

USF 2013-14 Common Reader
The Immortal Life of Henrietta Lacks
by Rebecca Skloot

Summary

The following summary is taken directly from Rebecca Skloot’s “A Reader’s Guide” found at:
http://rebeccaskloot.com/wp-content/uploads/2011/03/HenriettaLacks_RGG.pdf.

In 1950, Henrietta Lacks, a young mother of five children, entered the colored ward of The Johns Hopkins Hospital to begin treatment for an extremely aggressive strain of cervical cancer. As she lay on the operating table, a sample of her cancerous cervical tissue was taken without her knowledge or consent and given to Dr. George Gey, the head of tissue research. Gey was conducting experiments in an attempt to create an immortal line of human cells that could be used in medical research. Those cells, he hoped, would allow scientists to unlock the mysteries of cancer, and eventually lead to a cure for the disease. Until this point, all of Gey’s attempts to grow a human cell line had ended in failure, but Henrietta’s cells were different: they never died.

Less than a year after her initial diagnosis, Henrietta succumbed to the ravages of cancer and was buried in an unmarked grave on her family’s land. She was just thirty-one years old. Her family had no idea that part of her was still alive, growing vigorously in laboratories—first at Johns Hopkins, and eventually all over the world.

Thirty-seven years after Henrietta’s death, sixteen-year-old Rebecca Skloot was a high school student sitting in a biology class when her instructor mentioned that HeLa, the first immortal human cell line ever grown in culture, had been taken from an African American woman named Henrietta Lacks. His casual remark sparked Skloot’s interest, and led to a research project that would take over a decade to complete. Her investigation of the true story behind HeLa eventually led her to form significant—and in some cases, life changing—relationships with the surviving members of the Lacks family, especially Henrietta’s daughter, Deborah.

In telling Henrietta’s story, Skloot draws from primary sources and personal interviews to provide insightful narrative accounts of Henrietta’s childhood, young adulthood, diagnosis, illness, and tragic death. She also explores the birth and life of the immortal cell line HeLa, and shows how research involving HeLa has changed the landscape of medical research, leading to not only scientific and medical breakthroughs, but also new and evolving policies concerning the rights of patients and research subjects.

As the story of HeLa unfolds, so does the story of Henrietta’s surviving children, who for two decades were unaware of the existence of their mother’s cells—and the multimillion-dollar industry that developed around the production and use of HeLa. Central to this narrative is the relationship between Skloot and Deborah. As Skloot tenaciously worked to gain Deborah’s trust, Deborah struggled to understand what had happened to her mother and her mother’s cells. The result of their relationship is an illuminating portrait of the enduring legacy of Henrietta’s life, death, and immortality

About the Author

Rebecca Skloot is an award-winning science writer with a B.S. in biological sciences and an MFA in creative nonfiction. Her work has appeared in *The New York Times Magazine*, *Prevention*, *Discover*, and *O, The Oprah Magazine*. She has taught creative nonfiction and science journalism at the University of Memphis, the

The Academy for Teaching and Learning Excellence (ATLE)

"Office hours for faculty."

(813) 974-1841 | atle.usf.edu | atle@usf.edu

University of Pittsburgh, and New York University. *The Immortal Life of Henrietta Lacks* is her first book and has been a *New York Times* bestseller since its release in 2010.

Discussion Questions

The following questions were taken from *LitLovers: A Well-Read Online Community* and can be found at: <http://www.litlovers.com/reading-guides/14-non-fiction/1251-immortal-life-of-henrietta-lacks-skloot?start=3>.

