

Lessons from the Tuskegee experiment, 50 years after unethical study uncovered

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Dr. Martin Tobin revisits the Tuskegee Syphilis Study with a fresh, new perspective. Credit: ATS

This year marks 50 years since it came to light that the nation's leading public health agency, the Public Health Service, conceived an unethical "research study"—the Tuskegee Experiment—that lasted for 40 years. The participants? Black men in a rural community in the South who existed in a state of quasi-slavery, making them extremely vulnerable and the agency's treatment of them that much more sickening.

In "Fiftieth Anniversary of Uncovering the Tuskegee Syphilis Study: The Story and Timeless Lessons," Martin Tobin, MD, former editor of



the American Journal of Respiratory and Critical Care Medicine (AJRCCM), revisits this dark period in American history, expertly illustrating how present-day health disparities have roots in the racism that made the Tuskegee study possible.

The inhumane treatment doctors inflicted on the 400 men who participated in the study only ended after a <u>social worker</u> shared his discovery with the media in 1972. Subsequently, the government took measures to protect patients enrolled in research. Those measures are not enough, argued Dr. Tobin: "All of the research regulations in the world will never substitute for the conscience of the investigator."

In the paper, published in the AJRCCM, Dr. Tobin stressed "the three central lessons of the Tuskegee Study for researchers (and for people in every walk of life): the importance of pausing and examining one's conscience, having the courage to speak, and above all the willpower to act."

He added, "It is easy to articulate these steps but carrying out the steps requires a willingness to place oneself in jeopardy—a willingness to risk getting into trouble with supervisors and even losing one's job."

Whether you are a student embarking on a career in medicine or a seasoned professionals in health care, one could argue that the Tuskegee experiment is an exceptional way to learn about research ethics.

"Readers can acquire a better understanding of research ethics by reading about the Tuskegee Study than by reading about abstract principles of research integrity in a bioethics textbook," pointed out Dr. Tobin. "The story provides a vivid narrative with real live characters—victims, villains and a hero— and readers can relate these characters to people they encounter in their daily lives."



While there are no published studies showing a correlation between the Tuskegee Experiment and the erosion of public trust, particularly among African Americans, it is tempting to think there is.

The COVID-19 pandemic has laid bare the discrepancies in <u>health care</u> access as well as the staggering difference in mortality rates between Black and white individuals in the U.S. Social media communities are rife with rhetoric lambasting scientists and defending their refusal to get vaccinated. There is no peer review process on social media platforms, making them ideal places for <u>conspiracy theories</u> and misinformation to proliferate.

"A considerable portion of vaccine hesitancy, however, reflects a real decrease in trust in physicians and scientists—and especially in physicians with links to government," said Dr. Tobin.

Science is at its best when it invites critical thought and makes room for meaningful dialogue and self-examination. Silence can be deadly. And, when scientists around the world failed to criticize the Tuskegee Study's methods or question the integrity of the lead investigators, they jeopardized the integrity of the entire medical profession, contributed to the deaths of the participants and extended the suffering of family members.

"Medical societies, including the ATS, can educate members about research integrity and health equity by publishing articles pertinent to these topics and by featuring these topics at their major meetings," said Dr. Tobin.

At the upcoming <u>ATS 2022 International Conference</u> May 13-18, attendees can attend presentations that address health equity and disparity and engage colleagues on these issues in relation to their practice and research interests.



"ATS is strongly committed to creating a just and equitable future," said ATS President Lynn Schnapp, MD, ATSF. "As a medical society, we must always question how our own biases, whether conscious or unconscious, impact our activities and prevent us from keeping the needs of our patients front and center. We must actively work towards dismantling the structural racism that allowed studies like the Tuskegee Syphilis Study to begin and persist."

More information: Martin J. Tobin, Fiftieth Anniversary of Uncovering the Tuskegee Syphilis Study: The Story and Timeless Lessons, *American Journal of Respiratory and Critical Care Medicine* (2022). DOI: 10.1164/rccm.202201-0136SO

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