

The story of the first human cells grown in culture, p 1250

VIEWS & REVIEWS

What happens beneath this World Cup frenzy

PERSONAL VIEW David Barr

When is a disaster not a disaster? In the male medical ward of this ex-mission hospital 400 km north and inland of Durban—right in the heart of Zululand—the answer is easy to find. It is defined by the disaster management posters on the wall: a disaster is a fire, explosion, bomb, war, flood, earthquake, volcanic eruption, tornado, mass food poisoning, hysteria.

More recently these posters have been joined by elaborate swine flu protocols. Strictest standards of barrier nursing and high dependency care are advocated. The hospital management has described swine flu as “a crisis, a disaster.” In total there has been one suspected, unconfirmed, case in these wards.

In contrast here in KwaZulu, as the HIV pandemic has taken off, admissions to medical wards have increased 300% in the last 15 years. Average age of patient, length of stay, and survival to discharge have all plummeted. National life expectancy has fallen from 62 years in 1992 to 50.5 years in 2007. Statistics South Africa indicates that all cause mortality in adults aged 25-49 has increased from 92 829 to 251 067 between 1997 and 2006 (www.statssa.gov.za/publications/P0302/P03022006.pdf). This rise of 170% is similar to the increased mortality seen among young adults in France in the first world war. The Medical Research Council South Africa, the World Health Organization, and the Actuarial Society of South

“This ward is the scene of disaster: an unrelenting daily disaster unparalleled in modern medicine”

Africa all agree that AIDS is killing about 350 000 South Africans annually.

So this ward is the scene of disaster: an unrelenting daily disaster unparalleled in modern medicine. This isn't the only contradiction to be found. Nurses in pristine uniforms diligently record twice daily temperatures on immaculate charts. But none of the thermometers works. A psychotic young man is locked in a cell devoid of windows, lights, bedding, or a toilet. Just out of his line of sight (limited by a 30 cm slit in the iron door) is a bill of patients' rights poster certifying his dignity. Children with marasmus



Villagers living in mud houses next to one of the new stadiums in Nelspruit, February 2009

are lined up in cot spaces of the paediatric ward across the compound. In the other direction is the doctors' accommodation where top of the range BMWs are lined up in parking spaces. This was the scene of a recent illegal strike by doctors demanding more pay; junior doctors in South African district hospitals are paid a similar wage to those in the United Kingdom, but surprisingly they generally work fewer hours.

At times this hospital seems like a facade, a role play with real patients as props, official policy and medical norms reduced to absurdist stage dressing wall posters.

In the nearby town the contradictions continue. Some dilapidated road and shop signs are still in Afrikaans—in a town that is 100% isiZulu speaking—and point to a historical perspective. These signs are drowned out by billboard adverts attempting to tie all kinds of consumer goods to the spectacle of the 2010 FIFA World Cup. Flyers advertise Dr Feelgood's “risk free” abortion service. Most ubiquitous in this trading town, after food staples and cell phone air time stalls, are peddlers of medical mismanagement. Cheek by jowl, traditional healers hawk their muthi, private doctors flog their unnecessary injections.

At the national level are the biggest contradictions. This is an upper middle income country: gross domestic product per capita is about \$10 000 (£6900; €8160), similar to the Republic of Ireland in about 1987. More than half the population, however, live below the poverty income line (for a household of four

this is less than \$160 per month). This income inequality didn't occur by chance. Rather it is the lingering result of deliberate apartheid policies: denial of access to education, regressive taxation, proscription of unions, state control of the job market, undermining of indigenous entrepreneurship and agriculture, and forced labour migration to the gold and diamond mines. These are the same policies that facilitated the tuberculosis and HIV epidemics that cause people to end up in medical wards like this one.

Disasters are easy to spot. Floods, mass food poisoning, and volcanic eruptions are not draped in a poisoned legacy of decolonisation and apartheid. They do not have sinister political, racial, and historical undertones. They are not borne of exploitation and warped psychologies. They can be rationalised in a disaster management poster. They demand only simple, short term, moral, and emotional responses.

