



## What Is the Body Worth?

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In 1951, a thirty-year-old woman living in Baltimore was experiencing abnormal bleeding and felt a lump on her cervix. She checked herself into the Johns Hopkins Hospital, where four months earlier she had given birth to her fifth child. The doctor found a tumor the size of a nickel—which was surprising, as it had not been seen in the checkup following her recent delivery. A biopsy confirmed the presence of what turned out to be an unusually aggressive cancer.

The woman returned to begin treatment; with the patient under anesthetic, the doctors cut two tissue samples—one from the tumor, another from her healthy cervical tissue—before inserting pieces of radium in an attempt to shrink the tumor. The samples were passed along to a researcher who was continuing a decades-long, so far unsuccessful scientific effort to keep human tissues alive in culture indefinitely. While the healthy cervical tissue failed to culture, the tumoral

cells began dividing at a remarkable rate—doubling every 24 hours. It soon became clear that the culture was the first line of human cells that could potentially be kept alive forever. By the end of the year, the power of those cells had taken the life of the patient they were taken from.

*The Immortal Life of  
Henrietta Lacks*  
By Rebecca Skloot  
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The woman's name was Henrietta Lacks. She was descended from slaves and raised working the same Virginia tobacco fields they had.

But even as she was being buried in an unmarked grave, her cells were already beginning to transform medical research. Known as HeLa, this cell line was immensely valuable as a readily available, self-sustaining, standardized subject for human cell experimentation. HeLa cells were integral in the development of the polio vaccine, research on cancer and viruses, the sequencing of the human genome, and the development of in vitro fertilization, and were used in early testing of the effects of atomic bombs. These cells from a woman

preceded men into outer space. They are still alive and remain in regular laboratory use worldwide.

But despite the incalculable benefit to science of HeLa cells—and the perhaps more calculable profits reaped by the medical industry from them—not only were the cells taken without the knowledge or consent of Henrietta Lacks or her husband, but her family knew nothing about them until researchers published Lacks's name in a 1973 article, and a family friend who had worked with the cells later put two and two together. Today, the Lacks family still has received no financial compensation, and remains living in poverty in Baltimore and southern Virginia.

A recent book seeks to finally set straight and tell the story of this central, yet unwitting and for years anonymous, figure in medical research. *The Immortal Life of Henrietta Lacks* resulted from a gnawing curiosity by author Rebecca Skloot, beginning when she learned about and experimented upon HeLa cells in the course of pursuing a degree in biology but could find no information about the woman whose cells her professor said “were one of the most important things that happened to medicine in the last hundred years.” Early in her career as a journalist, Skloot spent much of a decade and a great deal of her own money researching the Lacks case, all in pursuit of information from a family that had become hostile toward anyone

inquiring after their mother's cells. The book, a semi-novelistic account of the struggles of Henrietta Lacks, of her children, and in a different sense of Skloot herself in investigating the story and gaining the trust of the Lacks family, is an engaging and sensitive work of reporting that more than vindicates its author's efforts. It has justly become a bestseller, is slated for a film adaptation, and, one hopes, will become required reading for courses in which students begin to think seriously about medicine, bioethics, or the human meaning and social implications of science and technology more generally.

But at least as much as scientific issues, *The Immortal Life of Henrietta Lacks* is a book about race and poverty in America. The injustice of Henrietta's story pales in comparison to the outright atrocity of her daughter's sad tale. Though a happy and strikingly beautiful child, Elsie Lacks was considered by her family to be “deaf and dumb.” In fact, she had epilepsy and an inherited hearing impairment—the latter common in her family—though apparently no effort was ever made to correct the impairment or to teach her sign language. About a year before her mother began treatment for cancer, Elsie was committed to an institution once known as the Hospital for the Negro Insane, with a diagnosis of “idiocy.” This so-called hospital was in truth a dumping ground in which, as the *Baltimore Sun* put it

not long before Elsie's admission, "sex-offenders, ex-prostitutes, epileptics, and idiots are thrown together with young children who are only feeble-minded or mentally retarded." There Elsie lived in wretched conditions, subject to neglect, abuse, and involuntary experimentation. Elsie died a few years later at the age of fifteen, from causes that are left unclear in the book—though she apparently suffered from neurosyphilis and self-induced vomiting, and was quite likely subjected to, among other research, the medically unnecessary experimental testing of pneumoencephalography—a procedure in which a hole is drilled in the skull and the fluid around the brain drained and replaced with gas, so that the brain will show up more clearly on x-rays. The family did not know of these conditions until Skloot uncovered them. And although Henrietta came to visit Elsie every week until she became seriously ill herself, no mention is made of anyone ever visiting Elsie in the four years between Henrietta's death and Elsie's. Aside from the culpability of medical and state authorities, hanging over all of this is the unsettling question of why nobody until Skloot tried to find out what had happened to Elsie.

