Advocacy for Henrietta Lacks and for Family Medicine

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This past May, Morgan State University in Baltimore posthumously awarded an honorary doctorate in public service to Henrietta Lacks, an African American sharecropper who died in 1951. When I heard this, I had tears of happiness as I imagined the pride and also vindication of her living adult children. I feel that I partially know them, as do thousands who have read the compelling biographical, cultural, and medical history, *The Immortal Life of Henrietta Lacks.* Author Rebecca Skloot masterfully weaves the life history of Ms Lacks and her family, with the parallel history of how Ms Lacks’ (HeLa) cells have been the core of much cancer research. Either the biography or the history of science would be fascinating reads alone. With the stories side by side, however, readers cannot separate the cultural, social, and ethical implications from human biomedical research.

Henrietta Lacks, a tobacco farmer from Virginia, moved to Turner Station, MD, with her children to join her husband and other African Americans in steel production. Less than 10 years later, she died at Johns Hopkins University of cervical cancer after several surgeries and early painful cancer treatments, including radium implantation. The head of tissue culture research, Dr George Gey, with his wife Margaret, had spent nearly 3 decades trying to grow malignant cells apart from the host. Since he accepted all samples he could, it was not remarkable that he received Ms Lacks’ cells. What was remarkable was that the HeLa cells grew in culture, doubled every 24 hours, and did not die.

Contacted by the National Foundation for Infantile Paralysis (NFIP), Gey learned that the cells were susceptible to poliovirus. The NFIP chose the Tuskegee Institute to be a distribution center, and the growth and distribution of hundreds of thousands of HeLa cultures each week began in 1952. HeLa cells have been used not only for the polio vaccine but for significant work in AIDS, cancer, and in vitro fertilization. HeLa was used to discover that human cancer cells contain telomerase that explained regeneration, and which describes how HeLa cells outlive and take over so many other cultures. The HeLa cancer cells continue to replicate and remain the most significant strain of cancer cells used in multiple lines of research.

The legal and ethical implications are vast. Federal Policy for the Protection of Human Subjects doesn’t actually govern most tissue research. Informed consent is required if an investigator wants to collect tissue for a specific project. However, most tissue research occurs with tissue stored from past diagnostic procedures and therefore doesn’t require consent. Skloot cites a 1999 Rand report that more than 307 million tissue samples from more than 178 million people are stored in the United States and are available for research.

Meanwhile, back in Turner’s Falls, Henrietta’s widower, Day, worked two jobs while other family helped care for the young children, who were not told how their mother died. The children were abused by a cousin’s wife but eventually lived with their older brother and his wife. The early damage of physical, emotional, and sexual abuse went untreated, and the implications for each of Henrietta’s children are well described throughout the book.

In 1973, at the First International Workshop on Human Genome Mapping, geneticists learned that Henrietta’s family were still patients at Hopkins and that it could be possible to compare their DNA to HeLas and create a
map of Henrietta’s genes. A postdoctoral fellow contacted the family, who later reported that they understood the request as “testing the family to see if they had the cancer that killed their mother.” The mismatch between what the researchers thought they requested and what the family understood is a poignant example of the need for communication clarity and informed consent. It also reflects patterns of longterm discrimination and unequal health care treatment based on race and class.

By the time that Rebecca Skloot tried to contact the family, more than 40 years after the death of Henrietta, her descendents had unsuccesssfully tried to learn the results of their repeat blood tests. They each had unsatisfactory and untrustworthy experiences with the health care system, several had no health insurance, and were furious to learn that their mother’s cells had been used in significant research, with some companies receiving financial gain. The book chronicles Ms Skloot’s patient work to estabilish trust with some members of Ms Lacks family, her attempts to help them understand the portion of science history that is associated with their mother, and her challenge to help others acknowledge Ms Lacks’ contributions.

I thought much about why this book is so popular. People are entranced by the merging of science, stories of real people, concern with social justice, and ethics. Readers have been outraged by some parts of the story, impressed by others, and left with questions with uncertain answers.

I was struck that this merging of science and human life stories also describes family medicine. It may be unusual to pair human conditions and science in a best-selling book, but the intertwined concerns are the daily work in family medicine. Family physicians are witness to the long-term biographies of patients and families. Life histories, science, and ethics must be considered together for effective health care. And, as Henrietta Lacks’ story forcefully presents, science and health care occur in socio-cultural contexts. Family medicine is the specialty where these concerns all come together.

We fortunate teachers of family medicine know that the complex richness of life biographies, exciting advances in science, and unending ethical decisions is what keeps us fascinated and committed to our patients and work. I wonder, however, if this can become such a familiar backdrop of our lives that we don’t make it as visible as we can to our learners or the larger public.

My husband and I have a dear friend, a physician of 30 years, who frequently shares at dinner some fascinating nonmedical aspect of his patients’ lives. He respects HIPPA, of course, but his enthusiasm shows how much he is inspired by a patient’s life experience or quirky hobby. As busy family medicine faculty, do we create similar opportunities to retell and celebrate—or mourn—our patient’s experiences?

Do our students and residents know that we enjoy our work so much that we talk with our families and friends about the ethical decisions we participate in every day? Do we let them know that although we are busy, we are excited by new scientific advances and that we appreciate that we get to read journals and learn new science? Do we share with them how complicated, and therefore how rewarding, it is when we help family members who have strongly differing expectations for the care of their family member? Do we share with learners our strong emotions about how patient care continues to be unjustly impacted by race, ethnicity, or economics?

Learners are not the only ones who need to know about the richness and value of family medicine. Legislation and policy creation often occurs, not because of compelling statistics, but because of compelling personal stories. Family medicine personal stories are among the most compelling of all.

Advocacy for family medicine occurs in our daily interactions with students, residents, and colleagues. We advocate for family medicine when we demonstrate our passion with patients, neighbors, and those in our communities of influence. The long hidden story of Henrietta Lacks honors all the forgotten patients, whose clinical treatments and research participations have advanced medical science. The rich and diverse stories of family medicine must not be hidden, for they too have power to advance our health care system. We in family medicine education have unique opportunities and even responsibilities to ensure that the compelling stories of family medicine are heard.

Reference


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