Revisiting HeLa: A Family's Quest for Informed Consent

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https://doi.org/10.7916/vib.v1i.6597

Note: The following excerpt by Obiora N. Anekwe is the extended version of an opinion editorial from the recently published book, Chronicling the Tuskegee Syphilis Study: Essays, Research Writings, Commentaries, and Other Documented Works. The book is now available on Amazon and through the website link: https://www.createspace.com/4460161

Earlier this year, scientists at the European Molecular Biology Laboratory published the genome of a line of HeLa cells, which made it possible for the public to digitally download the information through the internet. 1 The scientists made the genome of Henrietta Lacks available to the public at-large without consent from her family. Eventually, the researchers took down the public data from its website, but their actions call into question a need to reform privacy laws based on the transmission of genome data available through the internet. But more significantly, the researchers' actions also shed light on the issue of informed consent for families such as the Lacks, who were unaware of the laboratory's unethical, but legal means to transmit family genome data.

Henrietta Lacks was stricken with cervical cancer more than 60 years ago. Before her death in 1951, doctors who treated her at Johns Hopkins Hospital in Baltimore, Maryland extracted cells from her tumor without her consent.2 The doctors' cell acquisition procedures were considered legal at the time; but in retrospect, have been rendered unethical. Recently, the National Institutes Health (N.I.H.) announced an agreement with the Lacks family that restricts N.I.H. financed research on the genome of HeLa cells without the explicit consent of two family members on a committee that approves such research.2

An ethical concern with the European Molecular Laboratory's internet publication was the release of full genomic sequence of HeLa that may reveal abnormalities in genes that could be transmitted to later generations. This brings to question whether it is ethical and even legal for families to own their full genome sequence. One disturbing, unresolved issue regarding the N.I.H. agreement with the Lacks family is the fact that non-funded N.I.H. research entities can still publish the full genome sequence of the Lacks family without informed consent.

But more directly, disclosure of the genome line of HeLa cells brings to the forefront a research ethics issue for much debate: Is it ethically permissible for researchers to publish the genome line of HeLa cells without the consent of the Lacks family? I argue that it is ethically impermissible to publish the genome line of HeLa cells without the expressed consent of the family of Henrietta Lacks. Although this research practice is currently legal, it does not erase the fact that it is unethical and goes against everything we know about good science. In releasing the genome line of HeLa cells, the living family members of Henrietta Lacks are directly affected because private genetic information about family members are exposed to the general and scientific community without their consent. As I stated earlier, the release of genome data may also reveal abnormalities in genes that could be transmitted to later generations of the Lacks family. Therefore, I would recommend formulating a type of family consent in which representatives from the Lacks family provide written consent allowing the release of family genome data.

Because issues of privacy are paramount to ethical research practices, researchers should be sensitive to the expressed wishes of the Lacks family and allow them to play a role in deciding whether genetic data about the family should be released. Some critics may argue that the scientific community does not legally need permission from the Lacks family to release the genome line of HeLa cells. I agreed. But I contend that although scientists may not currently need legal permission from the Lacks family to release the genome data, it does not make such practices ethical. The scientific community should be held to a higher standard of research practice. If the release of genome data of HeLa cells is released through the internet, private data that affects living family members could be compromised, manipulated, or even destroyed if the wrong parties have access to this information.

The policy efforts by the N.I.H. are progressive, but unfortunately, fail to address the fact that other research entities can release sensitive genome information about the Lacks family. Comprehensive informed consent policies need to be introduced in order to address contemporary privacy challenges such as internet mass deliveries of family genome sequence data. John Hopkins Hospital, which treated Henrietta Lacks for cervical cancer and where doctors extracted her cells for research, should issue an institutional apology for their role in unethical research. To date, John Hopkins Hospital has yet to issue such an apology, which in my opinion, brings further shame to the institution and leaves the Lacks family devoid of healing. Although the N.I.H. policy reform concerning family genome restrictions does not address all the ethical and reconciliation attributes of family healing, it is a start. At least now, the Lacks family has a much deserved seat at the table of science.

On a more personal note, a few years ago I had the opportunity of attending an exhibition about the HeLa Experiment and the Tuskegee Syphilis Study at the Legacy Museum of Tuskegee University. At the time, I was a faculty member at Tuskegee University who also taught first-students in orientation about the Tuskegee Syphilis Study. One of the correlations I taught my students was that both Henrietta Lacks and the men involved as research subjects in the syphilis study were from a social segment of working farmers who knew little about the nuances of science and medicine. They saw medical doctors as people who would help, not hurt them. So, they trusted whatever their doctors said and did. It has been the belief that doctors involved in extracting HeLa cells and misleading the syphilis study participants believed that their medical actions were contributing to unknown scientific discoveries. But I have long held the belief that these doctors took advantage of people like Henrietta Lacks because of a lack of knowing physicians' true medical intentions. Much of what occurred to these two research populations has more to do with health and educational disparities than anything else. It is shameful that in an age of healthcare where Henrietta Lacks contributed so much to science and medicine, many of her family members still do not have basic healthcare coverage.

Needless to say, the younger generation of Lacks have stepped up and reached within themselves to educate other generations about their family saga. During the exhibition I mentioned earlier, I met the grandson of Henrietta Lacks, Ron. He spoke candidly and vividly about how his family, through the Lacks Family HeLa Foundation, has begun to tell the story about his grandmother- not to rewrite history-but to heal as a family and prevent other families from being taken advantage of again. The foundation has become the vehicle and voice for his family to take a stand and help end healthcare and education inequalities. I commend the Lacks family for their diligent efforts and truly believe that healing may finally begin to occur.

Although the scientific community has initiated some corrective measures to rectify past unethical practices concerning HeLa cells such as the N.I.H. policy, I believe that most of the laborious and intensive work has been upon the shoulders of the Lacks family. Policies that prohibit all research entities from publishing the genome sequence of HeLa cells without expressed permission from the Lacks family is the least we could do to correct unjust medical practices conducted on Henrietta Lacks. Too many science companies have financially benefitted from using HeLa cells in experiments without financial compensation to the Lacks family. Henrietta Lacks gave so much to scientific discoveries through her unknown extraction of cells. HeLa cells have helped in the discovery of the polio vaccine and many other cures in medicine. Although she could not be helped, so many other lives have been saved by her contributions to science and medicine.

I believe that allowing the Lacks family to help decide how genome data will be used in medical research would be an appropriate start in repairing the visible and invisible damages that have plagued the Lacks family. The release of genome data should be inclusive of family consent from descendants of Henrietta Lacks through an independent committee of researchers, Lacks family members, and informed consent specialists. This independent family consent committee can serve as a model for shared decision making that brings all pertinent voices to the table.

If we, as scientists, reduce ourselves to knowingly going against the expressed wishes of the Lacks family and release genome data to the world without family consent, we are as immoral in our own scientific practices as those who extracted the original cells from Henrietta Lacks. Science is not only a knowledge-based discipline, it is an ethical one. We are held to a higher standard because of the effect we have on human life. Our talents are gifts that bring healing, not further harm to patients. Unlike doctors who acted unethically in the medical treatment of Henrietta Lacks some 60 years ago, we should be courageous enough to act more ethically today. If we fail to do so, then not much in ethical reasoning has changed.

REFERENCE NOTES

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