Henrietta herself was descended not only from slaves but also their white owners, and was raised living in former slave quarters. Many of the descendants of those slaves and owners still live in the same town today as

the former plantation. But the white and black descendants—respectively prosperous and poor—remain segregated and, at least as depicted in the book, do not interact. Moreover, the white Lackses who agreed to be interviewed for the book do not acknowledge their kinship to the black Lackses who live in the other part of their town. Henrietta's direct descendants still live in Baltimore, but fare little better. Like that of Henrietta herself, the stories the book tells of her children and their children consist of a nearly unbroken line of poverty, illness, drug use, crime, and frequent abuse and neglect, all unaltered by Henrietta's odd fame. Opaque though such endemic social dysfunction is, how can one but see the brutal hand of slavery reaching through from the past to tear at the fabric of human lives?

**I**t is the particularly scientific ethical questions of this story, however, that seem to have given fresh life to the more familiar issues it raises, leading to the great public interest in the book—perhaps because issues of scientific ethics seem relatively more tractable. Indeed, while Skloot takes pains to leave final judgment up to the reader, her book is written in such a way as to push us to think about this case in the conventional terms of mainstream bioethics. Its strong implication is that, aside from the broader racial and socioeconomic questions, most of what was wrong in how the

medical field treated Henrietta Lacks and her family could have been averted by properly informing Henrietta and her family of what the doctors were doing, by securing their consent, and by giving them some kind of compensation. If there are tough questions, they are mostly about how these things should have been done and could now be remedied.

Reviews of the book have also largely focused on issues of racism, consent, and compensation. The review in the *New York Times*, for example, sums up the “troubling questions” raised by the book as being “about the way Mrs. Lacks and her family were treated by researchers and about whether patients should control or have financial claims on tissue removed from their bodies.”

That Henrietta Lacks and her family should have been given much more information and asked permission for the sampling and use of her tissue rightly seems inarguable today. And one wishes that, at the very least, the companies that sell HeLa cells would out of decency offer some financial compensation to the Lacks family, perhaps directly tied to ongoing revenues from the cells.

But we should be cautious about extrapolating these sentiments into a broader system. In her closing analysis of the current state of policy regarding human tissue samples, Skloot avers that “the question isn’t *whether* human tissues and tissue research will be commercialized... [but] whether

scientists should be required to tell people their tissues may be used for profit, and where the people who donate those raw materials fit into that marketplace.” Though Skloot stops short of the next step, many scholars and journalists in recent years have begun to advocate explicitly for the obvious extension of this reasoning: not only the granting of property rights to people over their organs and tissues, but the creation of regulated tissue markets where patients or their deceased relatives can become “vendors” of this raw material.

The idea of organ and tissue markets has become increasingly popular because, sobering as the particular story of Henrietta Lacks is, it is but one example of what has become a common practice worldwide of dissecting and harvesting human bodies for useful parts after they have died, often in illegal underground markets. Consider the 2005 case in which the New Jersey-based company Biomedical Tissue Services was found to have paid funeral homes to illegally procure body parts from over a thousand corpses without the consent of the families. As Kerry Howley notes in a 2007 *Reason* magazine article, the media uproar over this scandal concealed the fact that much of the “basic business model was perfectly legal, common, and necessary to the biotech industry.” Howley goes on to describe the firms that “recover” tissues from donated cadavers;

the facilities, often barely more than industrial garages, in which tissue orders are fulfilled, bodies disassembled, and parts distributed; the ends which these tissues meet—from life-saving transplantations, to reconstructive breast surgeries and skin grafts, to being literally ground into pastes used in dental work, lip enhancements, and penis enlargements; the tactics used to pressure families into consenting, while providing them minimal and deceptive information about what will happen with the tissues; and the fact that the families, though consenting, also receive no compensation, while the tissue industry receives revenues of over \$1 billion annually.

