The Immortal Life of Henrietta Lacks - and Beyond

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Overview

Henrietta Lacks (Aug 1, 1920 - Oct 4, 1951) was an African-American woman, a tobacco farmer from the neighborhood in Dundalk, Maryland, and a mother of five. She died of cervical cancer at the age of 31. Little did she know that she was going to become the heroine of the modern medical science. A sample of her cells (known as HeLa) was taken without her knowledge when she was being treated, cultured in the lab, and have become an immortal cell line. HeLa cells have helped the scientists make some of the most important breakthroughs in the scientific history, such as cloning, gene mapping, AIDS research, etc..

Despite her great (though unwitting) contribution to modern medical science, Henrietta Lacks remained virtually unknown years after her death. Her family had been kept in the dark about the existence of the cell line until 1976. Whereas her cells were being bought and sold regularly, creating a multi-million dollar industry, her family could not afford health care, and was never compensated financially. Whereas HeLa cells were widely known in the field of medicine, Henrietta, as a woman, a wife, and a mother, had hardly been recognized for a long time.

Stained HeLa cells under microscope
After 60 years of anonymity, Henrietta Lacks was honored with a new headstone in Clover, where she'd rested for decades in an unmarked grave. The marker reads: "In loving memory of a phenomenal woman, wife and mother who touched the lives of many. Here lies Henrietta Lacks (HeLa). Her immortal cells will continue to help mankind forever. Eternal Love and Admiration, From Your Family."

Since 1990s, efforts have been made to commemorate Henrietta Lacks. A BBC documentary on HeLa was made in 1998; her family received honors from research institutions. There were even songs made on "Helen Lane," a journalist's pseudonym for Henrietta Lacks. One of the most noteworthy efforts was made by Rebecca Skloot, a freelance science writer. Her book, The Immortal Life of Henrietta Lacks, published in 2010, documents both the histories of the HeLa cell line and the stories of Lacks family. This book will soon be made into an HBO movie by Oprah Winfrey and Alan Ball. Skloot also created the Henrietta Lacks Foundation, which works to provide assistance for Lacks' s descendants, as well as individuals in need who have made significant contributions to scientific research without their knowledge or consent.

This unit focuses on the stories of this extraordinary African American woman, Henrietta Lacks, her life, her cells, and her family. The stories about the immortal life of Henrietta intertwine racial issues, community history, medical sciences, research ethics, even life and death. They are of concern not only for the medical profession, but also the general public; not only for the African American community, but also other communities regardless of race and background. While activities in the classroom will be focused on three major (and correlated) themes described as below, students are also encouraged to explore various related topics in their projects.
Some still call her Helen Lane, Helen Larson, or Henrietta Lakes, but her real name was Henrietta Lacks. She was born on August 1, 1920 in Roanoke, Virginia. Her mother died when Henrietta was four years old, and Henrietta was raised by her grandfather, a tobacco farmer in Clover, Virginia. She married David "Day" Lacks in 1941, and the couple left the tobacco farm in Clover in the same year and soon moved to a house located in New Pittsburgh Avenue in Turners Station, now a part of Dundalk, Baltimore County, Maryland. This community was one of the largest and youngest African American communities in Baltimore County at that time. Henrietta had middle-school level education. She was described by her families acquaintances as a beautiful, strong-willed young woman, a loving mother, and a capable hostess.

On January 29, 1951, Henrietta went to Johns Hopkins Hospital after she discovered that she had lumps and unusual bleeding. Diagnosed with Stage 1 cervical cancer, she received radiation treatments, during which doctors took two samples of Henrietta's cervix without her knowledge or consent. The cell samples were given to Dr. George Gey, who successfully use the cancer cells to grow the first immortal human cell lines, HeLa. At the same time, Henrietta continued to receive treatments, but her cancer developed fast and her condition deteriorated. She spent the last two months of her life in the hospital's "colored" ward, and died at the age of thirty-one.