1. Start by unraveling the complicated history of Henrietta Lacks's tissue cells. Who did what with the cells, when, where and for what purpose? Who benefited, scientifically, medically, and monetarily?
2. What are the specific issues raised in the book—legally and ethically?
3. Follow-up to Question #2: Should patient consent be required to store and distribute their tissue for research? Should doctors disclose their financial interests? Would this make any difference in achieving fairness? Or is this not a matter of fairness or an ethical issue to begin with?
4. What are the legal ramifications regarding payment for tissue samples? Consider the RAND corporation estimation that 304 million tissue samples, from 178 million are people, are held by labs.
5. What are the spiritual and religious issues surrounding the living tissue of people who have died? How do Henrietta's descendants deal with her continued "presence" in the world...and even the cosmos (in space)?
6. Were you bothered when researcher Robert Stevenson tells author Skloot that "scientists don't like to think of HeLa cells as being little bits of Henrietta because it's much easier to do science when you dissociate your materials from the people they come from"? Is that an ugly outfall of scientific research or is it normal, perhaps necessary, for a scientist to distance him/herself? If "yes" to the last part of that question, what about research on animals?
7. What do you think of the incident in which Henrietta's children "see" their mother in the Johns Hopkins lab? How would you have felt? Would you have sensed a spiritual connection to the life that once created those cells or is the idea of cells simply too remote to relate to?
8. Is race an issue in this story? Would things have been different had Henrietta been a middle class white woman rather than a poor African American woman? Consider both the taking of the cell sample without her knowledge, let alone consent and the questions it is raising 60 years later when society is more open about racial injustice?
9. Author Rebecca Skloot is a veteran science writer. Did you find it enjoyable to follow her through the ins-and-outs of the laboratory and scientific research? Or was this a little too "petri-dishish" for you?
10. What did you learn from reading *The Immortal Life of Henrietta Lacks*? What surprised you the most? What disturbed you the most?

The following questions relate to current issues.

The Academy for Teaching and Learning Excellence (ATLE)

“Office hours for faculty.”

(813) 974-1841 | atle.usf.edu | atle@usf.edu

11. Recent political discourse and controversy has surrounded the issue of affordable health care in the United States. How do the story of Henrietta Lacks and her family impact this issue? What do they add to the discussion? What about the stories of John Moore and Ted Slavin? Do you think this book makes a case for universal health care?
12. Although the timeframe in the book is set in a period of transition for minorities in the United States, are the issues raised in *The Immortal Life of Henrietta Lacks* still relevant today? Identify those issues that are still a part of American society and discuss how they have evolved, improved, or not changed. What are some practical ideas or ways that these issues could be addressed?
13. Pharmaceutical companies yield huge profits for drugs that are developed using human cells, tissue, and other biological material. What are your thoughts on compensating donors for successful development of pharmaceutical drugs? Do you think that donors *should* be compensated? What are the potential issues or consequences that could arise from this?

Lesson Ideas

Research Topics:

- The following research ideas came from the Random House, Inc. Teacher’s Guide under topics for further discussion found at: <http://rebeccaskloot.com/wp-content/uploads/2011/03/RHsklootTeachersGuideLORES.pdf>.
- Investigate the history of participation in scientific studies. What are the laws or ethical debates involved in offering monetary compensation for participation or donation of biological material (blood, sperm, eggs)? Do people have the right to sell their body, tissues, or organs? What ethical dilemmas could result from financially compensating donors or participants? At what point can compensation become coercive and is it a problem if it does?
- Research the history of mental institutions in the United States. Explore the role scientists and journalists have played in influencing public opinion toward the mentally ill and altering how the mentally ill are diagnosed and treated.
- Research the history of scientific experimentation on humans in the United States and/or world. What types of experiments have been done? How did researchers find test subjects? Why did scientists find it necessary to test humans? What are the ethical issues involved in using the findings of such studies? How did HeLa cells change the way research could be conducted? What attempts have been made to regulate the way this research is conducted and how successful have these attempts been?
- Study the recent legal disputes over the collection and use of tissue samples. Specifically look at the lawsuit filed by the Havasupai tribe against Arizona State University, the lawsuit filed by Texas parents over the collection of blood samples from their newborn children, and the controversy over the University of California at Berkley’s request that incoming freshman submit DNA samples.

Writing Prompts:

- The following research ideas came from the Random House, Inc. Teacher’s Guide under writing prompts found at: <http://rebeccaskloot.com/wp-content/uploads/2011/03/RHsklootTeachersGuideLORES.pdf>.
- Although the right to privacy is not explicitly state in the Constitution, the Supreme Court has determined that the right is protected. Explain the ways that the Lacks family’s right to privacy was violated. How important is the right to privacy? How has the right evolved over time? How has it been challenged by emergent technologies? How have groups of people like African Americans, women, and immigrants fought for legislation to protect their right to privacy? Cite specific court cases and current events.

The Academy for Teaching and Learning Excellence (ATLE)

“Office hours for faculty.”

