

The Ethics of the Publication of the HeLa Cell Genome Through a Duty Ethics Lens

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By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Introduction

In 2013, a German research group, the Steinmetz research group, published a scientific journal article containing the full genome sequence of HeLa cells, an immortal cell line that originated from Henrietta Lacks. This publication was met with severe concerns for patient privacy as well as the family's privacy (Callaway, 2013; *NIH, Lacks Family Reach Understanding to Share Genomic Data of HeLa Cells*, 2015). The case of Henrietta Lacks's cells being taken without consent and the publication of this dataset has since been used to bring up issues of privacy and informed consent in clinical research and the publication of genomic databases. However, while there is consensus in academic papers that it was wrong for the research group to publish this data, there was no methodical analysis of why this was (Callaway, 2013). Analysis of the ethics of this case is very important to perform, as it will highlight the specific points at which unethical practices occurred for future researchers to be able to avoid those same mistakes.

Examining this case through a duty ethics lens will provide a methodical way to understand if the research group was morally right or wrong for their actions. Duty ethics establishes the idea that everyone has a duty to uphold certain moral laws, regardless of the situation (van de Poel & Royakkers, 2011). Specifically, I will demonstrate that the Steinmetz research group acted unethically when they published this data due to their violation of a set of moral rules for researchers in their disregard for privacy and lack of respect for the subject and her family and their lack of compliance with the reciprocity principle in duty ethics. These violations are evident when looking at the published journal article and statements made by Steinmetz since the incident.

Background

Henrietta Lacks was an African-American woman who had a very large tumor on her cervix. In 1951, she was treated at Johns Hopkins Hospital, one of the few hospitals that treated African American patients. Her doctor, Dr. George Gey, had been collecting cells from all of his patients and collected Lacks' cells from her biopsy to investigate them in his lab. Gey discovered that Lacks cells had a unique property that made them immortal, that they would not die like cell lines he had collected from other patients. Once he made this discovery, Gey distributed these cells, later nicknamed HeLa cells, to other researchers. HeLa cells have been used in thousands of studies since then and are the most commonly used cell in research (*Morehouse School of Medicine Celebrates the Instrumental Immortal Life of Henrietta Lacks*, n.d.). In 2013, the Steinmetz research team in Germany published a scientific paper that included the full HeLa genome sequence, sparking concern among researchers, bioethicists, and the Lacks family themselves. After some discourse with the family, the Steinmetz team removed their data set from the public. The NIH then worked with the Lacks family to establish a controlled access database where the full genome sequence could be accessed by researchers after going through an approval process, with two members of the Lacks family serving on the board to review proposals (*NIH, Lacks Family Reach Understanding to Share Genomic Data of HeLa Cells*, 2015).

Literature Review

Since the book "*The Immortal Life of Henrietta Lacks*" was published in 2010 and the HeLa cell genome was made public in 2013, there has been extensive discourse on the topic. Conversations range from the collection and use of these cells to how they impact general policy on informed consent (Callaway, 2013). Most scholarly articles that discuss the collection, use,

and publication of HeLa cells and their data choose to use this instance as a reason why policy changes are necessary for biospecimen collection.

In *Lessons from HeLa Cells: The Ethics and Policy of Biospecimens*, Laura Beskow discusses the criticism that the Steinmetz research team faced after publishing the genetic sequence of HeLa cells despite them not breaking any rules or laws for using the cells or publishing the data. Beskow details that at the time of the genomic data publication, the rules on consent would allow for cells collected for clinical purposes to not necessarily require consent to be used for research purposes. She does state, however, that generally, the personal information of the source of biospecimens would not be accessible to the researchers. Beskow uses this to set the scene for her discussion of public opinion on informed consent, noting that in several studies, many prospective participants want to be asked for consent before their biospecimens are used in research. Beskow concludes by discussing that public input is an important tool for developing new policies on informed consent when it comes to biospecimens (Beskow, 2016).

Genomic data-sharing: what will be our legacy? by Callier et al. discusses informed consent specifically in the context of the importance of publishing genomic data for personalized genomic medicine. This article begins by outlining the story of the origins of HeLa cells and the controversy over the publication of its genomic sequence. This article uses this case as an example of what not to do when making genomic data available to the public. The article discusses the major privacy and consent issues that came up in the HeLa cell case. For example, insurance companies could use a subject or a family member's genetic data to determine coverage. Callier et al. mention the possible solution of including clauses in consent forms that warn subjects that they will lose ownership of their samples and that reidentification may occur.