And it is not just the dead and their families who are subjected to involuntary and uninformed tissue “donation”—there are other cases, like Henrietta Lacks’s, in which the tissues come from the living. These cases are rampant in the black markets for organs in Third World countries. But even in the United States, where the ban on paid organ donation generally seems to be effectively enforced, there are loopholes, especially when it comes to tissues. To name just one example, the foreskins of circumcised infant boys—sold often without the consent of the parents and, needless to say, always without the consent of the boy—have become a source of cell lines used in an array of reconstructive procedures and cosmetic products, including

certain anti-wrinkle creams. (The most well-known of these creams is a product called SkinMedica that has been repeatedly touted by Oprah Winfrey—who is also coproducing the HBO movie adaptation of *The Immortal Life of Henrietta Lacks*.)

These are unsettling stories calling out for policy remedy. But we should be wary of resting easy that the disquiet we feel at these cases can be entirely reduced to violations of ownership, compensation, and informed consent. A host of difficult questions arises: What precedent is set by considering compensated and informed consent to be sufficient for rendering the “donation” of one’s body tissues ethical? These principles partially underlie the existing standards for unpaid blood and organ donation, and are applied also in clinics that pay people for tissues such as plasma, sperm, and eggs. What is implied by the practice of calling the paid sale of one’s body tissues “donation”? Is the idea that organ and tissue donation is a “gift”—whether or not one receives money for it—something we ought to preserve or abandon?

Skloot makes clear that, under current law, once tissues are taken from a person’s body, they are no longer considered that person’s property—but they can become the property of someone else. Many are seeking to remedy this by changing the law to grant some form of property rights to individuals over those tissues. But what is the meaning of

regarding a person's body, or parts of it, as property? If property rights for a detached portion of one's body can be sold, can the rights to a still-attached portion, or to the whole living body itself, also be sold? If not, why not? If advocates are truly confident in the wisdom of markets and property rights to resolve organ and tissue shortages while protecting "donors," would they fully commit to the logic of market incentives by allowing third-party entrepreneurs to seek out and persuade people to sell these materials, and then resell them to hospitals, medical researchers, or other customers?

**A**lthough Skloot avoids explicitly endorsing any particular policy solution, her book reminds us again and again of one of the most common refrains of those who advocate organ and tissue markets—that tissues are *already* being bought and sold, and everyone is making money off them except for donors. These advocates often argue that, so long as medical safety is not a concern, informed consent by a donor to enter a market and be paid a going rate would be sufficient to render these exchanges ethical. Moreover, with the current chronic shortage of organs, markets would surely be a boon to patients awaiting transplant. And for donors, not only would such markets resolve the unfairness of the current system—in which patients and families are often the only ones who do not make money

from their donations—but they could even be seen as financially empowering those who elect to sell their organs and tissues.

The case is persuasive—but most strongly so, as libertarian prescriptions tend to be, in terms of individuals abstracted from society and history. One way to better understand what is at stake in organ and tissue markets is to ask how they would have altered the case of Henrietta Lacks had they existed at the time she went in for treatment. The unavoidable sense one has in reading about the Lacks case is that she was exploited by a racist medical system; might the injustices of this have been averted by a tissue market?

A central theme of the book and most of the discussions surrounding it is that the exploitation of Henrietta Lacks owes to the fact that researchers used and profited from her body without giving her or her family any compensation. But this is perhaps the biggest misconception about the case—for it can easily escape notice that, in real terms, Henrietta Lacks herself *was* compensated. As Skloot notes, "Many scientists believed that since patients were treated for free in the public wards, it was fair to use them as research subjects as a form of payment." And unlike the subjects in the notorious Tuskegee experiments, Lacks's treatment was not evidently compromised as a result of being a research subject: the book makes clear that

she received excellent (if ultimately futile) care from Johns Hopkins. One might argue that Lacks's compensation was inadequate—but her uninsured treatments for cancer and other ailments had a large market value, while the researchers who sampled her tissue had little prospect of scientific or financial gain. (In fact, the initial researchers themselves did not profit; the money has mostly gone to the biomedical companies that sell HeLa cells.) Lacks's case, then, was already a form of exchange.

Surely the more significant source of injustice in the case of Henrietta Lacks is that she did not consent to or even know about the sampling of her tissue, or to that sampling being the price of her treatment. Though the situation is better for patients today, Skloot's book documents the check-box mentality that many in the medical field still take toward informed consent, which they often see as an impediment to their research. And Kerry Howley's *Reason* article describes in striking detail how existing organ and tissue procurement agencies conceal the unsettling facts about what they do, and employ sophisticated marketing strategies on their websites and literature to manipulate grieving families into consenting to donation. Howley mentions one sociologist who says these companies have "industrialized altruism by turning it into a 'resource-extraction problem.'"

