

Breach of Privacy

Despite her fears, Deborah didn't die on her thirtieth birthday. She just kept raising her kids, working various jobs as a barber, notary public, chemical mixer at a cement plant, grocery store clerk, limousine driver.

In 1980, four years after divorcing Cheetah, Deborah took her car to a mechanic named James Pullum, who also worked at a local steel mill. They married in 1981, when Deborah was thirty-one and Pullum was forty-six, soon after he got called by the Lord to moonlight as a preacher. Pullum had some run-ins with the law before he was saved, but with him, Deborah felt safe. He rode around Baltimore on his Harley with a knife in his pocket and always had a pistol close. When he asked Deborah why he'd never met her mother, she laid the *Rolling Stone* article on the bed for him to read, and he said she should get a lawyer. She told him to mind his own business. Eventually they opened up a little storefront church, and for a while Deborah stopped worrying so much about her mother's cells.

Zakariyya was out of prison after serving only seven of his fifteen-year sentence. He'd gotten himself certified to fix air conditioners and

work on trucks, but he still wrestled with anger and drinking, and on the rare occasions when he found jobs, he lost them quickly. He couldn't afford rent, so he slept most nights on a bench on Federal Hill in downtown Baltimore, or on the steps of a church across the street from his father's house. Day would sometimes look out his bedroom window and see his son lying on the concrete, but when he invited him in, Zakariyya snarled and said the ground was better. Zakariyya blamed his father for Henrietta's death, hated him for burying her in an unmarked grave, and never forgave him for leaving the children with Ethel. Day eventually stopped inviting him in, even though it sometimes meant walking past Zakariyya sleeping on the sidewalk.

At some point, Zakariyya noticed an ad seeking volunteers for medical studies at Hopkins, and he realized he could become a research subject in exchange for a little money, a few meals, sometimes even a bed to sleep on. When he needed to buy eyeglasses, he let researchers infect him with malaria to study a new drug. He volunteered for research on alcoholism to pay for a new job-training program, then signed up for an AIDS study that would have let him sleep in a bed for nearly a week. He quit when the researchers started talking about injections, because he thought they'd infect him with AIDS.

None of the doctors knew they were doing research on Henrietta Lacks's son, because he'd changed his name. Zakariyya and Deborah always figured that if Hopkins had found out he was a Lacks, they wouldn't have let him leave.

The biggest payday any of the Lacks children ever saw came when Day and other workers got a settlement from a class-action lawsuit against a boiler manufacturer over the damage done to their lungs from asbestos exposure at Bethlehem Steel. Day got a check for \$12,000, and gave \$2,000 to each of his children. Deborah used hers to buy a small piece of land in Clover, so she could someday move down to the country and live near her mother's grave.

Sonny's rough period was only getting worse: most of his income now came from a food-stamp ring he ran out of Lawrence's convenience store, and soon he found himself in jail for narcotics trafficking.

And it looked like Deborah's son Alfred was taking the same path as his uncles: by the age of eighteen, he'd already been arrested several times for minor offenses, like breaking and entering. After bailing him out a few times, Deborah started leaving him in jail to teach him a lesson, saying, "You just stay there till your bail come down to where you can afford it." Later, when he joined the Marines and quickly went AWOL, Deborah tracked him down and made him turn himself in to the military police. She hoped some time in minimum security would convince him he never wanted to end up in a penitentiary. But things just got worse, with Alfred stealing and coming home on drugs, and eventually Deborah realized she couldn't do a thing about it. She told him, "The devil got you, boy—that stuff you on make you crazy. I don't know you, and I don't want you around here no more."

In the midst of all this, someone told Deborah that as Henrietta's next of kin, she could request a copy of her mother's records from Hopkins to learn about her death. But Deborah didn't do it, because she was afraid of what she might find and how it might affect her. Then, in 1985, a university press published a book by Michael Gold, a reporter from *Science 85* magazine, about Walter Nelson-Rees's campaign to stop HeLa contamination. It was called *A Conspiracy of Cells: One Woman's Immortal Legacy and the Medical Scandal It Caused*.