Callier et al. argue that this is not a good enough solution, as there is currently no way for the participant or their family to be fully protected (Callier et al., 2014).

While both of these articles provide important insights into how the HeLa cell case impacts policy and public opinion on informed consent and privacy in medical research, they both claim that what occurred with the Henrietta Lacks biospecimen was unethical without providing evidence other than the general public opinion (Beskow, 2016; Callier et al., 2014). These articles both use the HeLa cell case and turn outwards, whereas this paper will look at the case and turn inward to investigate the ethics of the publication of the HeLa cell genome. This paper will use a duty ethics framework and a set of moral laws to determine if the Steinmetz research group was acting ethically when publishing the HeLa genomic data set.

Conceptual Framework

Duty ethics was developed by Immanuel Kant in Enlightenment era Prussia and was an alternative to utilitarianism, which focused on the consequences of actions and how they affect others. Alternatively, duty ethics focuses on the actions themselves and whether or not they are in agreement with certain moral rules. Kant described one main principle from which all moral rules should be derived, coined the categorical imperative. This imperative states to “act only on that maxim which you can at the same time will that it should become a universal law” (van de Poel & Royakkers, 2011). According to Kant, these moral rules are not dependent on context and should always be followed no matter the situation. If someone were to not always uphold these universal laws, there would be no grounds for others to uphold them in their treatment of each other. If all actions that a person takes do not stray from the set of moral rules, they are acting in goodwill. In an expansion of the categorical imperative, Kant established the reciprocity principle, which was to “act in such a way that you treat humanity, whether in your own person

or in the person of any other, never merely as a means, but always at the same time as an end” (van de Poel & Royakkers, 2011). This principle states that one should not treat others as a means to an end, but should recognize that all humans have intrinsic value and are capable of making their own rational decisions (van de Poel & Royakkers, 2011). These imperatives also imply the equality postulate, prescribing people to treat all others with equal respect and consideration (van de Poel & Royakkers, 2011).

Duty ethics extensively discusses this set of “moral rules” that one has an ethical duty to follow at all times but does not specifically identify what these moral rules are, and discusses that this universal set of moral rules could be derived from the categorical imperative. In this specific case, the moral rules of the researchers who published the HeLa cell genome are unknown. However, in the case of research practices it is extremely important to establish a set of moral rules to make sure researchers stay within the bounds of duty ethics. If all researchers were not always held to specific standards, there would be no way to prevent mistreatment of subjects and misuse of data. The NIH has published “Guiding Principles for Ethical Research,” which I will use as the working “moral rules” for the research group in question. These principles include social and clinical value, scientific validity, fair subject selection, favorable risk-benefit ratio, independent review, informed consent, and respect for potential and enrolled subjects (*Guiding Principles for Ethical Research*, 2015). According to duty ethics, these established moral rules for researchers must be followed strictly and without exception (van de Poel & Royakkers, 2011). It is a very important ethical lens to use especially in research cases, as researchers must be objective and follow specific rules and guidelines.

Using the lens of duty ethics and this code of moral rules, I will investigate whether or not the Steinmetz research team was following the main principles of duty ethics with these

guidelines applied as the moral code when they published the genetic code of HeLa cells. I will do this by looking into the origin of HeLa cells and the effects of this information being released. Through this analysis, I will use duty ethics to determine whether or not it was ethical for the Steinmetz research team to publicize this data.

Analysis

The Steinmetz research team violated duty ethics in publishing the HeLa cell genomic sequence both by violating the reciprocity principle and by breaking certain of the moral rules for researchers: informed consent, and respect for potential and enrolled subjects. Following all of these moral rules and following the main principles of duty ethics is required to be considered as acting in goodwill. In this case, the research team broke the moral rules and the principles of duty ethics, making it impossible for them to have acted in goodwill. Through the duty ethics lens, because the research team did not act in goodwill when publishing the HeLa cell genome, their actions were ethically wrong. In the following paragraphs, each way that the principles of duty ethics were broken by the Steinmetz research team will be outlined.

