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Informed Consent in Scientific Testing

' Instructor's Name'

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Informed consent is the process of getting the prior consent of the patient, before choices about his/her health care is made. This concept is based on the, rights a patient has on her body, and the ethical duty of the physician to inform the patient about the things happening to her body. The consent might be required both for performing a therapy for the ailment of the patient, or to make them participate in a clinical trial. An informed consent is said to have been obtained from a patient, when she is fully aware of the facts and consequences of the treatment meted out to her body.

Informed consent as a concept originated after the Nuremberg Trials, which took place following the World War II. During the WWII, many Nazi prisoners were used for medical tests, and the results of these experiments left many prisoners, mostly Jews, dead and disfigured. Karl Brandt, a Nazi physician, and 22 others were found guilty of war crimes, for forcefully performing medical tests without subjects' consent, in a trial held at Nuremberg. Most of the accused physicians argued that, their experiments did not vary much from the pre-war experiments, and that there was no separate laws that differentiated legal and illegal testing. Brandt famously said that, " Any personal code of ethics must give way to the total character of the war". Like Brandt, many researchers argue that, for the greater good of humanity, and for immeasurable good that will arise out of it, certain sacrifices are to be made at individual levels. For the last few decades, the concept of informed consent has been central to any discussion concerning medical

ethics. This essay is an attempt to analyze the doctrine of 'informed consent', by exploring the case of Henrietta Lacks and HeLa cells.

Henrietta Lacks was an African American woman, whose cells have contributed immensely to medical science. Henrietta was suffering from cervical cancer, and while undergoing treatment for this ailment, some cells from her body were extracted and used for medical experiments. These cells were named 'HeLa' cells, and they went on to become the source of many important discoveries in the medical field. Many pharmaceutical companies reaped millions of profit from the researches based on these cells, and there are over seventeen thousand patents based on the HeLa cells today.

However, the Lacks family did not get any monetary compensation, and neither did Henrietta, who succumbed to cancer in 1951, or her descendants receive any sort of credit for their role. The consent of Henrietta or her family was not obtained before extracting their tissues for research, and they were not consulted or informed during the experiments. This case raises many serious questions about issues such as, the role of morality in scientific research.

Her story has given birth, to many ethical debates on, property rights of the cells extracted for research purposes, cost vs. benefits of medical progress, and how medical ethics has evolved over the past century. Henrietta's story is not a straightforward one of, Whites exploiting the Blacks, but it is a complex intertwined account of medical ethics, legal issues, class, poverty and race. In the 1950s, the segregated treatment facilities for the Blacks, did not treat them well, and always handled them in a manner inferior to the affluent Whites of that era.

This was not a standalone incident and in 1950s it was a common occurrence, whereby the bodies of Blacks were in a segregated place with little privacy, and thus vulnerable for misuse. While HeLa cells have brought huge fortune to the medical fraternity, some members of the Lacks family were not even able to afford their health insurance payment, and this is the irony that is found throughout the entire story of the Lackses.

Howard Jones, the doctor who treated Lacks and extracted her cells for research once wrote,

“ Hopkins (the hospital in which Lacks got her treatment), with its large indigent black population, has no dearth of clinical material.”

Like most of the doctors of that period, he used patients from public wards for his research purposes and usually without their consent. At this juncture, it is pertinent to also recount the medical contributions done by Dr. Jones. He was not a calculating or a money-minded physician, who extracted cells from Lacks to make profits. In fact he did not patent HeLa cells, but simply passed it on to a fellow researcher to aid his research. Jones also is credited for the first test tube baby and sex reassignment surgery.

Jones extracted two thin slivers of tissue from a dying cancer patient, Henrietta Lacks, and these cells proved to be the main reason behind many medical discoveries. He sent the cells to George Otto Gey, who found that these cells were remarkably durable and were able to divide unlimited times in a laboratory cell culture plate. Gey, realizing the potent of these cells, donated these cells to many researchers with the aim of aiding medical research. Later, the cells which were named HeLa after Henrietta Lacks, made a profound contribution in scientific studies.

The HeLa cells were used by Jonas Salk, to test the polio vaccine developed by him. Since HeLa cells were easily infected by poliomyelitis, they were suited for testing the vaccine, and the National Foundation for Infantile Paralysis found a separate facility to mass produce the HeLa cells. These cells were also the first human cells, to be successfully cloned. After this, the cells have been used for many researches for treating cancer, AIDS, genetic disorder and the like. Skloot in her book says,

" More than 60, 000 scientific articles had been published about research done on HeLa, and that number was increasing steadily at a rate of more than 300 papers each month."

Terry Cooper states that, ethics weighs the adequacy of one's principles and beliefs, and analyzes how they are justified. So, in the concept of bioethics is Gey's act of extracting the Lacks cells justified? As Cooper further elucidates, ethics involves reasoning about causes, implications and consequences, of an act, and the benefits incurred from it to the society. From the discussion above, it is proved beyond doubt that the act of extracting the cells from a dying Lacks have benefited the society in a huge way.

