

The story of Henrietta Lacks: an opportunity to make up for past mistakes

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Abstract. At the present time, when COVID-19 is disproportionately affecting black people in several countries, the Henrietta Lacks centennial year reminds us of our responsibility to strive for a fairer era of research. The cells of Henrietta Lacks, which were taken without her consent, have been reproduced billions of times for medical purposes. The Henrietta Lacks anniversary urges us to face an issue that is still unsolved, since consent to the collection of patients' data, the methods of their archiving and their possible dissemination remains a complex question that is still largely outstanding. In addition, in this pandemic era, the anniversary constitutes an opportunity to make up for past injustices and discrimination of the healthcare system.

Key words: informed consent, discrimination, Henrietta Lacks

One hundred years ago, Henrietta Lacks, an Afro-American woman affected by an aggressive adenocarcinoma of the cervix, died (1). Today, her name is still little known (if at all). By contrast, the genetic code of the woman's cell line, named "HeLa" (from the first two letters of her first and last names), is well known and widely used in research.

To Henrietta Lacks we owe the famous cells made "immortal" by the presence of a mutation of the papilloma virus. These cells have been utilized for key research in various medical fields: the vaccine against poliomyelitis, HIV infection and - recently - the vaccine against SARS-COV2.

Nobody asked for Henrietta Lacks' consent to the use of her cells for research purposes, because - at that time - the practice of informed consent, which necessitates the patient's authorization, was not yet required. The cell line developed from Henrietta's cells was obtained in a medical context in which economically and socially disadvantaged patients had no rights. HeLa were patented and marketed at the Tuskegee Institute, Alabama, generating enormous profits.

Moreover, the history of HeLa is intertwined with one of the most controversial pages of contemporary medicine. Indeed, Tuskegee is sadly famous for the experiments conducted by the US Public Health Service on 399 Afro-American sharecroppers suffering from syphilis, who were deliberately denied access to penicillin. Henrietta's family never benefited from her (unconscious) "gift". She died so poor that she was buried in an unmarked grave in Clover Cemetery, Virginia. Only a few years ago was a memorial plaque unveiled at her burial place. This is not only a story of scientific achievements, but also one of misery, marginalization and racial inequities, which are still embedded in research, raising unresolved ethical questions. In 2013, the situation became further complicated after the genome of Henrietta's cells was published in a public database, thereby violating the privacy of her family members (2).

From an ethical point of view, this story raises the *vexata quaestio* of consent (3), but it also urges us to tackle an issue that is still unsolved, since consent to the collection of patients' data, the methods of their

archiving and their possible dissemination remain a complex question that is still largely outstanding. For example, the recent Italian law on body donation for research and teaching re-proposes the theme of the value of corporeality (4) and the historical fate of the body (5).

What has the story of Henrietta Lacks taught us? One hundred years later, it is worth highlighting the words that Henrietta's grandson Jeri Lacks-White said when interviewed by *Nature*: "I want scientists to recognize that HeLa cells come from an Afro-American woman who was made of flesh and blood, who had a family and a history" (6).

The dramatic events of the pandemic and the unequal access to vaccination against COVID-19 in black communities offer an opportunity to make up for past injustices.

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