None of these criteria is met by the ongoing disaster on this male medical ward. So it's business as usual for Dr Feelgood of Zululand and his peers.

Previous South African leaders have been infamous for their denialist stance on HIV/AIDS. But denial can have many forms. In his book *AIDS and Power: Why There is No Political Crisis—Yet*, Alex de Waal delineates how “higher states of denial” are being employed in the HIV pandemic: “ever-more-complex mechanisms are developed for explaining the unacceptable while maintaining a facade of social and moral normality.” Putting disaster management posters up that deal with volcanic eruptions and swine flu in the midst of a real disaster is maintaining a facade of social and moral (and medical) normality. It is also a form of denial.

As Rudolf Virchow, father of modern pathology, wrote: “It is the curse of humanity that it learns to tolerate even the most horrible situations by habituation, that it forgets the most shameful happenings in the daily shame of events.”

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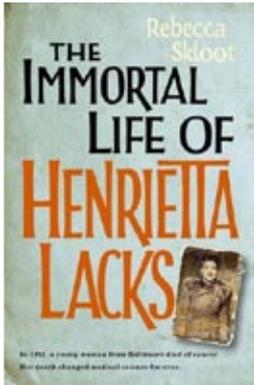
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REVIEW OF THE WEEK

Who owns my cells?

Henrietta Lacks's cells, the first human cells grown in culture, had a great impact on medicine for more than half a century, finds **Janice Hopkins Tanne**



**The Immortal Life of
Henrietta Lacks**

Rebecca Skloot

Macmillan, £18.99,

pp 352

ISBN 978-0230748699

Rating: ★★ ★

Henrietta Lacks was a beautiful young black woman, the mother of five children, when in 1951 she came to the “colored wards” of Johns Hopkins medical centre in Baltimore, Maryland, complaining of “a knot on my womb.”

She had moved from the tobacco farm where she worked in rural Virginia to a segregated community on the outskirts of Baltimore, where her husband worked in a plant turning out steel for the war effort. She had an aggressive cervical adenocarcinoma that killed her within a year, when she was only 31.

Her cells, removed in a biopsy, became an industry. No one told her or her family; they were distraught when they finally heard her story in poorly understood bits and pieces.

Seldom do you read a book that is science, social history, and a page turner. Rebecca Skloot's book about Henrietta Lacks and her immortal cells is one.

The doctors who treated Mrs Lacks had been doing research for decades, trying to prove the then controversial idea that cervical carcinoma in situ often developed into invasive cervical cancer. They wanted to grow cells from normal cervical tissue, carcinoma in situ, and invasive cancer for comparison. But trying to grow malignant cells outside the body had proved impossible.

Mrs Lacks was being treated for free in a public ward. Her doctors thought it was fair to use such patients in research as a form of payment and that there was no need to tell them. She signed a broad consent form saying that her doctors could perform any operative procedure they thought necessary for “proper surgical care and treatment.”

No one told Mrs Lacks that while she was anaesthetised a doctor had removed small specimens of her cervical tumour and of the normal tissue nearby. Anyway, patients deferred to doctors in that era. Nor did anyone tell Mrs Lacks that the doctor would try to grow her cells in culture.

Previous attempts to grow cells had failed, but Mrs Lacks's cancer cells multiplied in test tubes, multiplied again, were transferred, multiplied again . . . and never died.

Her doctors were delighted to have these immortal cells for experiments. They shared them freely with colleagues. Companies were set up to package and sell her cells. They made millions. The doctors did not share in the profits, and nor did her family.

You may have worked with Henrietta Lacks's cells. They're known as HeLa (from the first two letters of her names), and there are billions of them in laboratories around the world.

Her cells were used in the development of the polio vaccine. They revealed that people have 46 chromosomes, not 48, as had been thought, and helped scientists diagnose genetic diseases. The cells were exposed to nuclear radiation to see how nuclear bombs destroyed cells and perhaps find ways to reverse the damage. Drug companies began using

them to test whether new drugs harmed cells. They were spun in centrifuges to discern the effects of gravity during space flight or deep sea dives.

