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The Medical Ethics of HeLa Cells (2020-2021)

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“The Medical Ethics of HeLa Cells” Elizabeth Pratt (research inquiry example)

Questions to Consider For Discussion and Reflection

In this research inquiry, readers are introduced to multiple aspects of a famous medical ethics case in which Henrietta Lacks’ cancer cells were removed and later used for over seven decades of medical research under the name of “HeLa” cells. Pratt’s essay asks us to consider the implications of this breach of ethics. As you read Pratt’s essay, consider:

- The organization of Pratt’s essay moves from issues of medical agency (sovereignty over one’s own body) to financial, legal, and even privacy issues involved in taking tissue without consent. Why do you think Pratt chooses this particular order of ideas? How do you choose the order in which you organize your points and sub-points?
- One of the counterarguments that Pratt presents involves the lack of regulations at the time in which Henrietta Lacks’ tissue was removed and the far-reaching medical benefits that the exploitation of HeLa cells has helped to develop. How does Pratt use these counterarguments effectively to strengthen the ethical argument as opposed to weakening or confusing the stance against appropriation of biospecimens? How could you use counterarguments to acknowledge other viewpoints or complexity within an issue or conversation that you are researching? What should you keep in mind?
- In the conclusion, Pratt identifies the need for further regulations and consideration of medical agency and ethics. How do you see this conversation continuing? What other issues or areas could you see as connected to this main example? How might you keep the idea of a research “conversation” open within your own research inquiry?

The Medical Ethics of HeLa Cells by Elizabeth Pratt

Henrietta Lacks was an African American woman who had cervical cancer. Lacks was receiving treatment at the Johns Hopkins University Hospital where doctors had removed some tissue from her cervix to study it. The doctors and researchers were able to successfully have Henrietta Lacks’ cervix cells become immortal. Having immortal cells in the medical field means that the cells continuously split apart and create new cells. Henrietta Lacks’ immortal cells became known as HeLa cells and have been used to help develop treatments for various cancers and have helped lead the way with various other medical advances. While her cells have helped lead the way in the medical field for decades, there are various issues regarding the ethics behind the use of HeLa cells that have recently come to light. The way that medical professionals are able to take advantage of their patients is unacceptable. In order to prevent the appropriation that occurred with Henrietta Lacks’ cells, new rules and regulations must be put in place in the medical field that deal with the use, storage and extraction of genetic material.

Henrietta Lacks was one of thousands of people to fall victim to the loss of medical agency. Thousands of people around the world are experiencing the same thing that has happened to her; the appropriation of tissue by doctors and researchers. In the article “Bioethics in Popular Science: Evaluating the Media Impact of *The Immortal Life of Henrietta Lacks* On the Biobank

Debate,” Matthew C. Nisbet and Declan Fahy introduce the issue regarding biobanks. Biobanks are storage facilities that contain genetic material that is used in medical research (Nisbet and Fahy 2). In order for biobanks to run efficiently, they require thousands of samples of genetic material and since most people do not know what biobanks are or that biobanks even exist, they do not receive enough samples from patients who willingly allow their genetic material to be stored there (Nisbet and Fahy 2). Unfortunately, a lack of consent from patients does not stop biobanks from storing their genetic material there and using it for further research (Nisbet and Fahy 2). This is allowed because of the lack of enforcement of current regulations that are in place. One of the regulations that currently exists is the Nuremberg Code. As stated by George J. Annas, JD, MPH in the article *Beyond Nazi War Crimes Experiments: The Voluntary Consent Required of The Nuremberg Code at 70,*” the Nuremberg Code states that doctors are required to get “the voluntary, competent, informed, and understanding consent of the human subject” (Annas 42). Without proper enforcement, doctors can do whatever they want, and when it comes to extracting, storing, and using someone’s genetic material, there must be stronger enforcement of these laws in order to protect the patients whose tissue is being used. If doctors are able to extract and use their patients’ tissue without getting consent from or informing their patients, then they are appropriating their patients. The doctors are taking something from someone else and using it as their own and for their own benefit. In the case of Henrietta Lacks, doctors around the world conducted research using her cells for decades without ever having received consent from Henrietta Lacks or the Lacks family.