Advocates claim that markets would provide a means for imple-

menting much stronger informed-consent procedures—and, more broadly, that by legitimizing organ and tissue exchange and bringing it out into the open, markets would create transparency in place of the dishonesty inherent in the current system. It is true that markets would at least make plain the currently *de facto* profit motive of the researchers and companies involved in tissue transactions. But those researchers and companies today already have incentives to be transparent and obtain consent, including regulations that are currently in place to enforce those principles. And while those regulations evidently leave plenty of room for the deceptiveness and other abuses that plague the current system, it is the profit motive itself, and not its concealment, that provides the main incentive for such abuse. Stronger regulations and better enforcement seem to be called for; but it is difficult to see how an open market for tissues and organs would in itself reduce the abuses of informed consent and transparency we see today.

What if companies could offer compensation to patients and grieving families in exchange for their consent to organ and tissue donations? Cash payments are not the only option—coverage of medical and funeral costs are among the forms of compensation market proponents have suggested as perhaps more ethically palatable alternatives. But consider that a tissue market based on compensation

via medical treatment would in fact entail exchanges of the same form as the one Henrietta Lacks actually did participate in. There remains the crucial difference that Lacks did not consent to this exchange, but given the informed option—relinquish a small, nonessential piece of her body for research or else refuse the only treatment she could get that might save her life—how much of a choice would she really have had? In point of fact, although members of the black community did not know the full extent of these practices, they were already widely suspicious that the medical community used them as research subjects, which was part of the reason that, as Skloot writes, “[Lacks], like most black patients, only went to Hopkins when she thought she had no choice.”

This context helps to show what is missed in the argument that advocates often make about how organ and tissue markets would be a boon to the poor. Henrietta Lacks was treated in a segregated hospital, by a doctor who once wrote that “Hopkins, with its large indigent black population, had no dearth of clinical material.” The exploitation that statement implies is about something more than patients’ lack of consent or material gain. These are violations that arise from a deeper failure to regard every person as an end rather than a means—and the patient in particular as a subject in need of healing and respect, and

never as a valuable object for use, even for the good of others. A person may still be exploited in a transactional relationship even though she has the choice not to participate in it, and even though participating would provide her material gain.

This point becomes clearer when we consider not only medical care but cash as compensation. Receiving cash for, say, selling one’s kidney would be a means of financial gain for the poor; would it thus be a form of empowerment? If the backwardness of this notion, sometimes suggested by market advocates, is not evident on its face, it should be more so when considered in the context of history. In the case of Henrietta Lacks, she did not just happen to be poor, uneducated, and vulnerable; her plight was historically rooted in a society that once created and later enforced these conditions in order to exploit them. The idea that we should embrace the prospect of poor Americans—including some descendants of those whose bodies were sold against their will—working their way out of poverty by now voluntarily selling parts of their own bodies and the bodies of their deceased relatives is strange and disturbing. The question is one not only of ethical principle or historical injustice, but of the kind of freedom such a society would purport to have secured for its citizens—of how individuals would understand their place and potential in that society in light



of the forms of striving it has made plausibly available to them. What would it mean in such a society to “make something of yourself”?

Regulations for transparency and patient protection in organ and tissue donation could be strengthened with or without the creation of a market. And though we have an obligation to provide medical care to the poorest members of society, we should not accomplish this through a system that could effectively condition that care upon patients’ bodies being used as sources of material for sale. While the inconsistency, unfairness, and deceptiveness of the current system of organ and tissue exchange are wrongs that should be righted, even this flawed current system may be preferable to creating a new one that is consistently, fairly, and transparently unethical. In the market advocates’ refrain of “others profit off of our bodies—why shouldn’t we?,” surely the first part should also be open to question.

Market considerations aside, it is rightly a point of wide agreement among bioethicists and patient advocates that informed consent procedures ought to be strengthened. But it is wrong to think of informed consent as a panacea for bioethical concerns of all sorts—a mistake derived in part from the presumed sufficiency of information in making good decisions. Before turning to the question of how much infor-

mation is necessary for consent to be considered adequately informed, it is worth examining how difficult it can be to obtain information that is even *reliable* about complicated scientific subjects. *The Immortal Life of Henrietta Lacks*, for better or worse, provides an instructive case study—for considering that it is the product of years of research, and has effectively become the canonical public discussion of HeLa cells and the Lacks story, it turns out not to have been as carefully fact-checked as readers might suppose.