No one in the Lacks family remembers how they learned about Gold's book, but when Deborah got a copy, she flipped through it as fast as she could, looking for her mother. She found the photo of Henrietta, hands on hips, at the front of the book, and her name at the end of the first chapter. Then she read the passage out loud to herself, shaking with excitement:

They were all the cells of an American who in her entire life had probably not been more than a few miles from her home in Baltimore, Maryland. . . . Her name was Henrietta Lacks.

In the ten-page chapter that followed, Gold quoted extensively from her medical records: the blood spotting her underwear, the

syphilis, her rapid decline. No one in Henrietta's family had ever seen those medical records, let alone given anyone at Hopkins permission to release them to a journalist for publication in a book the whole world could read. Then, without warning, Deborah turned the pages of Gold's book and stumbled on the details of her mother's demise: excruciating pain, fever, and vomiting; poisons building in her blood; a doctor writing, "Discontinue all medication and treatments except analgesics"; and the wreckage of Henrietta's body during the autopsy:

The dead woman's arms had been pulled up and back so that the pathologist could get at her chest . . . the body had been split down the middle and opened wide . . . greyish white tumor globules . . . filled the corpse. It looked as if the inside of the body was studded with pearls. Strings of them ran over the surfaces of the liver, diaphragm, intestine, appendix, rectum, and heart. Thick clusters were heaped on top of the ovaries and fallopian tubes. The bladder area was the worst, covered by a solid mass of cancerous tissue.

After reading that passage, Deborah fell apart. She spent days and nights crying, imagining the pain Henrietta must have been in. She couldn't close her eyes without seeing her mother's body split in half, arms askew, and filled with tumors. She stopped sleeping. And soon she was as angry at Hopkins as her brothers. She stayed up nights wondering, *Who gave my mother medical records to a reporter?* Lawrence and Zakariyya thought Michael Gold must have been related to George Gey or some other doctor at Hopkins—how else could he have gotten their mother's records?

When I called Michael Gold years later, he didn't remember who'd given him the records. He said he'd had "good long conversations" with Victor McKusick and Howard Jones, and was pretty sure Jones had given him the photo of Henrietta. But he wasn't sure about the records. "They were in somebody's desk drawer," he told me. "I don't remember if it was Victor McKusick or Howard Jones." When I talked

to Jones, he had no memory of Gold or his book, and denied that either he or McKusick ever gave Henrietta's medical records to anyone.

It wasn't illegal for a journalist to publish medical information given to him by a source, but doing so without contacting the subject's family to ask additional questions, verify information, and let them know such private information was being published could certainly have been considered questionable judgment. When I asked Gold whether he tried to speak to the Lacks family, he said, "I think I wrote some letters and made some calls, but the addresses and phone numbers never seemed to be current. And to be honest, the family wasn't really my focus. . . . I just thought they might make some interesting color for the scientific story."

Regardless, it was not standard practice for a doctor to hand a patient's medical records over to a reporter. Patient confidentiality has been an ethical tenet for centuries: the Hippocratic Oath, which most doctors take when graduating from medical school, says that being a physician requires the promise of confidentiality because without it, patients would never disclose the deeply personal information needed to make medical diagnoses. But like the Nuremberg Code and the American Medical Association Code of Ethics, which clearly said that doctors should keep patient information confidential, the Hippocratic Oath wasn't law.

Today, publishing medical records without permission could violate federal law. But in the early eighties, when someone gave Henrietta's medical records to Gold, there was no such law. Many states—more than thirty, in fact—had passed laws protecting the confidentiality of a patient's medical records, but Maryland was not one of them.

Several patients had successfully sued their doctors for privacy violations, including one whose medical records were released without her consent, and others whose doctors either published photographs or showed videos of them publicly, all without consent. But those patients had one thing going for them that Henrietta didn't: They were alive. And the dead have no right to privacy—even if part of them is still alive.