'Immortal' cells, moral issues

Case of Henrietta Lacks shows need for ethical component in health care reform

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By Ruth R. Faden

Much has been written and discussed recently about Henrietta Lacks, the African American woman from Virginia whose cancer cells, collected for research 60 years ago -- as she was being treated for the cervical cancer that took her life -- inexplicably but astoundingly grew in the laboratory without end. The cells, named HeLa, have contributed to cancer therapies, the polio vaccine and a myriad of other biomedical advances.

Sadly, in 1951, tissue from patients destined exclusively for biomedical research -- and not, for example, to diagnose or treat disease -- was commonly taken without their consent, stored and used by scientists.

Happily, today, consent is regularly obtained to take tissue or other body components for research purposes. But Mrs. Lacks' story has brought new focus to many tough bioethical and public policy questions that persist. Chief among these are: What, exactly, should patients be asked to consent to if the fruits of the research are unpredictable? Should they be compensated if, years or decades later, institutions, scientists or drug companies benefit financially? Should each and every subsequent or conceivable use of human tissue require a separate consent from patients or their families? How do we protect patient privacy in such situations?

As the new book "The Immortal Life of Henrietta Lacks" reminds us, behind every biological sample is a human being. And while Henrietta Lacks died a largely anonymous death 60 years ago, many members of her family still live right here in Baltimore.

What I suspect especially grips many of us about Mrs. Lacks' story, however, is that, although neither the scientists at Johns Hopkins Hospital nor the institution itself benefited in a direct financial way from the development and distribution of Hela (hee lah) cells, they clearly went on to make -- and continue to make -- lots of money for some in the biomedical-industrial complex. At the same time, members of the Lacks family have remained profoundly poor and unable to afford consistent, basic health care over the years.

The contrast is stunning between the well-endowed world of biomedical research and the situation of the Lacks family, and it contributes to our unease about the inequities in our society generally, but especially when it comes to health care.

Even if America developed a system that would guarantee a royalty stream to donors from anything of commercial value derived from their cells or tissues, the only individuals likely to receive significant compensation would be the rare exceptions like Henrietta Lacks -- whose cells were, and still are, singularly potent and useful in biomedical research. Much more often, breakthroughs stem from hundreds or thousands of specimens.

On the other hand, we could have a society in which people freely donate their tissue to research without expectation of compensation because of an understanding that the treatments and cures that result will benefit us all.

That line of thinking holds that when it comes to improving our health by advancing biomedical research, all of us are "in this together" -- and donating our cells, blood or other tissue constitutes an act of communal commitment to the common good. In this scenario, giving samples of our tissue is similar to giving blood and would require only cursory privacy protections and a brief consent process.

Many of us believe strongly that this "common good" approach is the one to strive for.

But it also is clear to us that for it to work, it needs to be fair. And as Henrietta Lacks" story powerfully reminds us, high scientific tides do not raise all boats. In our current system, we capitalize everything and rely on the promise of profits to fuel biomedical innovation. But some of the very scientific advances made possible by HeLa cells quite possibly did not benefit her family members. As with so many others who do not have access to adequate health insurance or medical care, there was no guarantee that their lives would benefit from the medical advances made possible by access to human tissues.

In this way, the Henrietta Lacks story touches the very heart of the current debate over health care reform, and the need for universal coverage and access to care. Her tale, like health care reform and the ethics of biomedical science, is tied up in how the least of us live.

We need a national conversation about more than health care costs and cost shifting. *W*e need one about the ethical foundations of access to care and their relationship to biomedical science -- and what is the right thing to do. It is to be hoped that the newly Presidential Commission for the Study of Bioethical Issues will get that conversation going.

Meanwhile, the saga of Henrietta Lacks tells us that without genuine health care reform, her scientific legacy will forever overshadow her human one.

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