Consider one of the pieces of information mentioned early in the book and repeated in the publisher’s description: “If you could pile all HeLa cells ever grown onto a scale, they’d weigh more than 50 million metric tons—as much as a hundred Empire State Buildings.” This claim is so stunning, and seems to so well illustrate the proliferation of Henrietta’s cells outside her body, that it has become one of the stock figures repeated just about everywhere the book has been reviewed or discussed: in the *New York Times* and the *Washington Post*, on ABC and CBS, on the website of Oprah Winfrey, in the *American Journal of Bioethics* and the *Stanford Law Review*, on the educational website Talking Science, and so forth.

The 50-million-ton figure appears in the opening pages of Skloot’s book, along with an estimate that “if you could lay all HeLa cells ever grown end-to-end, they’d wrap around the

Earth at least three times, spanning more than 350 million feet.” But numbers like these don’t give us any sense of the scale on which HeLa cells have actually been used in tangible human activity. Stunning though they are, they are more or less meaningless to anyone who is not accustomed to dealing with figures in terms of millions of feet or metric tons—which is to say, almost everyone. The meaning and effect would be about the same if one said that there have been 50 bazillion tons of HeLa cells; as Skloot herself says in the book and interviews, the number is “inconceivable.” If Henrietta Lacks or some future potential donor were given similar information to weigh before making a decision about giving or selling tissue, it would more likely confuse than help.

More importantly, however, if you try to make sense of these figures you will find that at least one and probably both are obviously false. Consider first the figure about placing all of the cells in a line end-to-end around the Earth, measuring 350 million feet. HeLa cells measure about 20 millionths of a meter across. This works out to about 15,000 cells per foot, so that if you lined up enough cells to extend 350 million feet, you would have around 5 trillion HeLa cells. That may sound impressive, but in fact there are somewhere between 50 and 100 trillion cells in a single adult human body. So the statistic about 350 million feet tells us very little

about how many HeLa cells were made; instead, it just shows us how incredibly minuscule and numerous are the cells in the human body.

Meanwhile, if all the HeLa cells ever produced amount to just a fraction of the number of cells in a single adult body, how can the other statistic—about weighing as much as a hundred Empire State Buildings—possibly be true? That figure of 50 million metric tons is equal to 110 billion pounds, or approximately the mass of a population of one billion people. The two figures, to say the least, do not match: they have the total mass of HeLa cells ever created at variously one-tenth of or one billion times the number of cells in an adult human body—a difference of ten orders of magnitude. While the first figure intuitively sounds too low, the one-billion-people figure breaks the bounds of plausibility: If that amount of living human cells had really been created over the last six decades, they would have required something similar to the amount of nutrients needed to sustain a billion people, meaning that a substantial portion of the global economy would have to be dedicated just to feeding HeLa cells.

In an online Q&A session, Skloot clarified that the wrapped-around-the-Earth figure was now out of date and so likely too small. As for the other, she said, “The 50 million metric tons figure was calculating how many cells could have ever grown,

so it was a forward looking figure when it was calculated.” In response to a second questioner, she firmly stood by the figure, and to a third, she added, confoundingly, “The 50 million metric tons figure is not exaggerated, and the method for calculating it is in the notes section of the book.” Both of these figures remained, with the wording unaltered, in the paperback reprint of the book, published nearly a year after the Q&A session.

Here is what Skloot writes in the book’s notes section:

The estimate of the possible weight of HeLa cells comes from Leonard Hayflick, who calculated the greatest possible weight potential of a normal human cell strain as 20 million metric tons and says HeLa’s potential would be “infinitely greater” since it’s not bound by the Hayflick limit. As Hayflick wrote to me in an e-mail: “If we were to grow HeLa for just 50 population doublings it would yield 50 million metric tons if all the cells were saved. Clearly that is impractical to do.”

It seems from this note that Hayflick was just talking about how HeLa cells, unlike normal cells, have a *theoretically* infinite growth potential. To illustrate this point, he provides an estimate for their unconstrained growth after the occurrence of just 50 population doublings. But this is an estimate neither of how many HeLa cells actually have been grown nor of how many could

have been grown. Hayflick knowingly chose this obviously impossible figure just to illustrate the fact that HeLa cells are limited only by the resources we have to feed and store them. (If Hayflick had gone a little further in his estimate, he could have noted that it would take only about 205 unconstrained population doublings for HeLa cells to consume the mass of the entire universe. And since the cells divide about every 24 hours, they have divided not 50 or 205 but about 22,000 times since the culture was created in 1951. Fortunate for the universe that we don’t save all the cells.) It seems that Skloot misread or misunderstood Hayflick’s e-mail when putting the figure of 50 million metric tons into the text. When challenged, she stuck by her guns. And a wide variety of news and academic outlets repeated the figure without stopping to make sense of or look into it. Some of those sources compounded the error by saying that *more* than this amount of cells had been produced.

