

Biomedical Experts Respond to “The Immortal Life of Henrietta Lacks” Film

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Rebecca Skloot’s 2010 book, “The Immortal Life of Henrietta Lacks,” tells the story of an African American woman whose cancerous cells are extracted from her without her knowledge or consent during treatment in 1951. When these cells become the source of the immortal HeLa cell line, there are profound consequences for the scientific community, as well as for Lacks’s family. The book received numerous awards, including the National Academies Best Book of the Year, and was a New York Times bestseller.

Earlier this year, HBO released a film of the same name based on the book starring Oprah Winfrey and Rose Byrne. After the movie aired, “AABB News” asked three experts in the biomedical research field how they felt the movie handled complicated ethical issues in human subject research, such as informed consent, patient privacy, and the interplay between researchers and minority patient populations.

Below, these experts offer their perspective on the movie.

How did the movie grapple with ethical issues involved in human subject research?

Holly Fernandez Lynch, JD, MBioethics, executive director of

the Petrie-Flom Center for Health Law Policy, Biotechnology and Bioethics at Harvard Law School in Cambridge, Mass.:



Holly Fernandez Lynch

The movie effectively depicted the history of racism in the United States, which has had serious implications in the context of human subject research. Henrietta Lacks was an African American patient treated in the “colored” ward at Johns Hopkins. However, her cancer treatment appears to have been what any patient would have received at the time, and the same is true about the collection of her cells for research. Her privacy was not adequately protected but the rules around medical privacy have changed a lot since then. Lacks was not told her cells would be used for science. Meanwhile, the health care industry profited from her specimens. The movie showed how exploited and angry her family felt about that, but whether it was wrong is something ethicists are still debating today.

The movie also brought up an important question: To what extent do people identify themselves with their biospecimens? Lacks’s family clearly thought of the cells as “mom’s cells.”

Brent Schacter, MD FRCPC, president of the International Society for Biological and Environmental Repositories (ISBER) and professor at CancerCare Manitoba:

I was disappointed that the movie made no real attempt to illustrate



Brent Schacter

how things have improved since 1951. When the movie talked about informed consent, it was frozen in time. In the 1950s, there were no informed consent regulations in place. A lot of the policies were up to the individual researcher. A lot has changed since then. We have regulations aimed to protect patients, and we have institutional review boards. Of course I understand that the movie is an entertainment piece, but I feel like there was a lost opportunity.

Adriana Brigatti, JD, LLM, MPH, director of compliance special services at Children’s National Health System in Washington, D.C.:

We should remember that Lacks’s physician didn’t behave any differently than another physician at that time. I do think the movie portrayed the mistrust that exists within minority populations very well. You see the



Adriana Brigatti

family hesitant to share their medical records, not trusting of Johns Hopkins. There is a cultural mistrust of researchers that needs

to be acknowledged. The movie showcases the impact of the lack of consent. When it is missing, there is a lot of mistrust and pain.

What do you hope viewers take away from the movie?

Lynch:

I want people to walk away from the movie realizing the value of biomedical research. The montage at beginning was effective in showing many of the scientific advances that stemmed from HeLa cells. I wished there was something similar at the end. I hope people are inspired to donate and support the use of their specimens for scientific research, realizing that it is a low risk to them, with high value to society. I don't want people to walk away thinking that science and medicine are nefarious enterprises.

Schacter:

I hope people understand that the movie was a historical piece. A lot of improvements have been made to protect patients and their privacy. ISBER has standards that protect patient rights' and the ethical use of biospecimens. We have a public education committee focused on emphasizing the societal benefits of this research. And we find that when patients understand the research

and what is being asked of them, the overwhelming majority want to donate their biospecimens.

Brigatti:

The movie was also focused on Rebecca Skloot, the author of the book. Through her research, Skloot humanized Henrietta Lacks and her family. I hope that people recognize the important role of investigative journalism in telling patients' stories. There has been a gap between vulnerable patients and the research community, which has led to generations of mistrust of the medical establishment. In their important work, journalists are showing why this mistrust exists so that we, as a society, can address it.

How can the movie help continue the conversation about biospecimens in research?

Lynch:

I hope the movie can be used as a tool in the clinical setting. Oncologists, for example, could reference it when talking with patients about using samples in research. Not only could this help the research endeavor, it also may allow patients to find some meaning in their illness. They would feel good contributing to a broader social endeavor.

Brigatti:

It is great when movies convey ethical message — they draw in the public much better than any PowerPoint presentation. The film shows that as we continue to perform

biomedical research, we must reach out to minority communities and other vulnerable populations and assure them we are conducting research ethically.

Schacter:

Human subject research will only become more complicated. As new technologies arise, especially in the genetics realm, we have to make sure we continue to respect patients' privacy. We must continue to review ethical practices to ensure we are doing the right thing by our patients. We have to make sure we don't abrogate their trust. ¶¶

