

Reflection on Henrietta Lacks' Legacy

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Scientific research is a balance between a need to conduct research and to conform to ethical guidelines and principles. There are no absolute norms, values and morals and any ethical issue is bound to differ from one setting to another and along a continuum of place and time. Henrietta Lacks' case is no different in this regard; while we celebrate the contribution of the "HeLa cell" for many scientific breakthroughs, discoveries, innovations and advancements and we celebrate the best time for science yet we are reminded about the deep ethical implication it has on an individual and societies as a whole and that it may have been the worst of times for the Lacks' family [1].

Henrietta Lacks was a beautiful wife and mother from a poor African American background who suffered cervical cancer. She lived in a time when there was no Pap's smear screening program and the diagnostic options were limited. The tissue taken from her cervical cancer is immortal; cells grow continuously and uncontrollably in Petri dish outside her own body almost like a spiritual fulfillment of life after death [2], her cultured cells are used in many laboratory centers to test the polio vaccines, to irradiate it, to bombard it with chemicals and have been studied in space etc.

An extraordinary 50 million metric tons of HeLa cells are used inside the laboratories globally and there has been 70,000 peer reviewed paper that uses the HeLa cell such as studies on poliomyelitis virus which helped in the development of polio vaccine [3], carcinogenesis [4], apoptosis [5] and development of anti-neoplastic drugs [6] and understanding of Parkinson's disease [7] etc. and scientists have ever since tried to discover other cells like HeLa to try to understand the biology of the cancer cell and to determine the effect of drugs on the cells [8].

Was Henrietta Lacks a victim? Of ten times vulnerable groups were used to advance scientific discovery at the cost of their lives while not even considered as equal citizens. One example of such exploitation is the infamous Tuskegee experiment in which the US public health services continued to study for 40 years the natural progress of untreated syphilis among African American men despite the availability of treatment while subjects were suffering from syphilis, spouses were being infected and their offspring contracting congenital syphilis [9].

Similarly the National Institute of Health in US funded the Guatemala study infecting Guatemalan soldiers, prisoners and mental health patients with sexual transmitted disease to track the course of infection. These are instances in history reminding us of injustices to vulnerable groups in the name of science and medicine [9,10]. The issues of Henrietta Lacks being a victim of HeLa cell use is a really complicated matter that puts 60 years or more of research under ethical, legal and moral scrutiny. Briefly, the issues can be reduced into three artificial divisions: The person "Henrietta Lacks" herself, the "HeLa Cells" and "Henrietta Lacks' progeny and family".

According to a physician's record, she was admitted to the John Hopkins University and was provided with the standard treatment for cervical cancer at the time, which included radiation therapy, excisional biopsy and follow up [11]. In fact, John Hopkins hospital was one of the few hospitals that allowed admissions of patients from African-American background. The tumor was advanced despite aggressive

therapy and she died leaving all her young children orphans. Let's remember that Henrietta was a patient not a research subject then.

The second issue is that of the "HeLa" cell. Who should possess the human cells? Or need we ask consent from the person from whom these cells are taken? The ownership of the human cell is problematic and still unresolved once the tissues are removed from the body [12]. Genetic and cell biology research ethicists will need to define and give greater clarity to the ethical guidelines because tissue ownership is contentious issue [13].

At the moment, you can only ask consent to use the human tissue if, prior to the tissue being taken, you already had research in mind. But if excised tissue specimen had been available already and used for other research, individuals have no right over them as confirmed by the California Supreme court decision on Moore's case related to the cell line of hairy cell leukemia [14].

When the HeLa cells were taken from the Henrietta Lacks, there was no informed consent and at the time, Henrietta was not considered an equal citizen. However, it is not clear if research on the cell had been anticipated but what is known is that almost by chance, Henrietta cells unlike other cells start growing and the scientist Dr. George Guy and his team recognized their importance.

In the third issue we see elements of victimization to the Lacks family. The publicizing and linking of the "HeLa" tissue to the mainstream media without the family's consent was a violation of their right, privacy and confidentiality. It has had a psychological and moral effect on the family. And when it was publicized to the media, wrong names were attributed such as Helen Lane or Helen Larson.

A human person was reduced to a mere laboratory item and there was considerable disrespect in the action of scientists at a research laboratory would call the husband Mr. Lack in his old age telling him "we have got your wife, she is alive in the lab". Finally, the commercialization of the HeLa cell while her family are living in poverty and were destitute with a lack of education & healthcare and her children and grandchildren incarcerated in prison are issues that ought not to have happened.

The John Hopkins hospital and the scientist George Guy did distribute the cells freely to other research centers however many research institute and industrial organizations have commercialized the cells and benefitted financially [1].

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What can be done to undo past injustices? The individual Rebecca Skloot has been fascinated since her childhood about the HeLa cell and she made it her mission to tell the story of this great woman and her family. Her first book went far to highlight the ethical issue related to the cell [1]. She founded the Henrietta Lacks foundation and she donates a portion of her book proceeds to the foundation. The Morgan University also posthumously awarded Henrietta Lacks an honorary degree in public service [15].

However, what about the industry that gets richer and fatter with the "HeLa" cells? The government? Research institutions? How do we make sure this unjust does not happen again to vulnerable research participants and how do we ensure compensation is available to research subject participants. A draft guideline has been proposed for compensation of research related injury in India, which has already backfired on the clinical research community [2], but at least it was a good initiative and any financial benefit should be used in developing the infrastructure of the higher education among the vulnerable groups, community and individuals.

How did the "HeLa" cell benefit the Henrietta Lacks family? Not much in terms of their education, healthcare accessibility, employment or finance. In fact the reverse is true they became the spotlight of media sensation and scrutiny about their DNA made them feel like living guinea pigs.

To conclude, it is asserted that science happens while bioethics reflects on possibilities, considers risks & advances in proposals [16]. Thus, there will be myriads of ethical reflection and contemplation on informed consent, privacy & data sharing however the main ethical challenge in the future is how bio-bank research responds to a public perception and attitude to using part of their own tissue. The public interest indicate overwhelming focus on issues related to informed consent, welfare of the vulnerable, and compensation [17].

It seems scientific progress is of least concern to the public. Notwithstanding these problems harmonious balance between ethics and science can be achieved. For instance, the Finns were supportive of setting up of national Biobank as well as public-private partnership, which allowed Finland to enforce the Biobank act last September 2013, allowing researchers to ask for several unspecified future research purposes [18,19].

The debate will continue and there may yet be an opportunity to rebalance the injustice to Henrietta Lacks through future reform.

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