

The Immortal Life of Henrietta Lacks: Being informed to be able to give consent

“The Immortal Life of Henrietta Lacks” by Rebecca Skloot is likely one of the more provocative books that you might read this year. It covers a wide range of important topics, including racism during the era of Jim Crow, graphic stories of violence and rape, and systemic levels of oppression and unethical practices in the medical community. Though each of these topics, as well as many others covered in this book, deserve much attention in writing, it is on the ethical practices of medical treatment and research that this essay will focus our attention. When thinking about medical ethics, many of us may think about human experimentation done by historical villains like the German Nazis during World War II. We will certainly talk about that. But real problems have often gone largely unnoticed in our own backyard here in America. Whether it is the Tuskegee syphilis experiments, experiments on the institutionalized disabled, or the passages of this book that discuss what happened to Henrietta and her family, American history is filled with examples of medical malpractice that has taken place all around us. Being informed in order to truly give consent to medical treatment or research goes hand in hand. The importance of informed consent is inseparable from ethical medical practice and research.

Perhaps the most widely known and glaring example of the abuse of informed consent remains the Nazi experiments conducted on prisoners of the concentration camps around the time of World War II. Though experimentation was recorded as early as the mid-1930s, the bulk of the studies were conducted during the early 1940s and continued until the very end of the war in 1945. Nazi researchers forcibly exposed prisoners to a wide array of extreme situations such as low air pressure chambers to simulate how high an altitude a German pilot might survive during a plane malfunction, or to freezing water temperatures to see how long a German soldier might survive in arctic water. Prisoners were infected with many diseases such as malaria,

tetanus, typhus, and typhoid in order to study experimental treatment therapies or better understand how the diseases can end someone's life. For those who were killed, their bodies were carefully dissected and studied. Hundreds of Jewish children were subjected to grotesque twin research where they were systematically tortured. In some cases, officials sewed twins together in an attempt to study conjoined twins. Victims were the young and old, men and women, of countless different nationalities and backgrounds. Although most were Jews, many were prisoners of war or political enemies of the Reich. Several thousand were killed as a direct result of these experiments. According to one exhaustive study, there may have been as many as 27,759 total victims of these inhumane experiments (Weindling et al. 3). Many were killed, but "there were more victims who survived...as part of or as a result of the experiments, and the survivors often had severe injuries" (Weindling et al. 1). While most of the survivors lived with severe disabilities and suffered life-long consequences of the ethics of the Nazis, the victims also offered important testimonies that corroborated the charges against the Nazi officials during the Nuremberg trials. Many Nazi researchers were held to account for these experiments.

It might be easy for us to throw stones at the Nazis, but serious examples of medical malpractice can be found near us in America's recent history. Rebecca Skloot even made note of this commonly held idea that the Nuremberg trials were for the Germans and had no bearing on us here in America. When researchers injected patients with cancer without getting informed consent, they said that the "Nuremberg Code didn't seem to apply in the United States, and that there were no laws protecting research subjects" (Skloot, 133). Rebecca Skloot offered numerous examples of patients having tissues removed, or patients being injected with cancer or infectious material, not only without getting the consent of the patient but without the patient having any idea of the procedures being conducted.

Probably the most glaring example of this from the book was how the physicians and researchers treated Henrietta Lacks and her family. After Henrietta was diagnosed with cancer, there were several situations where doctors took tissue and blood samples, without consent, that had no bearing on her diagnosis or treatment. During her treatment, it seemed clear that she was not ever really asked what she wanted to do as far as treatment options. She was told what “they” were going to do. She died a terrible and painful death and had her treatments discontinued by the will of the physicians, and not by the will of Henrietta or her family. After Henrietta died, her husband Day was essentially coerced into authorizing an autopsy. He eventually consented under false pretenses but gave specific parameters that the researchers did not honor. Later, the family was misled into giving blood to continue the research into Henrietta’s tissues that were taken unethically in the first place. The entire nature of how Henrietta and her family were treated throughout the book was astounding. Though this was just the story of one family, this family serves as a testimony of a systemic problem with how medical practice and research was conducted on many people at the time. Physicians are the experts, and they tell these “poor uneducated” people what’s best for them. People like the Lacks family are just expected to make sacrifices without consent for the greater good of the many others. It is wrong and unethical and Rebecca Skloot portrayed that well.

Another great example of unethical research was when Rebecca Skloot and Deborah started to learn about what was happening to Elsie and others who were institutionalized at Crownsville. Skloot mentioned how “scientists often conducted research on patients there without consent, including one study titled ‘Pneumoencephalographic and skull X-ray studies in 100 epileptics’ ...Pneumoencephalography involved drilling holes into the skulls of research subjects, draining the fluid surrounding their brains, and pumping air or helium into the skull in

place of the fluid...the side effects—crippling headaches, dizziness, seizures, vomiting—lasted until the body naturally refilled the skull with spinal fluid, which usually took two to three months” (Skloot, 275-276). People with epilepsy or other disabilities were probably in no position to offer informed consent if they were ever asked at all. They were subjected to terrible pain without any regard for their well-being.

Another example discussed in the book has come to be known as the Tuskegee Syphilis Experiments. Rebecca Skloot made a number of references to these experiments, but probably the most pointed description came in chapter 6. Skloot said, “They recruited hundreds of African-American men with syphilis, then watched them die slow, painful, and preventable deaths, even after they realized penicillin could cure them” (Skloot, 50). Other sources have very closely corroborated the information from the book.

According to the Centers for Disease Control and Prevention, the study initially “involved 600 black men – 399 with syphilis, 201 who did not have the disease” (“U.S. Public Health Service Syphilis Study at Tuskegee”). In exchange for their voluntary participation, they were promised free medicine, food, transportation to and from the hospitals, and some burial compensation for those who died. The promises of medicine were deliberately misleading as they were never treated for the syphilis being studied. In fact, researchers told them that they were being given free treatments for “‘bad blood,’ a local term used to describe several ailments, including syphilis, anemia, and fatigue” (“U.S. Public Health Service Syphilis Study at Tuskegee”). This research continued for about 40 years relatively unknown until a reporter for the Associated Press named Jean Heller broke the story on July 26, 1972. The article, published most notably in the New York Times, caused nationwide uproar when Heller shined the light on this study with statements like “penicillin was found to be a cure for syphilis...and while its use

probably could have helped or saved a number of the experiment subjects, the drug was denied them” (Heller). An investigation quickly ensued, and it was found that the participants were misled into volunteering for the study and many died from various treatable infections.

The need to study infections and diseases is obviously a noble cause. If we were to chronicle the vast amounts of medical knowledge that was gained by many of these studies, we would see clearly that countless lives have been saved through medical advancement. Medical advancement is good, but it cannot come at the cost of the oppression and sometimes murder of others. The importance not only of consent but being informed to give consent cannot be overstated. If someone is unable to truly understand the procedure with its risks and benefits, they are unable to give true consent. We as a nation and as a human race have made significant strides towards the goal of eliminating unethical medical practice and research, but we still have a long way to go towards the goal of all people being treated with dignity and value.

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