These are not the only questionable factual statements in the book. Another widely repeated claim, meant to illustrate the role HeLa cells played in the very beginning of many famous scientific and technological breakthroughs, is that they were sent up on early space missions—a true fact, but one that seems to have been overstated. Skloot writes:

Henrietta’s cells went up in the second satellite ever in orbit,

which was launched by the Russian space program in 1960, and almost immediately afterward, NASA shot several vials of HeLa into space in the Discoverer XVIII satellite.

But the second artificial satellite ever flown in orbit was Sputnik 2 in November 1957 (the month after Sputnik 1), and it did not carry any HeLa cells. This error apparently traces back to a source listed in the book's notes—a 1991 paper which shows the earliest case of HeLa cells being sent into space as a flight called “2nd Soviet Satellite.” But that was just a translation of the *name* of the Soviet flight (Korabl-Sputnik 2); that flight was not actually the second Soviet satellite. By the time of that 1960 flight, scores of previous satellites had been launched by the United States and the Soviet Union.

A few sentences later, Skloot claims that what space researchers found “was disturbing: in mission after mission, noncancerous cells grew normally in orbit, but HeLa became more powerful, dividing faster with each trip.” This suggests that HeLa cells have such great powers they might have become the Blob from Outer Space. Yet the 1991 paper actually shows about as many spaceflights in which HeLa cells were slowed or unchanged in their growth rate as flights in which they grew faster. The paper also shows many cases of *noncancerous* cells that grew faster

in orbit (as well as many where they grew slower). Other sources that Skloot doesn't cite paint a similarly ambiguous picture: a 1964 Soviet paper found that HeLa cells divided more *slowly* with each successive trip, while a 1966 NASA publication claims that U.S. flights showed no significant change.

These may seem nitpicky problems—and indeed, they are in themselves relatively minor flaws in an accomplished work of storytelling and investigative journalism that was clearly researched extensively and, in its most important aspects, in great depth and detail. *The Immortal Life of Henrietta Lacks* rightly deserves to be considered a great achievement of scientific reportage. But the stories behind these figures illustrate how readily scientific-sounding information is simply accepted as authoritative, even as it tends to become progressively more distorted from its original context as it is disseminated in media and subsumed into efforts to construct larger narratives. There is a lesson then in how widely some of this erroneous information has been repeated, without context or doubt—a lesson, as it happens, that matches up with one of the central themes of the book, but that pushes us even further beyond its obvious conclusions.

Aside from policy issues—which are ultimately raised only as questions, and are mostly ancillary to

the main purpose of the book—there are two intertwined conclusions toward which *The Immortal Life of Henrietta Lacks* seems to push us. The most important one is suggested in the book's epigraph by Elie Wiesel: "We must not see *any* person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph." Skloot seems to have set this as her book's goal: to pierce through the abstraction of HeLa cells to the real person behind them—to show us the humanity, in all its anguish and triumph, of Henrietta Lacks and her family, and to offer the same charity and respect in the depictions of the doctors and researchers involved. In this the book succeeds with sensitivity and grace.

A larger point of the book is about the danger of placing too much authority in the hands of doctors and scientists—especially when that means seeing individuals solely under the abstractions of *patient* or *subject*, and so overriding the respect and autonomy they are owed in making decisions about their own bodies. We must be wary, however, of accepting the principle of informed consent as the whole answer to the problem of authority, thereby replacing one abstraction with another. Treating informed consent as an adequate bulwark against ethical violations means treating ethical problems as primarily a matter of who is hold-

ing the information and making the decisions. The "informed consentor" becomes an extension of the "educated consumer." But the principle teaches us nothing about how to regard information properly or use it well. It implies that information is always empowering, and is itself adequate to making good decisions—and so ironically ends up emphasizing information itself over the reflection and wisdom to which information is meant to lead, as if being presented with the bare medical facts will be enough for us to understand our choices and then choose well.