Moral Rules Violations

The Steinmetz research team violated two of the rules highlighted in the NIH Guiding Principles for Ethical Research. The first rule violated was informed consent. According to these guiding principles, informed consent is based on the following criteria: the individuals are informed of the purpose, methods, risks, and benefits of the research, they understand the information and how it applies to their own situation, and they make a voluntary decision on whether or not to participate (*Guiding Principles for Ethical Research*, 2015). In this case, none of these criteria was followed to obtain consent before data was published. When Henrietta Lacks originally went to Johns Hopkins for the biopsy from which HeLa cells originate, she did

sign a consent form. However, it mentioned nothing about the use of biospecimens for research (Skloot, 2011). The consent form that Lacks filled out read “I hereby give consent to the staff of The Johns Hopkins Hospital to perform any operative procedures and under any anaesthetic either local or general that they may deem necessary in the proper surgical care and treatment of: _____” (Skloot, 2011). The line on the consent form was the space to put her name (Skloot, 2011). As seen in this text, there was no mention of any research, let alone its risks and whether or not she wanted to participate so it was impossible for Lacks to make an informed decision.

Once the significance of HeLa cells was discovered, this doctor continued to use these cells in his own research and distribute HeLa cells to other researchers. This point in time would have been another opportunity to obtain a new consent form. While Henrietta Lacks had already passed away, this consent could have been obtained from her family. Over the next few decades, HeLa cells were utilized in over 80,000 published scientific studies, with the Steinmetz research team being one out of thousands of groups utilizing these cells (*Morehouse School of Medicine Celebrates the Instrumental Immortal Life of Henrietta Lacks*, n.d.). The Steinmetz research team then went on to sequence the HeLa cell genome, with the goal of uncovering unknown data about a very widely used cell line (Landry et al., 2013). This data was then published in 2013 to the public and at no point was consent obtained from the family or from the patient herself (Coghlan, 2013). One of Lacks’ granddaughters said, “It shouldn’t have been published without our consent... That is private family information” (Coghlan, 2013). This shows that the research team did not acquire consent to publish this data. Thus, the Steinmetz research team is guilty of breaking the moral rules for researchers by not obtaining informed consent.

The second moral rule violated was respect for potential and enrolled subjects. The NIH guidelines discuss what this rule means and state that it includes respecting the privacy of

subjects and keeping their private information confidential, respecting their right to change their mind, informing them of new information, monitoring their welfare, and informing them of the results of this research (*Guiding Principles for Ethical Research*, 2015). Because Henrietta Lacks had passed away by the time HeLa cells were being used by the Steinmetz group, I will be considering the Lacks family to be an extension of the subject of the study. This is because the use and publication of HeLa cell data has implications for the entire family, as it can be used to identify genetic traits in family members alive today (Callaway, 2013). The first violation of Henrietta Lacks's privacy occurred in 1971 when a tribute to the doctor who first took her cells identified her as the origin of the cell line. At that point, HeLa cells had already been widely distributed (McCarthy, 2013). The major violation of privacy to be discussed here, however, is the publication of the HeLa cell genomic data by the Steinmetz research group in 2013. In response, the Lacks family reached out to the research group with concerns about this data being so public. After a few months of discourse, Steinmetz and his team removed the genomic data from public access (*NIH, Lacks Family Reach Understanding to Share Genomic Data of HeLa Cells*, 2015).

After the Lacks family reached out to Steinmetz, he said "We were surprised, we did not expect this to happen at all. We wanted to respect the wishes of the family, and we didn't intend to cause them any anxiety by the publication of our research" (Callaway, 2013). While it is clear that Steinmetz did not realize there would be such pushback, he claims that he wanted to respect the wishes of the family. However, as stated before, there was no consent form acquired at any point to be able to determine what the family desired. One of Lacks' granddaughters said, "For more than 60 years our family has been pulled into science without our consent" (McCarthy, 2013). Additionally, whether or not Steinmetz and his team had good intentions when it came to

sharing this data, it still violated the privacy of the family and the original patient. The Steinmetz research team also failed to report the genomic data to the family or subject, which is another hallmark of respect for the potential and enrolled subjects. Rather than communicating with the family that this sequencing was happening and would be published, the Lacks family found out when the rest of the world found out when the journal article with the data was published (Coghlan, 2013). For these reasons, the Steinmetz research team is guilty of further breaking the moral rules of ethical researchers.