The impact of the appropriation of the medical agency can affect more than just the patient. The doctors can profit off of the use and appropriation of their patients’ cells and tissues. In the article “Opposed To The Being of Henrietta: Bioslavery, Pop Culture and The Third Life of HeLa Cells,” Marlon Rachquel Moore describes how patients’ or their families cannot profit off of the use of their cells. For example, a man named John Moore had cancer cells from his spleen removed (Moore 1). Moore’s cells had been turned “into a commercial cell line” that was “worth \$3.5 million” (Moore 1). Moore ended up suing both the hospital and his doctor “on the grounds of theft” and bioslavery (Moore 1). Bioslavery occurs when a patients’ cells or tissue are taken from them and they lose control over their biological property. Moore believed that “humans have sovereign rights over our bodies and we are entitled to profits gained from the use of materials excised from our bodies in today's commercial age” (Moore 1). Moore’s argument was simple and sound. People should have the right to collect any revenue that is generated from their personal property, in this case, their cells. Cells are unique to every individual because they contain DNA, which is also unique to every individual. If someone’s specific cells with their DNA are being used to conduct groundbreaking research and is also being used to generate revenue, then the person that the cells came from should also receive some of the revenue. With Henrietta Lacks, she unfortunately died before she could figure out that her cells were being used to conduct research. Moore is not the only person to feel this way. The Lacks family, along with many other doctors and lawyers, feel that patients should have the right to access the revenue generated from their cells.

Many lawyers feel that the medical agencies must change their ways, and fast. In the article “Paying Patients for Their Tissue: The Legacy of Henrietta Lacks,” Robert D. Truog et al. goes into further detail regarding the legal side of tissue removal, specifically addressing who has ownership of that tissue. Many lawyers agree that cells are human property and that cells belong to the person that they came from (Truog 37). Along with the legal rights to their cells, some

lawyers also feel that doctors must also provide “compensation for effort and burden” along with the “rights to revenue streams” to their patients (Truog 38). By giving patients the “rights to revenue streams” to the patients, they can access any money that is made from the use of their cells for research or patents (Truog 38). In order for this to work, doctors must see the “exchange” of tissue as an “economic exchange rather than a gift” (Truog 38). The cells must be considered an economic good that is being sold by the patient, who can also be considered a business, to the doctor, which is considered the buyer (Truog 38). Just like normal businesses, when the owner dies, the remaining relatives of the owner now take possession of the business and can profit from it. The same principle should be applied to the exchange of cells. The cells can be thought of as a successful business and since the cells are continuously being reproduced and used for new research, the revenue that is being created from the cells should be given to the remaining family. Some families, such as the Lacks family, can seriously benefit from the money generated by the cells. The Lacks family have health issues and do not have stable incomes, so being able to receive the revenue generated by the cells can greatly help cover medical bills and help them out financially. In the article “Johns Hopkins Names Building to Honor Henrietta Lacks and Her ‘Immortal’ Cells,” DeNeen L. Brown addresses how the Lacks family is handling the situation regarding the use of HeLa cells and how Johns Hopkins plans to pay homage to Lacks. Lawrence Lacks, Henrietta Lacks’ oldest son, is suing in order to get ownership of the cells and get the right to the money generated by the cells (Brown 1).

Another aspect of the legal debate over human cell usage has to do with the publishing and sequencing of the human genome. In her article titled “The Digital Life of Henrietta Lacks: Reforming the Regulation of Genetic Material,” Kelsey Russo addresses the legal issues surrounding the use of genetic material in research studies and their presence on the internet. Back in 2013, Lacks’ genome was sequenced and published by the European Molecular Biology Laboratory without consent from Lacks’ family (Russo 450). The publication of Lacks’ genome raised some concerns regarding the privacy of her family as well as their assets. The European Molecular Biology Laboratory claimed that none of the information posted would link the Lacks family with Henrietta Lacks’ genome or would put the family in harm (Russo 453). However, this has been proved wrong by various lawyers and scientists (Russo 453). Some say that the online presence of one’s genetic information causes it to be easily accessed by millions which can affect peoples “financial backing or loan approval, education opportunities, or adoption eligibility” (Russo 453). Putting patients’ private genetic information online, even on protected medical websites, is still hazardous. Anyone who wants access to that information can and will find a way to gain access to it. Having access to someone’s genetic information is just like having access to their social security number or bank account information. With access to genetic information, people can now actually steal your identity, the one thing that makes each individual truly unique. Easy access to people’s genetic information can lead to increased exploitation and appropriation of people of color (Russo 453). This means that the information could be used to find correlations between peoples of color and their genetic codes which do not mean anything (Russo 453). The inferior correlations could then be sold to or used by companies who are trying to sell products and target specific groups of people, leading to more stereotypes among different groups. People of color are being taken advantage of constantly and by trying to find correlations based on their genetic information is just another way in which they will be taken advantage of and appropriated.

