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Learning Activity 1: Alternative Narratives for Henrietta Lacks and HeLa HeLa Cells & HPV Genes: Immortality & Cancer Module

by Katayoun Chamany Updated July 2017

With new advances in biomedical and genomic research, an interesting confluence of ethical controversies has emerged involving privacy, ownership, control, and compensation. As human tissue and DNA are being collected and mined for data, new paradigms are needed to address the patenting and commercialization of products derived from these sources. The development of preventions and treatments for disease and disability has also created a market where human tissues and their derivative products are viewed as commodities within a culture of altruistic donation. An analysis of the establishment of the first human cells in culture, HeLa cells, can be instructive in understanding these shifts in biomedical research and biospecimen acquisition.

The following articles, video clips, film, and artwork offer a glimpse of the alternative narratives of the establishment of the HeLa cell line and the future of biomedical research. The Learning Activity moves through the issues in three part:

Part I: Recognition and Responsibility Readings Part II: Consent and Contamination Readings Part III:Mixed Media--Speaking For Those Whose Voices Have Been Silenced

Some of the questions this activity addresses are

- Who was Henrietta Lacks?
- What is unique about Henrietta Lacks' cells?
- Why was the HeLa line established?
- What research questions were biomedical researchers asking at that time?
- What were the leading causes of disability, disease, and death at that time?
- How did scientists test their hypotheses and establish the growth of a human cell outside the body?
- What do "gift" and "contamination" mean in these various narratives?
- Who are the people responsible for this cell line?
- How do cells move from the clinic or hospital, to the lab, and eventually into markets?

At the completion of this activity you will be able to:

- · Have an appreciation for the intersection of basic scientific research and clinical medicine
- Provide biological and social reasoning to explain why Henrietta's cells were able to be cultured in vitro
- · Pose questions about how genes and environment can influence cell division and "immortality"
- Explain how and why cell lines are used in biomedical research and list their limitations
- Offer more than one narrative for the establishment of the first human cell line
- Provide evidence for opposing views on privacy, compensation, and ownership of human biospecimens
- Recognize the influence that advances in basic science, medicine, business, human rights, and politics can have on one another.

For Part I, II, and III address these questions to prepare for class discussion

- 1. What kind of document, product, or publication is this?
- 2. When was this published or showcased and where?
- 3. Who is the author/creator? What is their bias?
- 4. Who is the audience? What is its purpose?
- 5. What narrative or story is being told and to whom?
- 6. What issues are being raised?
- 7. What is most striking about this resource?
- 8. What questions does it prompt you to ask?

Part I Reading and Discussion: Recognition and Responsibility Readings

You may be assigned to read all four references below, or your class may be split in half, and those with a last name beginning with A-M will read the even-numbered resources and those with last names beginning with N- Z will read the odd-numbered resources. Read the resources assigned and generate a list of comments and questions for discussion.

- 1. Ehrlich, R. June 4,1997. In Memory of Henrietta Lacks. Congressional Record.143(75):E1109. Link
- Perriello T. May 28, 2010. Honoring Henrietta Pleasant-Lacks. Congressional Record. 156(83):E1008-1009. Link
- ErinC. Jan 30, 2009. The Story of Henrietta Lacks: A Lesson in Biology and Ethics. Spittoon. 23andme blog. Link
- 4. McLellan, D. Oct 13, 2001. John Moore; 56; Sued to Share Profits From His Cells. *Los Angeles Times.* Link

Part II In-Class Reading and Discussion: Consent and Contamination Readings

You may be assigned to read all the references below, or your class may be split in half, and those with a last name beginning with A-M will read the even-numbered resources and those with last names beginning with N- Z will read the odd-numbered resources. The last two references relate the HeLa cell line history to contemporary challenges regarding cell research and stem cell derivations. Read the assigned resources and generate comments and questions for discussion.

- 5. Katsnelson, A. June 2010. Biologists tackle cell's identity crisis. Nature. 465:537. Link
- 6. Culliton, B. J. 1974. HeLa cells: Contaminating cultures around the world. Science. 184:1058-1059. Link
- 7. Zimmer, C. August 8, 2013. A Family Consents to Medical Gift, 62 Years Later. *The New York Times Science Blog.* Link
- 8. Hudson, K. and Collins, F. 2013. Biospecimen policy: Family matters. Nature. 500:141-142. Link
- 9. Morrow, J, May 1, 2015. Seeded by weeds. The Scientist. Link
- 10. Anonymous. Sept 23, 2015. STAP revisited. Nature. 525 (7570): 426. Link

Part III Mixed Media: Speaking For Those Whose Voices Have Been Silenced

Review the material below to construct alternative narratives of the establishment of the HeLa cell line and the ways that bodies are used in research. The materials include a range of media and situate cell culture in a wider context of emerging biotechnologies that can result in contributions to the public good (polio vaccine), and the development of bioeconomies where cells are traded or sold to generate lucrative products. In Parts I and II the narratives were told by policy makers and journalists, while here the narratives are the less commonly heard, told by scholars and artists who address inequities with respect to race, class, ability, and gender.

