The New York Times

OP-ED CONTRIBUTOR

A Lesson From the Henrietta Lacks Story: Science Needs Your Cells

By Holly Fernandez Lynch and Steven Joffe

April 21, 2017

It's often portrayed as a story of exploitation. In the early 1950s, Henrietta Lacks, a poor, young African-American woman, learned she had terminal cancer. Cells collected from a biopsy of her cancer were cultured without her knowledge or permission to develop a cell line, called HeLa. Over the ensuing decades, research using HeLa cells led to scores of medical advances, saving lives — and making a lot of money for a lot of people, though not for Ms. Lacks's family.

Now enter Oprah. She's the star of HBO's new movie "The Immortal Life of Henrietta Lacks," based on Rebecca Skloot's best-selling book and making its premiere Saturday night.

All of this has gotten people talking about the previously obscure world of research with discarded biospecimens, the parts left over after we undergo surgeries, biopsies and blood tests. Some are calling to change the rules, to require consent from patients before biospecimens are studied or to pay patients if specimens lead to medical advancements down the line. The Obama administration rejected these arguments, and many people are surprised to learn that, so long as information identifying the source of the specimen is removed, what happened to Ms. Lacks can still happen today.

Many aspects of Ms. Lacks's story reflect genuine injustice: the racism that characterized the health care system of her day; the suffering of her young family after her death; their own lack of access to health care. But should we be outraged by what happened to her cells, and could happen to our own?

Actually, no.

First, no one is taking biospecimens from patients' bodies without their permission. Patients have consented to the clinical procedure as important to their medical care. What harm could come from using leftover materials, which would otherwise be thrown away, for research?

Perhaps we should be concerned about risks to a patient's privacy, but that is why we remove the identifying information. Although researchers have shown that it is possible to "de-anonymize" specimens — using clues to link them back to individuals — there have been no reports of anyone doing this for nefarious reasons. And even if there were, the answer would be to sanction the culprit through fines or criminal charges, not to make it harder for researchers to get these samples in the first place.

What is left, then, is our claim to autonomy: Many of us intuitively feel we should be able to control how biospecimens derived from our bodies are used. But leftover biospecimens are just medical waste to most of us, as we lack the expertise to imbue them with scientific value. Nor have we done anything to make them valuable, other than being born with a particular genetic variant or afflicted with a particular malignancy.

This is why calls to pay patients are misplaced. In addition, unlike HeLa, in which one patient's biospecimens led to dramatic advancements, most developments come from studying materials from many patients — each biospecimen contributes only marginally to the result.

These relatively weak claims to control and compensation do not justify the demands more restrictions would place on biospecimen research. Hindering this research is worrisome because its benefits are so great. Among many examples, they include the identification of mutations in tumors (lung, skin and others) that can be targeted with drugs that markedly improve quality of life and survival.

Requiring consent might not seem like a big deal. But it is. Consent might require tracking patients down later, whenever a study is proposed, which can be difficult or impossible. Alternately, it might involve asking patients to agree generally to any future research at the time blood is drawn or a biopsy is taken. Either way, it can be a costly, bureaucratic headache. Which patients said yes, which said no, and to what, exactly?

Some wealthy research institutions have the resources to take on this challenge — and have. But others, especially community hospitals serving poor and minority populations, do not. If consent were required for any biospecimen research to proceed, it is quite likely that specimens collected from these populations would be unavailable for research. And if we exclude some groups from research, the resulting science may fail to provide answers to the health problems they face.

Of course, none of this is to say that patients should be kept in the dark about how biospecimens are used and why they are so important. HBO's movie should prompt education and dialogue on these points. Rather than demanding consent and payment, we should promote biospecimen research, shore up privacy protections and push for universal health care to ensure that the benefits of the research are available to all.

It’s not every day that scientists get Oprah’s help drawing attention to their work. Let’s not squander the opportunity.

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A version of this article appears in print on April 21, 2017, on Page A27 of the New York edition with the headline: Science Needs Your Cells