If You Think You Own the Rights to Your Cells, Think Again

A law says any biological materials remaining after diagnostic procedures may be used for research—usually without an individual's consent.

October 12, 2021 By Jeanette L. Pinnace

In 1951, doctors took cervical cancer samples from a Black woman named Henrietta Lacks without her knowledge and made millions of dollars from using her cells in biomedical research. Today, many people consider these tactics unethical. But to be clear, scientists are legally allowed to appropriate remnants of human tissue and cells from patient's medical procedures to use in research, according to a report published on Leaps.org on the anniversary of Lacks's death. Leaps.org is a nonprofit initiative dedicated to public discussion and awareness about science and medicine.

The report cites the case Moore v. Regents of the University of California as having established the legal precedent for the current practice.

The case involved a patient named John Moore who was diagnosed with leukemia in October 1976 and underwent an operation to have his spleen removed—a standard treatment—at UCLA Medical Center. Moore signed a written consent form for the surgery but was unaware that his tissue would be saved and used for research. Even after Moore moved to Seattle, his doctor had him return to Los Angeles multiple times to collect more blood and tissue samples under the guise that it was necessary for his treatment. (It wasn't.)

After Moore learned the truth, he sued for a share of the money earned from his biological specimens. Eventually, in 1990, the California Supreme Court ruled that Moore's cells and tissues ceased belonging to him once they were removed from his body.

Critics of this decision said the ruling paved the way for a sort of "biological slavery" and voiced their concerns about future developments in accepted practices in human research.

This month marked the 70th anniversary of Henrietta Lacks's death. The human cell line—dubbed the immortal HeLa cells—created from her tissues was key in developing vaccines for polio, expanding cancer and AIDS research and creating vaccines for dogs, cats and other animals, among other uses.

The Lacks family, like Moore, received no compensation from the billions generated by the cell line that contributed to these advancements in science and medicine. After all these years, the legacy passed down to Lacks's offspring consisted of just an acknowledgement from the National Institutes of Health of their matriarch's contribution to research and an agreement to pull her cells from the public domain.

"Surviving family members have spoken many times about seeking a share of those profits in the name of social justice; they intend to file lawsuits today. Such cases will succeed or fail on their own merits," wrote Bob Roehr, a biomedical journalist and the author of the story on Leaps.org. "But regardless of their specific outcomes, one can hope that they spark a larger public discussion of the role of patients in the biomedical research enterprise and lead to establishing a legal and financial claim for their contributions toward the next generation of biomedical research."

To learn more about Henrietta Lacks's role in HIV research, read "Bioethical Considerations."

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