No one contacted her family until about 20 years later, when Mrs Lacks's aggressive cells were contaminating cultures around the world. Scientists needed to find genetic markers that would identify HeLa cells. They called the family and asked for blood samples, but their explanations were not clear.

Mrs Lacks had only five years of education—and that was two years more than her husband had. Her children had little more and certainly had no understanding of genetics or cell cultures or cloning.

Before the civil rights movement of the 1960s, much of America was segregated. Black people distrusted Hopkins and other medical institutions, even before the Tuskegee scandal in which black men with syphilis were studied but not treated. The Lacks family believed that black people were kidnapped from the streets and used for experiments.

The family thought they were being tested for the cancer that had killed Henrietta and waited for the test results. They never came. They read about cloning of cells and thought that cloned Henriettas were walking around everywhere. They wondered whether the cells felt pain through the experiments.

They learnt that companies had marketed her cells for millions of dollars. They were angry that they couldn't even get health insurance. No one had asked for permission or paid them or their family for the cells.

Such questions as were faced by the Lacks family cut through ethical issues for patients worldwide. What are you doing to me? What information are you giving me? How well are you explaining it? What control do I have over my cells or tissues? Will you profit from my cells while I do not? How will my health insurance cover me?

Things have changed since the 1950s, but many issues remain. Skloot, a science journalist, examines them in this thought provoking book. She writes that she has been fascinated by the story of Henrietta Lacks since she first heard about her as a teenager in a school science class. She reports that in the United States today consent is not needed for storing blood and tissue and that courts have ruled that doctors have the right to use patients' tissues without paying the patients.

Skloot spent 10 years reaching out to the family, explaining science, and becoming a family confidant. She finally took Henrietta's youngest daughter, who wanted to know about her mother, to a laboratory where the daughter cradled her mother's cells in her hand, trying to warm them.

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You may have worked with Henrietta Lacks's cells. They're known as HeLa (from the first two letters of her names), and there are billions of them in laboratories around the world

In a world of its own

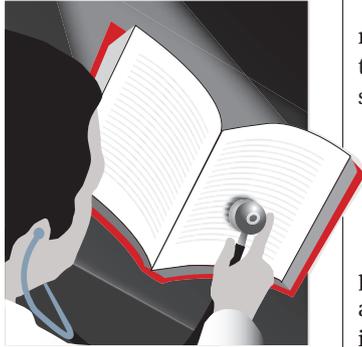
I was about 11 years old when I saw my first case of Pott's disease of the spine. My best friend of the time, who was paraplegic from polio, had been admitted to an orthopaedic hospital for an operation. It was a fine summer, and a young man, about six years older than we, was left out in the sunshine in his bed every day, his lower trunk encased in a plaster cast. The sun's rays were deemed complementary to the drugs and immobility that were to cure him.

Much later in my career I saw many cases of Pott's, in a far distant land where the patients came to us only after all the resources of magic had been exhausted. One case I remember was of a famous dancer who had become paraplegic; her relatives supposed that her illness had been caused by the malevolent magic of her envious neighbours. She recovered, but since she continued to receive magic potions as well as our treatment, her recovery was not the lesson in rationality that we had hoped.

Max Blecher (1909-38) was a Romanian writer who went to medical school until he was diagnosed as having Pott's disease aged 19. He spent the rest of his short life in sanatoria in France, Switzerland, and Romania, often in great pain. Never to walk again, he wrote two novels. One of them, *Scarred Hearts*, is a thinly fictionalised autobiographical account of his time in a sanatorium in Berck-sur-mer. Its protagonist is called Emanuel.

As some towns later specialised in the sale of secondhand books, Berck-sur-mer specialised between the wars in tuberculosis sanatoria. Blecher went to one that specialised in Pott's; the patients there were encased in plaster casts and spent their time entirely horizontal, sometimes for years on end. They spent their lives on

BETWEEN THE LINES Theodore Dalrymple



The patients were encased in plaster casts and spent their time entirely horizontal, sometimes for years on end. They spent their lives on stretcher beds, moved around by attendants

stretcher beds, moved around by attendants; they had horse drawn carriages or carts for outings.