When it comes to publishing health records online, people can have trouble distinguishing between the various types of information. In the article “I don’t want to be Henrietta Lacks’: Diverse Patient Perspectives On Donating Biospecimens for Precision Medicine Research,” Sandra S.-J. Lee et al. provides an inside view on how the general population views the use of genetic material and also shows their knowledge on the differences between electronic health records and biospecimens. Biospecimens are the physical samples, such as cells, tissue, or urine that are taken from the human body and used for testing. Electronic health records are the way that information about biospecimen testing is stored online and is also where doctors can access patient’s health records. A study to see if people could determine the difference between biospecimen data and EHR data was conducted that involved 20 focus groups filled with people for various walks of life and different racial backgrounds (Lee 1). The study showed that most of the participants could not determine the differences between biospecimen data and EHR data (Lee1). “Some participants identified” various concerns that they had regarding biospecimens (Lee 1). These concerns include “the need for special care and respect for biospecimens due to enduring connections between the body and identity; the potential for unacceptable future research, specifically the prospect of human cloning; heightened privacy risks; and the potential for unjust corporate profiteering” (Lee 1). For those who were able to successfully differentiate between EHR data and biospecimen data, most thought that the consent policy was necessary and they felt that they would not participate in EHR data if they were asked (Lee 1). The participants in this study raised some very important concerns that need to be addressed by the medical agency. For example, the concern regarding the potential of human cloning is a big concern lately. With the production and discovery of more high-tech machinery and the constant advancements in the medical field, the idea of human cloning is becoming more prevalent in our society. If a scientist was able to successfully clone a human cell, then both ethical and appropriation issues would become relevant. By cloning someone’s cell, the person who originally gave up that cell for research is being appropriated, especially if the scientist does not give credit to the owner of the cell. This would constitute as appropriation because the scientist is profiting off of something that does not belong to them and has not given proper credit to the owner. The true owner of the cell can be misrepresented with the cloned cell. Cloning may also start to cause issues when it comes to determining which cell was the original and which was the cloned one.

Some may argue that when Henrietta Lacks’ cells were removed at Johns Hopkins Hospital there were no regulations put in place that required doctors to inform patients about the removal of tissue or to get consent from their patients (Brown 1). Since there were no regulations, some may say that Dr. George Gey, the doctor who removed the cells and used them for research, was not in the wrong when he removed cell tissue from Lacks’ cervix. However, the doctors at Johns Hopkins Hospital are in the wrong for removing Lacks’ cells without her permission because it violates a simple ethical code that everyone should follow, regardless of your job. No one should have something done to them without their consent, especially when it comes to something that has to do with their body. The doctors at Johns Hopkins Hospital who removed cells from Henrietta Lacks and studied them violated Lacks’ body and privacy by doing so. They took something that was uniquely hers and used it for their own benefit as well as the medical fields benefit without ever getting consent from Lacks or her family. According to the National Institute of Health, Lacks’ cells have been used for more than seven decades (*Significant Research Advances Enabled By HeLa Cells*). Her cells have been used to help create the Polio Vaccine, experiments with X-Rays, new cancer treatments, studying how salmonella

affects humans, studying HIV, and many more (*Significant Research Advances By HeLa Cells*). No one wants something done to them without their permission. Rules must be put in place to prevent this from happening again.

Some may also say that since Lacks' cells contributed so much to improved medical treatments, that they consider what happened to her as a necessary evil. While Lacks' cells did vastly improve the medical field and allow for more progressive medicines and treatments, the doctors still broke their ethical codes that they must follow in order to practice medicine. If we consider an accountant who embezzled money in their business to be a criminal, then we should consider doctors who violate their patients' right to consent as criminals. Someone who takes advantage of certain aspects of their job in order to benefit from it should not be able to have that job. The damage that the doctor has caused the Lacks family is far reaching and while the laws did not require consent for patients back when Dr. Gey was practicing, any doctor that does not get consent from their patient before taking cell tissue from them should not be allowed to practice medicine (Brown 1). Dr. Gey and Henrietta Lacks should be used as a learning tool for present and future doctors on what not to do when removing cell tissue from a patient.

Henrietta Lacks had her cancerous cell tissue removed from her body without her permission and scientists have studied her immortal cells for years and have used them to help advance medical research and treatment for various diseases. While her cells have proved to be helpful in the advancements in the medical field, scientists have now aided in the continued appropriation of medical agency, taking advantage of the underprivileged, and have continued to violate ethical codes. In order to prevent the continuation of these, rules must be set in place that all medical professionals must follow. No one should have their cells or genetic material taken from them without their permission. Genetic material must be considered as the property of the individual who provided it. Medical agency must get better and be more aware of its flaws.

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