Day and Henrietta had five children together: Lawrence, Elsie, David "Sonny" Jr., Deborah, and Joseph (later converted to Islam during incarceration and changed his name to Zakariyya). After Henrietta passed away, her younger children were poorly cared for, until the eldest brother, Lawrence and his wife started to take care of them.
They did not learn about HeLa cells until 1976. The fact that their mother's cells continued to live and were making millions of dollars astonished and upset them. Without adequate background knowledge, the idea of immortal cells brought worries about Henrietta being cloned by scientists, or suffering internal pain in the afterlife. This particularly became a source of agony for Henrietta's daughter, Deborah. On the other hand, Henrietta’s sons were angry when they learned that people were making money out of Henrietta’s cells, yet her family was too poor to afford health insurance. However, the Lacks family sees Henrietta’s cells as a miracle, and they are “very glad that her cells are out there and being used in the way that they are.”

**Theme Two: HeLa Cells and the Modern Medical Science**

Derived from the cervical cancer cells taken from Henrietta Lacks and propagated by Dr George Gey, HeLa cell line was the first human cell line to prove successful in vitro, and is the oldest and most commonly used human cell line. Unlike other human cells that soon died in the lab environment, HeLa cells was found to be remarkably durable and prolific. In other words, they can divide an unlimited number of times in a laboratory cell culture plate, and are thus termed "immortal."

Dr Gey freely gave the cells to any scientist requesting them for the benefit of science. At that time, permission from the cell donor or his/her family was neither required nor customarily sought. The cells were later commercialized and became instrumental in countless medical research. For example, HeLa cells were used to test the first polio vaccine in the 1950s. Since then, HeLa cells have been used for "research into cancer, AIDS, the effects of radiation and toxic substances, gene mapping, and many other scientific pursuits". By 2009, "more than 60,000 scientific
articles had been published about research done on HeLa." (Skloot, 2010) The cells have been shot into space, as well as into the arms of prisoners in early experiment.

On the other hand, because of their prolificacy, HeLa cells have also become a persistent laboratory "weed" that contaminates other cell cultures, and led to many invalid biological research. It has been estimated that 10% to 20% of \textit{in vitro} cell lines are contaminated with HeLa cells. In the book \textit{A Conspiracy of Cells}, science writer Michael Gold wrote about the HeLa cell contamination problem, and stated that this problem almost led to a Cold War incident.

\textbf{Theme Three: Racial Equity in Medicine}

In Henrietta's time, the racial inequity and segregation existed in the medical field, just as in the other public sectors. African-American patients, doctors and nurses were typically restricted to providing and receiving medical treatment in separate hospitals. When Henrietta felt sick, Johns Hopkins was her only choice for a hospital, since it was the only one in proximity that treated black patients. Even in the hospital, Henrietta needed to go to separate waiting room and wards for the colored people. Another story involved Henrietta's first daughter, Elsie, who was considered "deaf and dumb" and sent to the Hospital for the Negro Insane and died there at the age of sixteen. Deborah Lacks and Rebecca Skloot found out later that the conditions in the hospital in the 1950s were abysmal, and the cause of Elsie's death remained unknown.

Even when the more explicit form of racial inequity is absent, racial issues linger. Henrietta's children dropped out of school, lived in poverty, and could not afford quality medical care. In the story of HeLa, the doctors refrained from telling the family any detailed information on how they were using HeLa cells. The racial issues
in medicine today involve equitable access to both quality care and medical information. Whereas educated medical professions have obligations in properly informing their patients, minority (including African American) communities also need to educate and inform themselves, obtain higher level of science literacy, and strive for racial equity.

**Activities**

1. Critical reading and discussion.

   a. Learning objectives:

      i. The students will read Skloot’s *The Immortal Life of Henrietta Lacks*.

      ii. The students will be able to recognize, critically analyze, and discuss key themes presented in the text (e.g., treatment of poor and/or African-American patients, ethical dilemmas in medicine, and the role of family in African-American culture, etc.)

   b. Group size: Whole class

   c. Description: This activity focuses on the importance of Skloot’s text, and the various themes found within. Students, particularly at a high school level, must be able to recognize and analyze written materials and effectively communicate both surface- and deeper-level meanings. As this text covers such a broad range of areas—such as race, culture, ethics, medicine, and history—it should stimulate students’ minds and passions. As respecting all peoples’ voices are important, critical and respectful listening practices are to be observed. Ideally, the teacher should act as a discussion facilitator, and the
students should be primarily responsible for keeping the discussion lively. However, if the classroom behavior is acceptable, a student may volunteer to lead the discussion and act as facilitator.

d. Evaluation:

i. The students’ discussions will be evaluated for accuracy of representation of the text, demonstration depth of thought, and respectfulness of the discussion process.

ii. Students will be evaluated on whether or not they actively participate in the discussions.

iii. Students will write a half-page exit slip discussing something they found intriguing from the either the day’s reading or discussion.

iv. Bonus points may be given for students who volunteer to facilitate the discussion.