Because the treatment (if that is quite the word for it) was so longlasting, some semblance of normality had to be kept up. The patients were fully dressed over their plaster casts; they ate together in a dining room, learning to balance the soup plates on their chests, and drinking the soup without spilling any. The description of Emanuel's first meal in the dining room is unforgettable.

The intense emotions of such an enclosed world are

beautifully conveyed, with restraint and economy. One of the characters, Quitonce, who is about to undergo an operation that proves fatal, gives Emanuel a memento of himself beforehand: a fragment of a diseased vertebra of his that has been removed at a previous operation.

One of the patients, released from the sanatorium after several years' residence, writes to Emanuel: "What puzzled me first about Paris was that I didn't see one single patient in a carriage anywhere."

This is a beautifully convincing detail that allows us to enter the mentality of the patients. The sanatorium is what Erving Goffman would have called "a total institution": a little world of its own, all absorbing, cut off from everything else and seemingly self sufficient.

Death is ever present in the book, accepted as a fact, but there is also a love of life. There is no hyperbole in it. Completed only one year before the author's own death, I finished the book feeling ashamed of my own long career of carping complaint. The effect, of course, will not be lasting.

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MEDICAL CLASSICS

The Social World of the Ants Compared With That of Man By Auguste Forel

First published 1921-23

Imagine a world where there are weavers, butchers, cattle rearers, masons, road makers, harvesters, bakers, mushroom farmers, excellent nurses of various kinds, gardeners, warriors, pacifists, slave makers, thieves, brigands, and parasites, but where we find no professors, orators, governors, bureaucrats, or generals, nor even corporals; nor do we find capitalists, speculators, or mere swindlers. This idyllic world was described almost 10 years before the great depression, and 80 years before our current recession, by one of the great medical polymaths of the last century, Auguste Forel (1848-1931).

That the world described in this exquisite two volume book belongs to ants should come as no surprise, since Forel was one of the world's greatest authorities on ants at the turn of the last century. By the outbreak of the first world war he had collected the largest known scientific collection of ants, and several species of ants are named after him. In a remarkable and extremely full life he was variously a pioneering neuroanatomist (hence the eponymous fields of Forel in the brain), a reforming psychiatrist, an innovator in treatment of alcohol dependency, the author of the first popular textbook of neurosciences, and that of the most widely read book on sexuality before the writings of Freud. However, myrmecology, the study of ants, was his earliest and deepest scientific love. Forel's obsession with ants was shared by his wife and extended to the name of his house — *La Fourmillière* (The Ant's Nest).



Forel: medical polymath and ant expert

The narrative of the book starts out with the phylogeny and ontogeny of the ant world, and leads into their anatomy and geographical distribution, where we learn among other things that there are no ants in Greenland or Iceland. Then we learn of the sense organs, physiology, and psychology of ants, as well as of their parasites, their symbiotes, and the structure of their nests. At this point the book really takes off, with a description of the social rituals and roles of ants that would do the anthropologist Margaret Mead proud. From nuptials to nurses, games to gardeners, miners to masons, and carton making to road construction, the range of roles and sophistication of the social organisation of the ant world unfolds.

Forel's own philosophies (he was a prominent social democrat and Bah'ai) act as a gentle undercurrent but do not intrude until the epilogue. There are intimations of a disposition towards eugenics that would eventually lead to a revision of Forel's reputation and the dropping of his portrait on Swiss 1000 franc banknotes.

Notwithstanding, the attractions of this work are many. The copious illustrations are superb, many from Forel's own drawings. As a scientist and intellectual he is generous, with constant reference to those who taught him, as well as to contemporary colleagues. It remains an encouragement to doctors that medicine, for all its subspecialisation, is a broad chapel that accommodates an extraordinary breadth of intellectual endeavour.