On one hand, this idea may lead to a foolish mistrust of medicine. It can encourage us to simply believe that because doctors do not always completely know best, we instead always do. Doctors are increasingly familiar with the phenomenon of the patient who comes to an appointment and has already researched his ailment on the Internet, made a diagnosis, and will not listen to the doctor's reasons why it might be wrong. And we can see this problem more severely in, for example, the irresponsible and dangerous movement to deny the scientifically uncontroversial consensus that childhood vaccines are safe and effective.

The opposite impulse, however, is already far more entrenched: the failure to challenge and question the information we are given—the information supposed to empower us to make our decisions, even to be

adequate in itself for making decisions. We are trained to accept as gospel whatever comes wrapped in the shiny package of science—no matter who is offering the package, no matter how accurate or comprehensive the information. We may think that the problem with giving undue authority to scientists and doctors is resolved by taking decisions into our own hands; but just as likely it has simply been displaced.

The widely repeated yet obviously wrong statistics in Skloot's book may provide some initial sense of why it is problematic to be inherently trusting rather than skeptical of information simply because it is presented as scientific. In a crucial way, this impulse actually shares something with the refusal to accept the scientific consensus on the safety of vaccines: it comes from the overconfidence in our own ability to know.

The deeper irony of inherently trusting scientific-sounding information is that scientific knowledge is supposed to distinguish itself from other forms of knowledge not only in being empirically based, but more importantly in being verified through rigorous skepticism on the part of scientific inquirers. The biggest virtue of the scientific method is that it pushes us to always question what we are told—not to reflexively resist information, but to look for holes, to test, to seek to understand for ourselves, and not simply to take claims at face value. This skepticism is what

is revolutionary about the Scientific Revolution: unlike many other claims to truth, those of science are not supposed to rest on authority. Yet somehow we have arrived at a cultural moment in which the name of science is routinely invoked to bludgeon people into accepting claims on the force of authority. Is it any surprise that some people, misguided though they are, react to this by reflexively rejecting that authority?

Some scientists are responsible enough to remind us not to simply take their word for what they're saying, and to take questions seriously instead of hiding behind the name of science. But just as often, scientists and scientific popularizers exhort us to just accept scientific authority—and on questions not only scientific but moral. Perversely, it is in part the very skeptical reputation of science that has convinced some that they should accept without skepticism any claims made in the name of science.

**I**n the characters of *The Immortal Life of Henrietta Lacks*, we can see the curious dynamics of scientific trust and mistrust playing out. In fact, aside from the obvious differences of class, wealth, and history, the most striking racial divide in the book is in terms of the relationship to science.

On one side are the book's well-educated, mostly white characters—including seemingly all of the doctors and researchers, as well as Skloot herself—who are versed in

science, and sober when they speak about scientific knowledge and practice. On the other side are the black characters—the Lacks family and its community—who are relatively ignorant about science, and in equal measures awestruck, appreciative, and wary of it, particularly in light of the historical abuses of the black community by medical researchers.

More than wary of science and scientists themselves, though, the black characters are religious and deeply superstitious. For them science is almost a kind of manmade magic, and they regard it with anything but dispassion. Skloot well describes this cultural divide between herself and Henrietta's daughter Deborah:

I tended to leave the room when religion came up in conversation because it made me uncomfortable; Deborah's family tended toward preaching, faith healings, and sometimes voodoo....I was a science journalist who referred to all things supernatural as "woo-woo stuff"; Deborah believed Henrietta's spirit lived on in her cells, controlling the life of anyone who crossed its path.

Skloot makes it her mission to bridge this divide—to be perhaps the first person to treat the Lacks family with enough respect to try to explain the science to them, and to separate the truth from the many bizarre and fantastical ideas they have about what has happened with Henrietta's cells.

This effort on her part is tremendously admirable, and the contrast it provides with the other stories about how doctors and researchers had treated the Lacks family does more than almost anything else in the book to illustrate how disrespectful that treatment had been.

But this effort is not entirely without problems. The book shows how Deborah had heard that her mother's cells had been cloned, and, after viewing science fiction films like *Jurassic Park*, she began to believe that in fact clones of Henrietta herself had been made. "Deborah realized these movies were fiction," Skloot notes, "but for her the line between sci-fi and reality had blurred years earlier, when her father got that first call saying Henrietta's cells were still alive." Skloot repeatedly assures Deborah that Henrietta has not been cloned—and at one point, annoyed, assures Deborah that Henrietta could *never* be cloned. This assurance was quite understandable in the context of the conversation. But the book never returns to the claim, and the notes provide no explanation. Skloot was most likely repeating the assurance a researcher had offered Deborah earlier in the book that Henrietta could not, through cloning, be "brought back to life."