(813) 974-1841 | atle.usf.edu | atle@usf.edu

- An important issue raised by Skloot is the importance of ethical journalism. What constitutes ethical journalism? Compare the difference between responsible and irresponsible reporting on HeLa cells and the Lacks family. What are some of the intended and unintended consequences of irresponsible journalism?
- Discuss the historical and contemporary influence that journalists writing about science have had on public perception and understanding of the subject. Why do you think science reporting is often sensationalized? Why is it important for science reporting to be accessible? How has fear or lack of understanding influenced public policy relating to science?
- Using the book as a guide, describe the process of scientific inquiry. Examine the often contradictory forces of altruism and profit as they influenced research related to HeLa. What are the risks and benefits of allowing profit to guide research? What are the obstacles involved with conducting research purely for altruistic reasons?

Assignments:

- Write a book review – after discussing the components of a good book review, have students write one of their own for *The Immortal Life of Henrietta Lacks*. Assign a word limit since many published book reviews are limited to a specific word count.
- Create a blog – create a blog for the class and have students post their thoughts and/or questions while they are reading the book.
- Debate - divide the class into groups and assign each group a position on one of the issues raised in the book. Once students have had enough time to fully prepare an argument for their position, hold a debate.
- Research paper - have students write a research paper or give a presentation to the class.
- Group activity – divide students into groups and provide each group with specific discussion questions. Once groups have had the opportunity to discuss the questions, bring the class back together and have each group report on their discussions.

Check out Kansas State University’s “Ways to Use the Common Book in the Classroom”: <http://www.k-state.edu/ksbn/lacks/assignments.html>

Resources

Websites:

- <http://rebeccaskloot.com/the-immortal-life/> - author’s website that has a ton of resources like photos, videos, blog posts, articles, news, and a HeLa Forum. In addition to this, there is information on the Henrietta Lacks Foundation founded by Rebecca Skloot. This is the resources that will provide faculty with the most information and ideas for the classroom.
- http://rebeccaskloot.com/wp-content/uploads/2011/03/HenriettaLacks_RGG.pdf - this is the reader’s guide found on the author’s website. It provides a detailed summary of the book, information on the author, an interview with the author, discussion questions, a timeline, and a cast of characters. It is geared more toward a book club, but still very informative for a college classroom.
- <http://rebeccaskloot.com/wp-content/uploads/2011/03/RHSklootTeachersGuideLORES.pdf> - this is a teacher’s guide to the book. It is focused for a high school audience, but it does provide discussion questions for each chapter.
- <http://www.ric.edu/obom/pdf/readersGuideArthur.pdf> - this is a teacher’s guide titled “HeLa’s Ancestors: Teaching about Race and Science”.
- <https://jeopardylabs.com/play/the-immortal-life-of-henrietta-lacks> - reader generated online jeopardy game. You can play with up to 12 teams.

The Academy for Teaching and Learning Excellence (ATLE)

"Office hours for faculty."

(813) 974-1841 | atle.usf.edu | atle@usf.edu

Videos:

- <http://www.youtube.com/watch?v=tnUp0xQlfK8> – an interview of the author on *The Agenda with Steve Paikin* shortly after the book's initial release.
- <http://www.youtube.com/watch?v=1vow1ePzugo> – the official trailer for *The Immortal Life of Henrietta Lacks* by Rebecca Skloot.
- <http://www.youtube.com/watch?v=4AuOWSOzdcA> – the author is interviewed by WKNO's Pierre Kimsey.
- <http://www.youtube.com/watch?v=tgC7Cm5YSTk> – the author talks about life after writing the book. It took her over a decade to write and was published in 2010, but the book is still talked about, used as a common reader across universities, and sparking controversy. This is a discussion with Rebecca Skloot about her life (some profanity involved) (23 minutes).
- <http://www.youtube.com/watch?v=hXRrhoA46-eA> – the author talks about how she decided to organize and tell the story of Henrietta Lacks.
- <http://www.radiolab.org/2010/may/17/henriettas-tumor/> - this is a radio discussion with Rebecca Skloot with audio from other people in her book (cousins, Deborah Lacks, doctors). Even though this is only an audio interview, it is powerful because more than Skloot's voice is heard (25 minutes).

Articles:

- <http://www.theopennotebook.com/2011/11/22/rebecca-skloot-henrietta-lacks/> - this article is an interview with the author from The Open Notebook.
- <http://chemlinks.beloit.edu/Ordman/classes/cls/FYI2012/SciLacks.pdf> - this link leads to the article "Paying Patients for Their Tissue: The Legacy of Henrietta Lacks".