes. When you leave tissues in a doctor’s office or a lab, you abandon them as waste, and anyone can take your garbage and sell it.”

Chapter 26:

- Day received $12,000 for inhaling asbestos in the steel mills. Is that a fair amount? Explain.
  - Research option: What is asbestos? What does it do to the human body when inhaled? What kinds of treatments are necessary, and what do they cost? What is the prognosis for someone suffering the effects of inhaled asbestos?
- On page 211, Skloot writes, “the dead have no right to privacy—even if part of them is still alive.” Why is this? How does our increased knowledge of genetic
information affect this situation?

Chapter 27:

• Evaluate the fairness of this statement: “Day’s infidelity cost Henrietta her life.”

Chapter 28:

• Why did Deborah ask Mary to tell the story of Henrietta’s red toenails in the morgue to the angry crowd in Turner Station? Why did that story make the audience fall silent? (p. 223)
• Keenan Kester Cofield is a classic con artist. What are the telltale signs of a con? Why did Deborah fall for it?

Chapter 29:

• Deborah is emotionally erratic in this chapter. How do you feel about her? Do you sympathize with her, or do you find her unfair? Explain. Consider some possible explanations for her behavior.

Chapter 30:

• Zakariyya is the most resentful of the Lacks children. On page 248, he says, “Maybe her cells have done good for some people, but I woulda rather had my mother. If she hadn’t been sacrificed, I mighta growed up to be a lot better person than I am now.” Do you sympathize with Zakariyya? Why does he use the word “sacrificed?” Is Zakariyya a bad person? Explain.

Chapter 31:

• On page 251, Skloot tells Deborah that she couldn’t pay her for the story. Why is that?
• Many of the Lacks boys and young men found themselves in trouble with the law, even those who had concerned parents like Deborah, Lawrence, and Bobbette. Think about why that happens.

Chapter 32:

• Why did it have such a profound effect on Deborah and Zakariyya to see the frozen vials of HeLa cells? Even after all the discussion about HeLa, why did Deborah still say, “she’s cold” (p. 263) and try to warm the vial?
• Why was Zakariyya receptive to Christoph, even though he worked for Johns Hopkins?
• Christoph asserts on page 266 that the history of the person behind HeLa is important, and this belief is also at the core of this book. Why does it matter who Henrietta Lacks was? Does it matter?
• What caused what Deborah called “a miracle” in Zakariyya during his visit with Christoph at Johns Hopkins?

Chapter 33:

• Paul Lurz at Crownsville says on page 271, “Sometimes learning can be just as painful as not knowing.” Do you believe this is true?
• Why did Elsie and the other hospital residents receive such terrible treatment? Are people sometimes cruel to other people for no reason?

Chapter 34:

• Why did Deborah become enraged when Skloot smiled?
• Does it make sense to you why Deborah lashed out at Skloot, even after all the time they’d spent together? Is her physical assault of Skloot justifiable on any level?
• What was the effect of Skloot getting angry back?
• Why did Skloot decide to quote herself using “the f-word?” What is the effect of including that word in the book?

Chapter 35:

• Why does Deborah keep making up reasons that Elsie is crying in the picture and telling people those reasons as though they’re fact?
• How did you respond to the scene on pages 291-292? Have you ever witnessed something like that first hand? How did Skloot respond to it, as an atheist?
• Skloot writes of Deborah’s behavior on page 292, “Oh my god…I did this to her.” Is that true? Or is Skloot over-emphasizing her influence?

Chapter 36:

• Gary believes the passage, “Those who believe in me will live, even though they die; and those who live and believe in me will never die,” describes the HeLa cells. What do you think?
• Skloot later writes on page 296, “that answer was so much more concrete than the explanation offered by science.” How do you think about when to look to science for the answers to life’s questions, and when to look to faith? Are there consequences to relying to heavily upon one or the other? What might those consequences be?
• Why didn’t Skloot find Gary’s point of view compelling enough for her to consider “converting?” (p. 296)

Chapter 37:

• Why did Pullum ask Skloot to speak before the church at Sonny’s granddaughter’s baptism? She doesn’t believe in God, and she didn’t have a
spiritual message, so what was the significance of that event?

Chapter 38:

- Many things happened as Skloot finished the book that were natural endings to the narrative: Clover was torn down, Day, Gary, and Cootie died, and most importantly, Deborah died. How could Skloot have finished this story if none of those things had happened?
- What kinds of ethical standards did Skloot hold herself to as she wrote this book? What kinds of journalistic standards?

Afterword:

- Skloot writes that there are two main issues when it comes to tissue that is on file: consent (who has the right to say how it’s used) and money (who should get paid if it is used). How do you think and feel about your own tissue, which is probably on file somewhere, in terms of these two issues? What kind of say and compensation do you feel entitled to, even if you did nothing except consent to a medical test and then walk away?
- Should you have the right to say what kind of research your discarded tissue is used in? What if future science wants to use your tissue for something not yet considered today?
- Research option: What is HIPAA? It what ways does it protect you? In what ways doesn’t it protect you?
- On page 321, Skloot quotes Lori Andrews, director of the Institute for Science, Law, and Technology at the Illinois Institute of Technology, as saying, “‘Science is not the highest value in society,’…pointing instead to things like autonomy and personal freedom.” Are some things worth sacrificing scientific breakthroughs, even if those breakthroughs would have saved lives?
- On page 322, Skloot writes, “It’s illegal to sell human organs and tissues for transplants or medical treatments, but it’s perfectly legal to give them away while charging fees for collecting and processing them.” This is part of the reason the Lack family will never profit from HeLa. Is this fair? Explain.
- On page 325, Skloot writes, “we live in a market-driven society, and science is part of that market.” Should some things be kept outside the influence of capitalism and the drive for profit? If so, what, why, and how? If not, why?
- In the last line, Sonny expresses his hopes that Johns Hopkins will “do something to honor [Henrietta] and make right with the family.” What could/should they do?