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A fashion for uniformity

FROM THE
FRONTLINE
Des Spence



I looked at the new pink patch on my jeans. I never wore a school uniform because in the '70s schools were keen for children to have freedom to express themselves. A result was that if you looked different you got picked on. So my pink patch meant that I was going to have a fight. I wished we had a school uniform. So as adolescents many of us joined the music gangs—new romantics, mod revival, metalists, and punks. As a teenager I donned a fishtail parka, sowed on a Jam badge, and joined the two other mods in Orkney because uniforms gave me a sense of belonging. Fashion, like school policy, constantly recycles ideas.

As a junior doctor I also wore a uniform: white (grey) coat, crumpled shirt, antibiotic stained tie, and unwashed chinos—literally a walking fomite. My pockets bulged with the paraphernalia of the junior doctor—tendon hammer, a “cheese and onion” (the *Oxford Handbook of Clinical Medicine*), the *British National Formulary*, cigarettes and lighter. But it was the stethoscope that was our badge of office. Most resisted the temptation to wear it around the neck: this was the placard of the inadequate. But then every vaguely health related professional started to wear white coats; everyone wore a stethoscope around the neck; and so the old order of identification started to unravel. Everyone was more informal: first names,

open and egalitarian—good for everyone. However, this has caused chaos on the wards, not even the staff know who's who. My wife complains about high heels, figure hugging clothes, and plunging necklines, all bordering on the unprofessional.

So Scotland is implementing a national NHS uniform—amorphous sack tops in a range of primary colours with combat trousers for a dramatic action look. Medicine is a litany of foolish ideas, like suggesting that the General Medical Council should regulate medical students, destroying the last period of normality before becoming a doctor.

But a national uniform is a good idea to re-establish our sense of professionalism and identity. What should doctors wear? In its profligate past the NHS would have commissioned a national review headed by a fading top fashion designer. But in these days of austerity, and to offer some contrition for our recent excess, perhaps it's time to return to utility wear, just plain “blues.” Uniforms will be popular for a time, but fashion will change again. However, I suspect that pink patches will never make a comeback.

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Bedtime stories

THE BIGGER
PICTURE
Mary E Black



All my life I have wanted to see the world through another's eyes for a day, someone famous living in a remarkable place or time. An artist in medieval Siena is a particular favourite or perhaps a whale.

My youngest is 13 and growing up faster than I can buy him new shoes. He is an athlete, training most days, competing in athletics and the national sailing team, and getting his share of bumps and scrapes. Like most teenagers he needs more sleep than he will admit to. He has only rare moments of actually acting on my advice, but I can keep him spellbound answering his questions about how the body works in an adolescent version of the bedtime stories he loved as a younger child.

How does one cell at conception know how to subdivide into such an array of specialists, from light sensitive retinal cells to heart muscle, beating away at its own pace? How can it be that these

muscles are actually getting bigger (cue myofibrils and the magic of satellite nuclei and slow twitch fibres)? Even the names are fascinating. The Latin roots tell a story: “osteo” means bone and “blast” means to build.

Why is the elbow so ingeniously shaped, balancing form and function yet having the odd design fault of an exposed ulnar nerve? What is acne anyway? How can the skin be so elastic, except around the scars on the knee, which are actually keloids. See how that patella is so perfectly formed that it will allow the hinge joint of the knee to open and close and yet protects it from being bashed, while having a smooth coating on the inside to reduce friction. And then an opportunity for some subliminal maternal advice: why is sleep important?

Well son, sleep is when your already size 45 feet (and no, they

do not look enormous) will do their work of getting bigger still; your bones will grow even longer; and your muscles will lengthen to fit. Sleep is when your body can repair all the damage done over the day, mending that scraped knee with an army of repair cells. I kiss his forehead good night, noting that this is not the skin I kissed a month ago because that has all been replaced.

Each year science adds more to our understanding of the human body; it also reaffirms that there are many more miracles yet to unfold. The universe inside each cell makes medieval Siena and the migratory patterns of an orca appear simple. These are the places the Discovery channel has yet to reach.

My escapist fantasy now is to be DNA for a day.

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