2. Independent exploration and presentation on interesting topics.

a. Learning objective:

i. The student will be able to independently select and explore topics related to classroom discussions.

ii. The student will be able to synthesize information from the text and their exploration to create a brief report on their chosen subject.

iii. The student will be able to provide a brief presentation of their findings to the class.

b. Group size: Individual

c. Description: In this activity students will have to select and explore a topic
related to African-American culture or the community. The students will have
to discuss their topic choice with the teacher prior to beginning research. They
will then have to write a brief report on the importance of their topic, why it
was chosen, and their findings. Appropriate formatting is expected. Finally, the
students will have to present their findings to the class. While typical
presentation styles such as PowerPoint are acceptable, students will be highly
encouraged to present in a manner that reflects their creativity and the history
of the African-American culture (e.g., poetry, performance, song, or short
documentary). Students will be given rubrics of how both the written report
and classroom presentation will be evaluated at the beginning of the activity.

d. Sample topics include: Exploration of the stories and histories of an African
American family (or community); the importance of African Americans in
medicine as doctors, researchers, or patients; etc.

e. Evaluation:

i. The written report will be evaluated on appropriate formatting and length,
   proper spelling and grammar, and most importantly the accuracy and
discussion of the selected topic

ii. The classroom presentation will be evaluated on creativity, clarity of
   information, and whether or not the allotted time limit was respected.


a. Learning objective: The students will be able to analyze and debate about
   important ethical, cultural, or historical topics.

b. Group size: Pairs of small groups (2-3 students per group)
c. Description: In this activity, students will be asked to debate important topics with their peers. Skloot’s text raises many important debate topics, and presumably the presentations given in the activity above will raise more. The class will select several topics for debate and be sorted into small teams of two or three people. They will have some time to prepare and explore their topic and their side of the debate. During the debate, the teacher will moderate, but the students will decide which argument is more persuasive.

d. Sample debate topics: Ethics of informed consent. Do my skin cells really belong to me? Alternative viewpoints on medical treatment: superstitious or cultural?

e. Evaluation: The students will be evaluated on their participation and enthusiasm for the debate, their respectfulness of their peers, and whether or not they used their exploration and debate time well. Some bonus points may be given to each team that the class decided had the more persuasive argument and to the best individual debater.

Bibliography

Books and Articles


Skloot, R. The Immortal Life of Henrietta Lacks: Homepage. (Internet resources)

http://rebeccaskloot.com/the-immortal-life/

Skloot, R. The Immortal Life of Henrietta Lacks: A Reader’s Guide. (Internet resources)


http://www.jhu.edu/~jhumag/0400web/01.html


**Documentaries, Videos, Songs, TV shows**


http://thoughtmaybe.com/video/the-way-of-all-flesh

Helen Lane (song by Mal Webb) song: http://www.youtube.com/watch?v=s-Bb4dmpKeE

lyrics: http://malwebb.customer.netspace.net.au/hela.html


Henrietta Lack - CBS Sunday Morning:  http://www.youtube.com/watch?v=wRrNjHYxP_o

A Conversation with Rebecca Skloot

http://www.youtube.com/watch?v=4AuOWSozdcA&feature=fvwrel

Henrietta Lacks Family:  http://www.youtube.com/watch?v=rllNobLQvlg

Panel Discussion: The Life and Legacy of Henrietta Lacks

http://www.youtube.com/watch?v=ODMOkNbkCXw
**Websites**


African American Medical Pioneers: [http://www.pbs.org/wgbh/amex/partners/early/e_pioneers_txt.html](http://www.pbs.org/wgbh/amex/partners/early/e_pioneers_txt.html)


Office of Responsible Research Practices (the Ohio State University): [http://orrp.osu.edu/](http://orrp.osu.edu/)

**News Reports**

