

*Student Ethical Viewpoint Paper*

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## Who Owns My Tissues

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When you go to the doctor for a routine blood test, or when you have an appendectomy, tonsillectomy or any other kind of ectomy for that matter, the stuff you leave behind doesn't always get thrown out. Doctors, hospitals and laboratories keep them. Some get consent with admission forms that say something like, I give my doctor permission to dispose of my tissues or use them in research. Others don't. Some of them don't even know what they are giving consent for and the kind of access the researcher gains with this consent.

John Moore was a man who learned that he had a rare form of Leukemia, and had his cancerous spleen removed. He had to return to UCLA where he was being treated to give tissue and fluid to the lab but decided that he wanted to actually get treated closer to home. The doctor then offered to pay his expenses and would allow for him to stay in a luxury hotel if he decided to continue to come in to give samples. This struck John as weird especially when they had him sign a release form saying "that him nor his heirs would have any right to a cell line developed from his tissues." So John Moore refused to sign the release form and he began to get harassed from the doctor, so he sent it to his lawyers to review. It turns out that the doctor he was seeing at UCLA had developed a cell line from his tissues, Mo, without his consent and without him knowing. So this led to a lawsuit, for property rights over his own biological material. After a long battle, the court ruled against Moore saying that once the cells are removed from your body consent or not they are no longer yours [1].

- Did you ever think that you would ask yourself this question ?
- Do i even hold ownership to my body and what it produces?
- Because if i don't have that? then what do i really have left to call my own?
- We have always thought of it as a birthright .
- I was born with it, I get to keep it.
- But did you know that your tissues that exist outside the body can't be called yours anymore?

One among the judges who was in favour of Moore stated that the court had given scientists and industrialists "the right to exploit a patient's tissue for their sole economic benefit" and has failed to recognize the patient's "property interest in his own body and its products [1].

Recent court decisions could make it more difficult for scientists to individually secure usage rights for research involving the study of human biological materials.

Tissue ownership and informed consent posed a lot of queries regarding the balance of power between the citizen, the government and commercial interest, and human being's perceptions of themselves and their bodies [2-3]

In short,

What it felt like for the men who enforce the law, was that they were in a quicksand and with every new case came the question, exactly what is granted—and to whom it is granted—when a patient signs an informed consent agreement.

A pattern seemed to take form of researchers exploiting a vulnerable population, a population that didn't seem to understand the power of consent and legislation that did not know how to tackle this or create specific boundaries.

A case that is close to my heart, is of Henrietta Lacks.

Ring a bell?

Okay let me try this again.

How about HeLa cells?

From our Ananthanarayan ?

You're probably thinking, do not talk about my arch enemy.

That was the past and we need to move on from such hideous moments.

A small reminder that it is because of these very HeLa cells that India was helped to eradicate polio through polio vaccine.

Henrietta Lacks is a magnificent woman, a kind mother, an understanding wife, and a fun sister who went through life in all its ups and downs and braved through them during a time when people of colour were neglected and treated like animals and that is whom we have reduced to this four letter word HeLa.

Back then John Hopkins was among the very few hospitals that treated people of colour who were also poor [4].

If someone gives you something for free that means they are up to no good.

Henrietta had cervical cancer for which she sought treatment from Hopkins.

A biopsy was taken, except it was not only used for her diagnosis, it was also used for scientific research which by the way was without her consent. During those days "participation" in the research was considered payback for the free services that was provided at this hospital. Information that this vulnerable population of coloured people were not aware of.

She endured excruciating pain. X-rays were performed everyday for a month, burning her skin. Henrietta described the side effects of this treatment as "the blackness be spreading inside her". They placed radium capsules on her tumor located on the cervix to kill the cells, and would do this multiple times [3].

What began as a stage 1 cervical cancer ended in an inoperable tumour. Henrietta's body began to be filled with toxins, as she was slowly dying from the inside out. New tumors grew everyday and she was in excruciating pain, but all they said was that "her cells will become immortal.

Notwithstanding the tremendous accomplishments achieved using the HeLa cell line, the case nevertheless evokes serious ethical issues regarding the consent of patients to having their tissue used for research.

Henrietta Lacks's story has brought public attention to a number of ethical issues in biomedical research, including the role of informed consent, privacy, and commercialization in the collection, use and dissemination of biospecimens.

Many reasons that patients should not be allowed ownership of their tissues for fear of decline in the progress of medical research and that the tissue donor would now begin to demand more shares in all the profits gained.

I believe that all this while, we have been looking at this from the wrong perspective,

Look at it this way,

I get to decide who gets my money after I die, it would not harm me if I died and you gave all my money to someone else. but there's something psychologically beneficial to me as a living person to know I can give my money to whoever I want.

The problem arises when you replace the word money with tissue.

What the Moore case failed to address was this , that those tissues are still yours when attached to your body. If you knew this ahead of time and if your tissues turn out to be valuable, you can control them and play the tissue market as well as any biotech company.

Before I end ,I'd like to tell you about an inspiring man by the name of Ted Slavin, who saw this market coming decades ago.

Slavin was a hemophiliac as a result of which he required multiple transfusion of clotting factors. But the donor blood was not screened for diseases and so Slavin was exposed to hepatitis B virus over and over again.

Upon doing a blood test , it was found that there were extremely high levels of valuable hepatitis B antibodies.

What makes this case special was that his doctor told him about those antibodies, and Slavin realized they were worth a lot of money.

He decided to sell them to laboratories and companies who were helping create the first hepatitis B vaccine.

Slavin wanted money, but more than that, he wanted somebody to cure hepatitis B.

He later on met Baruch Blumberg, a researcher who had won a nobel prize for discovering the hepatitis B antigen and who created the blood test that diagnosed Slavin's disease. Slavin figured that if anybody was going to cure hepatitis B, it would be Blumberg. So he sat down and wrote a letter: Dear Dr. Blumberg, he said, I'd like you to use my tissues to find a cure for hepatitis B. I'll give you all the antibodies you could need. And I'll do it free [2].

That has led to the birth of a vaccine that saved millions of lives and continues to do so.

The difference between Ted Slavin and John Moore wasn't that Slavin owned his tissues and Moore didn't. The difference was information. Someone told Slavin that his tissues were special and that scientists might want them. So, he was able to control his tissues by creating terms before anything left his body. In the end, the question isn't whether people have the ability to control their tissues; it is how much science should be obligated to put them in the position to do so.

### RECOMMENDED READING AND REFERENCES

1. <https://www.nytimes.com/1990/07/10/science/patient-s-right-to-tissue-is-limited.html>
2. <https://www.nytimes.com/2006/04/16/magazine/taking-the-least-of-you.html>
3. The Immortal life of Henrietta Lacks- Rebecca Skloot

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Acknowledgements – Nil

Source of Funding – Nil

Conflict of Interest – Nil