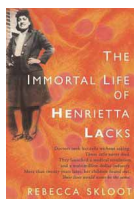


In the Bookstores



The Immortal Life of Henrietta Lacks
by Rebecca Skloot;
Pan Books, 2010.
ISBN: 978-0-330-53344-7.
7.99 GBP. 431 pages.

A personal view incorporating the insights of a UK-based book group

Henrietta Lacks was a 31-year-old African American who died in 1951 from cervical cancer. Her biopsied cancer cells were taken without her permission, propagated seemingly forever after and shared by research laboratories across the world. The resulting immortal HeLa cell line is an integral, multimillion-dollar constituent of the scientific and medical research industry from which Henrietta's family has failed to materially benefit. Her story is rooted in the institutionalised racism of the 1950s and 60s, unthinkable today. Skloot personalises the cell line that so many of us are familiar with, using gritty and sometimes depressing insights into the life of the real person behind it.

I suggested that my book group, based in Newcastle Upon Tyne, UK, read Skloot's book late in 2011. We are an eclectic mix of high-achieving women with a rough balance of arts and science/medicine backgrounds. Our system, by which the member hosting the book club for a given month, chooses the book in advance, ensures endless variety. Meetings can become quite lively as we thrash out often polarised views.

First, it was interesting to observe how the group handled the science. Although written with clarity for intelligent individuals with or without an in-depth understanding of science or medicine, it is clear that a significant proportion of readers, based on our small dip sample, tend to filter out or switch off altogether when science is discussed at more than a fairly basic level.

HeLa, the group universally grasped, led to the birth of virology, but quite why the cell line was so scientifically important was less well understood. In brief, although cancerous, HeLa cells exhibit many of the characteristics of normal healthy cells, communicating with one another, producing proteins, generating energy, dividing, expressing genes,

and exhibiting susceptibility to infection, particularly viral infection. Their immortality, and ability to reproduce aggressively means that once infected they churn out proteins, bacteria, viruses, etc. in copious quantities, and indefinitely. This key scientific information, although well-communicated, evoked a degree of skim reading in some quarters.

The HeLa research phenomenon was better understood. HeLa became general scientific property through uncontrolled sharing between laboratories in the 1950s, and remains a ubiquitous laboratory cell line today. Its early widespread dissemination heralded an exponential increase in cell culture experimentation, and significantly extended the boundaries in protein, hormone, bacterial, and especially viral research. HeLa disproportionately contributed to scientific and medical discovery and innovation – that was undisputed.

Second, we spoke as one regarding Henrietta's treatment by the establishment, and in particular, the ethical issues surrounding privacy and consent, or rather the lack of both. Shocking deficits in both areas in the 1950s meant that informed consent for use of Henrietta's tissue was never sought or obtained, and that her privacy, once the provenance of the HeLa cell line became widely known, was not protected.

A review of the privacy and consenting requirements of today to investigate how Henrietta would have fared on this side of the Atlantic (arguably more relevant to European-based medical writers) in the new millennium is interesting. With specific reference to the UK in 2012, there is little absolute clarity on either matter. The Human Tissue (HT) Act of 2008 resulted in the UK's Human Tissue Authority revising its codes of practice in September 2009 (<http://www.hta.gov.uk/legislation/policiesandcodesofpractice/codesofpractice.cfm/>). These are now codified into UK law. Under the HT Act, 'data about the tissue does not have to be permanently or irrevocably unlinked, and may be pseudonymised where, for example, a system of coding is used'. The HT Act also states that consent from the living is needed for storage and use of tissue research in connection with disorders, or the functioning, of the human body, but tissue may be stored or used without consent, provided the material is used for a specific research project with ethical approval. In addition, consent is not needed for storage and use

of tissue for ‘education or training relating to human health (including training for research into disorders, or the functioning, of the human body)’.

It is clear that loopholes for exploitation exist. It seems that in reality, we may not actually be better off in terms of privacy and consenting today in the UK than in the USA in the 1950s. That revelation came as a shock to the group, who mostly believed we are now part of a more informed and just society.

Third, Henrietta and her family made no monetary gain from the scientific use of her cells. Commercialization of tissue and associated research was and is the inevitable result of our insatiable appetite for new drugs and diagnostic tests. Who should own the tissue once removed from an individual is an indefatigable argument. Material benefit for donors is unlikely to ever happen, despite the huge gains by institutions and companies.

In discussing all these issues, the group clearly read the book on two different levels. The science and medicine easily comprehended by some was

brought to life by Henrietta’s personal story, and complemented by stirring ethical issues. For others, the focus was the tragedy of a strong and much-loved matriarchal woman and her family’s grief and incomprehension at what had unfairly befallen them all. The science for this latter contingent presented something of a distraction!

As a regulatory medical writer, with an audience of industry insiders, medical and scientific experts, this insight serves to remind that occasional forays into writing for a lay audience should be approached with a fresh perspective and great care. The versatile medical writer should never underestimate the breadth of the intended audience!

Editor’s note: The *Immortal Life of Henrietta Lacks* has previously been reviewed from a different perspective by Anne McDonough in *The Write Stuff* 2010;19(3):219–20.

Reviewed by Sam Hamilton
sam@samhamiltonmwservices.co.uk

Are you addicted to busyness?

Busyness is in vogue. Have you ever asked someone to do something and received the reply that they are too busy to entertain the idea, even when you invite them to join you for a social drink? Might you have given such a reply to someone yourself?

Tim Krieder, writing in *The New York Times*¹, has noticed that it is not people who work back-to-back shifts or commute to three minimum-wage jobs by bus who tell you they are busy. They are simply exhausted. Busyness is something else; a boast disguised as a complaint. The people who complain about being too busy are usually those who have brought it upon themselves with extra voluntary work or out of office activities. Busyness is a societal disease which we impose on each other. It is rooted in ambition or a dread of emptiness. We feel guilty

when we are not working or doing something to promote our work. As Krieder nicely remarks, “The Puritans turned work into a virtue, evidently forgetting that God invented it as a punishment”. He thinks life is too short to be busy and should you suffer from this disorder he has some intriguing universal cures, e.g. that work is divorced from income with each citizen receiving a guaranteed wage.

Reference

1. The ‘Busy’ Trap. Krieder T. *The New York Times*. Available at: <http://opinionator.blogs.nytimes.com/2012/06/30/the-busy-trap/>

Elise Langdon-Neuner
editor@emwa.org