According to the principles of duty ethics and the guidelines for research established by the NIH, the Steinmetz research group was unethical in their decision to publish the full HeLa cell genome due to not obtaining informed consent. Some would argue that Steinmetz cannot be held morally responsible for using these cells and publishing data due to the large amount of data on HeLa cells that have already been published. He stated, “If we take our data off it doesn’t change anything. There are more data already out than what we generated in our study” (Callaway, 2013). Steinmetz was referencing the fact that while there had not been a previously published full genomic data set, it could have been fully pieced together from other research articles on HeLa cells. While it may be true that removing this data from the public would not automatically solve the issues of privacy and lack of respect towards Lacks and her family, the duty ethics framework would still call for this data to be removed. This was acknowledged by a spokesperson from the research team's company in a statement made in response to the pushback on the publication of the data which said, “We take their concerns very seriously and have reached out to them with our apologies, and to express our determination to work with them towards an appropriate course of action for handling the availability of this data” (Coghlan, 2013). Despite Steinmetz’s attitude, the company itself recognized this publication as being a

potential violation of privacy. It was willing to correct the issue, meaning they recognized that there was an issue with the publication of this data and that they could be held morally responsible. Additionally, the duty ethics framework being used in this paper would say that any researcher who used and published data with HeLa cells should remove their research from the public until they were following moral rules for ethical research.

Reciprocity Principle

Not only did the Steinmetz research team break the moral rules that guide research, but they also violated the second version of the categorical imperative that states that one should recognize the intrinsic value of all others and treat humans as an end, rather than just a means to an end (van de Poel & Royakkers, 2011). This is seen in the wording of their acknowledgments to Henrietta Lacks in the paper published in 2013 that outlined the HeLa cell genetic sequence. The acknowledgments state that “Henrietta Lacks, and the HeLa cell line that was established from her tumor cells in 1951, have made significant contributions to scientific progress and advances in human health” (Landry et al., 2013). While at first this statement does not seem suspicious, upon closer look it is clear that it only focuses on how these cells from Henrietta Lacks were able to contribute to progress but not on the intrinsic value of the person herself, conflicting with the reciprocity principle. Rather than placing value on Lacks herself, the value is placed on the cells, showing that the Steinmetz research group only values this person for what she was able to provide them.

Furthermore, the abstract of the paper discusses the importance of their work, saying it is to “provide the first detailed account of genomic variants in the HeLa genome, yielding insight into their impact on gene expression and cellular function as well as their origins” (Landry et al., 2013). The abstract then goes on to discuss the importance of these findings in future

experiments that use HeLa cells (Landry et al., 2013). This further goes to show that the Steinmetz research group viewed Henrietta Lacks as a means to an end, as they were not interested in how their data could give insights into the specific clinical case of Lacks, but in why the cells that came from her acted the way they did. Steinmetz's research team was more interested in her cells and what they could do for the future of medical research in general rather than how the genomic data could be used to help members of her family. This attitude is one that conflicts with the main principles of duty ethics, making any actions taken that would further this goal unethical within a duty ethics framework.

Conclusion

Using a duty ethics lens, I have argued that the Steinmetz group's decision to sequence and publish genomic data on HeLa cells was ethically wrong. Although the actual thought process of the Steinmetz research team is unknown, it is possible to uncover the motives behind their actions based on the lack of an informed consent document, Steinmetz's statements on the issue, and the actual wording of the original journal article. These sources all showed that the Steinmetz research team did not consider the privacy, autonomy, and intrinsic value of Henrietta Lacks and her family, making this team unethical in their actions.

The case of Henrietta Lacks should continue to be at the forefront of all researchers' minds as it is an important example that highlights the need for open communication and respect between a researcher and their subjects. While scientific breakthroughs are incredibly important, there are right and wrong ways to go about making them happen. It is important for each researcher to not only abide by FDA regulations and their organization's guidelines on research ethics, but to establish for themselves a set of moral rules to promote integrity, the privacy of subjects, and proper treatment of said subjects.

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