Lacks herself lived for just 31 years, but her cells have lived for 63 years, double her lifetime, and have been the subject of close to 74000 biological studies. They have yielded valid insights into genetics, vaccines and cell biology. Gey distributed HeLa cells to any interested researcher for free, thus confirming that his aim was not financial benefit, but a sincere intention to extend the boundaries of science and medicine. Chi Dang, who is the present vice dean for research in Hopkins University says that, if anybody wanted to make money they would be in private sector and not academic medicine.

Cooper says, " Formal codes of ethics do serve a useful function, but without the support of other techniques involving day-day decision making, they tend to be ineffective." We see that, the physicians and researchers of those days lacked, these basic techniques or norms concerning the decisions they make on human experimentation. During the 1950s it was common for a doctor to use people for medical tests without their consents. The Nuremberg Code was just about published in 1949, and many researchers were yet to adopt it in real time.

Also, though the Nuremberg Code stated that a researcher has to get the consent of a person before involving him in medical experiment, it did not lay down any clear method that would ensure the implementation of the code. In the case of Moore v. Regents of the University of California, Henrietta Lacks issue was brought up, and the Supreme Court ruled that a person's discarded tissue can be used for medical experiments or commercialization, and it is no longer remained their property. However, the Court stated that informed consent laws should be amended, to accommodate a clause, whereby the individuals should be informed about the potential commercial applications their tissues might be used for. The Supreme Court in this case called for a balance between, upholding an individual's right over his body, and the need to encourage scientific innovation that would benefit people. It asked courts and legislators to safeguard an individual's autonomy. In Lacks' case, neither she nor any member of her family was asked for consent, and the law of that time did not require the researcher to do so. The physician, who extracted her cells, did not know at that time that these tissues will be so valuable in future.

Today, the times have evolved, but still bioethics remain a gray area in terms of legality over rights of a tissues extracted for research. Our current medical research system depends on researchers, who conduct research to profit out of it. So commercialization cannot be separated from scientific research. The right to control a person's body disposition is different from right to profit. So when a person submits himself to medical research, he should be careful about what he is agreeing to. Thus, anybody who donates their tissue for medical research has a right to receive compensation.

“ To best examine the ethical dimensions of administration, it is necessary to understand the administrative role as it relates to the social and cultural context”.

In, Lacks' case she was hardly given any information, and this had to with her social and economic background. Skloot delineates in her book, the segregation that was prevalent in the society, by painstakingly explaining how the Hopkins hospital was always filled with black people, who were generally poor and were not able to afford their medical bills.

She adds that, even in the Hopkins hospital there were separate wards for the Blacks and the Whites. Henrietta's plight with her cervical cancer is documented in detail in the book, and given the fact that she herself had five children and had her first child when she was thirteen, portrays her lack of sex education. She led a life of poverty and the doctors that treated her seem to be insensitive to her poverty, and blamed her condition on her non-compliance of the doctors' advice rather than on her lack of material resources. Thus, her background was definitely a bottleneck for the doctor's to get an informed consent.

Deborah, the daughter of Henrietta too lives in a world of poverty. When first told about her mother's cells being alive even after her death, her initial reaction was to worry whether her mother's cells would feel the pain due to the extensive researches carried on them by the researchers. So we see how generations of an African American family, one living during the Jim Crow era and one in the modern era, all suffer from similar evil - lack of education and poverty.

Likewise, even in today's society there are many barriers for obtaining a meaningful informed consent for medical research. So, the researcher obtaining consent from an individual should overcome barriers of language, religion and false expectations, and explain clearly to the subject, what the experiment is and what are the consequences of it. Since informed consent is vital for both scientific progress and human rights protection, it is important to acknowledge and rectify the problems concerning misunderstanding of facts.

The story of Henrietta Lacks is a perfect testimony to the ethical trade off the medical community does in the name of scientific progress. In 2013, years after those tissues were extracted from Henrietta Lacks an agreement has been reached between, the National institute of Health (NIH) and the Lacks family. Today both NIH and the Lacks family jointly control the rights for HeLa cells. Though much snippet information about HeLa cells, are already widely available, and many scientists may use them without the consent of the Lacks family, this development is a small step in the right direction.

As Cooper reiterates, when a decision maker is confronted with a problem he needs to first define his responsibility. In the case of bioethics, the legislators

are faced with the dual responsibility of protecting individual rights and dignity, and empowering scientific advancements. To insure that both these responsibilities are met, administrators should draft laws that actively promote informed consent as an indispensable norm of medical experiments.

Unfortunately, there are many different conceptions about individual autonomy and their ethical implications vary. The point of consent procedures should facilitate the patients and their relatives, to control the amount of information they receive and to back out of a project if the clauses are breached. However, if informed consent laws are amended to take these various perspectives into account, they could ensure that a patient is not coerced or deceived into participating in clinical trials.

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