That much is true, beyond a doubt. But as for human cloning, it is in fact far from clear that it is impossible. If it someday does become possible, though there would be additional difficulties for cloning Henrietta from

HeLa cells—since those cells are cancerous and so have any number of grave abnormalities—how much more far-fetched is it that someone might someday attempt to clone Henrietta Lacks from HeLa cells than any of the other once-incredible things that have actually been done to HeLa cells? There seems to be at least one case in which what appears to be Deborah’s paranoia may have been more perceptive and accurate than Skloot’s sobriety.

In a way, this potential factual problem is of much greater moral significance than the ones described above. If the family had been given some choice, in 1951 or later, about what should be done with Lacks’s cells, what would have been the ramifications of scientists mistakenly assuring the family of the impossibility of creating a clone of Lacks—perhaps the most morally fraught thing that could be done with her cells? The trouble of reflexively trusting information presented as scientific is most obvious here, and points us to the truth that it takes knowledge of a different and much more difficult kind than we are likely to be presented on informed-consent forms to gain wisdom about such questions.

A flash of that wisdom is found in the most haunting scene of the book. Lab assistant Mary Kubicek recounts Lacks’s autopsy:

[Kubicek] wanted to run out of the morgue and back to the lab,

but instead, she stared at Henrietta’s arms and legs—anything to avoid looking into her lifeless eyes. Then Mary’s gaze fell on Henrietta’s feet, and she gasped: Henrietta’s toenails were covered in chipped bright red polish.

“When I saw those toenails,” Mary told me years later, “I nearly fainted. I thought, Oh, jeez, she’s a real person. I started imagining her sitting in her bathroom painting those toenails, and it hit me for the first time that those cells we’d been working with all this time and sending all over the world, they came from a live woman. I’d never thought of it that way.”

The problem of abstraction runs deep. The practices of mind that allow for the technical advancement of medical science rely upon and cultivate, perhaps of necessity, a dogged insistence on the denuded nature of the stuff its beneficiaries are made of. How obscured must our vision be when we do not as a matter of course apprehend the person in her most immediate physical form—the body?

Henrietta Lacks, without question, should have been asked for permission for scientists to take, culture, and profit from her cells, and we are rightly indignant that she was not. But what would they have told her to help her make a decision that we could consider adequately informed? They could not have possibly conceived at the time of the things that would be done with her cells. And if they



somehow could have, if they had been able to foresee the future—at least what has come of it so far—at best they could have told her something like the following: Your cells will help defeat polio. Your cells will help sequence the genome and develop treatments for cancer. One rogue researcher will inject your cells into the healthy bodies of other people to see if they will contract the same disease that killed you. (They will.) Millions of people could be saved or helped using therapies created from your cells, and billions of dollars will be made from those treatments and your cells. Your cells will be tinkered with in labs for decades or centuries by tens of thousands of scientists, fused with cells from animals, infected with all manner of diseases. One day men will travel into space, and pieces of you will go with them. And they will be used to test weapons that could destroy the world. Eventually, your cancer cells will multiply outside your body to far exceed the mass of healthy cells in your own living body. The cells that killed you will make you famous and, in a way, immortal. Just maybe, someday, someone might use them to create a younger twin of you.

As they attempt to make sense of the literal and moral meaning of those facts, the book shows Henrietta Lacks's family as fraught with

confusion, turmoil, and false beliefs. This kind of thinking—passionate, superstitious, magical—is anathema to the rational mindset. Yet somehow it is the members of the Lacks family who end up being the most relatable characters in Skloot's book. For something is revealed in their expressions of turmoil that is absent from those in this story who comport themselves with the confidence and dispassion of modern science: something that allows them to come closer than anyone else to really grasping the meaning of this story—or at least to understanding that there is some meaning to be grasped, one not captured in the clinical language of doctors or the formalisms of economists and ethicists.

Beneath the willingness of the family to believe seemingly bizarre tales about what had been done with Henrietta's cells, there lies a better apprehension than the coolly rational have of the strangeness of biotechnical power. And beneath their professions of tormented confusion, there lies that beginning of wisdom so hard now to find in the acolytes of science: they know that they do not know. How, after all, can any of us truly claim to have good and easy answers to questions like these?

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