Letter

 Intersectional Retelling: Kumar, R. An Open Letter to Those Colleges and Universities that have Assigned Rebecca Skloot's The Immortal Life of Henrietta Lacks as the "Common" Freshmen Reading for the Class of 2016. Brown Town Magazine. <u>Link</u>. *This call to action was written by a first year writing instructor who urges educators to include alternative narratives in the teaching of the HeLa cell line.*

Videos and Slide Shows

- 2. **Slide Show and Theatrical Reading:** Covert, C., Chamany, K., and Elie, C. 2013. HeLa Cells and Tissue Culture Video. "They Called Me HeLa." <u>Link</u> *This slide show is a theatrical monologue from "Healing" involving a visual narrative of Henrietta's life and the impact of her cells as a research tool.*
- 3. **BBC Film:** Curtis, A. 1997."Modern Times: The Way of All Flesh." Aired on BBC. Modern Times Series, Editor Stephen Lambert. 52 minutes. <u>Link</u> *Documentary based on the history of Henrietta Lacks and the emergence of human cell lines. At position 18:58 min the video begins to discuss the lineage of the HeLa cell line and introduces ideas about race.*
- 4. Video: World Stem Cell Summit Conference. Sugarman, J., Zoloth, L. & Hempel, C. October 4, 2010. The Immortal Life of Henrietta Lacks - lessons for stem cell researchers and patients. World Stem Cell Summit, Pasadena, CA. (Zoloth portion 31-51 min; Hempel portion 51-1:04 min) Link-See Human Subjects and Biomedical Research. Laurie Zoloth, a bioethicist, discusses the HeLa cell line and Jimmy Sarkett's role as an altruistic human incubator in polio vaccine development, while Chris Hempel brings the story into the contemporary arena as a moth of a child with a genetic disorder.
- 5. **Video:** Benjamin, R. Feb 5, 2015. From park bench to lab bench. What kind of future are we designing? TEDxBaltimore. Youtube.(21:25 min) <u>Link</u> *Benjamin introduces three cases, one of which is Henrietta Lacks, to illustrate how biomedical research could be more responsive to community needs.*
- 6. Video Cell Culture: Association of American Medical Colleges. 1956. Living Cells in Culture. The HeLa Cell Strain Cervical Carcinoma. C.M. Pomerat Tissue Culture Laboratory University of Texas, Medical Branch, Galveston. Produces by Eastman, W. S. Reproduced with permission for Radiolab's "Famous Tumors" episode (#704).(10:47 min). Link Methodology of cell culture with embryonic extract via slide and Petri dish preparation. Uses time lapse, magnification of cell growth, identification of chromosomal abnormalities, and discussion of viral research.
- Prezi Presentation on Mental Health and Elsie Lacks: Hendren, K., Keater, E., Parham, L. and Schricker, C. Sept 5, 2012. Elsie Lacks and Crownsville Mental Hospital: An examination of Mental Health Care. <u>Link A comprehensive history of practices related to institutionalization of the "insane.</u>"

Artwork

- 8. **Mixed Media:** Versapaget, C. 2004. The Anarchy Cell Line. Biodifference- The Political Ecology as part of BEAP'04. The Lawrence Wilson Art Gallery. <u>Link</u> *This artist statement questions the idea of human boundaries using a philosophical lens and artistic expression.*
- 9. **Poem:** Davis-Faulkner, S. May 20. 2010. For Elsie Lacks. The Crunk Feminist Collective. <u>Link</u> *Poem depicts the institutionalized life of Elsie, Henrietta Lacks' daughter, who died in Crownville Asylum.*
- 10. **Paintings/ Video:** Wilson-Roe, H. 2013. A Brush With Immortality. *This artist did not obtain funding for this project and is donating all proceeds to the Lacks family who are portrayed in her painting and exhibitions*. Link
- 11. Letters: Johnson, L. Dear Henrietta: Letters to Henrietta Lacks. Play performed by students of the Mount Carmel Christian School Stone Mountain, Georgia. At 4 min students read the letters they created from the perspective of various stakeholders. In part 2, 6:20 min the student playing Henrietta speaks her response. Part 1 Part 2

Radio

12. **Radiolab.** April 18, 2017. Radiolab: Extra Henrietta Lacks. (35 min). <u>Link</u> Mary Kubicek, Howard Jones, Lacks family members, Rebecca Skloot, and others are interviewed. This update reviews the publication of the HeLa cell genome, the resulting backlash, and the assembly of Working Group to control access.

Articles and News

- 13. Feminist Scientist Retelling: Weasel, L. Winter 2004. Feminist Intersections in Science: Race, Gender and Sexuality Through the Microscope. *Hypatia.* 19(1):183-193. Link Weasel has written extensively on cell biology, equity, and values (cloning as well).
- 14. News: Fabregas L. and Balis, J. April 3, 2005. A Lasting Link to Discovery. The Tribune-Review. TribMedia. <u>Link</u> Jimmy Sarkett's role in the development of the polio vaccine which is also reviewed in the Radiolab episode & World Stem Cell Summit Video, but there is an interesting twist.