

Private Reparations

BY LARRY I. PALMER

Virginia Sharpe's review of Rebecca Skloot's *The Immortal Life of Henrietta Lacks* and John Lantos's essay "A Better Life through Science?" in the July-August issue of the *Hastings Center Report* join the chorus of favorable commentaries on Skloot's book that have appeared everywhere from the *New York Times* to the *Journal of Clinical Investigation*. The book's wide appeal appears to be in what some call its "compelling narrative" about race, science policy, and the U.S. health system. As readers experience Skloot's personal journey of "discovery," they are shocked to learn that the woman whose cancerous cervical cells were used to create an important cell line in modern biomedical research was poor, black, and from rural Virginia. Her children still lack health insurance, as she did when she died.

I am a discordant voice among Skloot's many readers. Would anyone care if the involuntary donor of the cells had turned out to be an upper-middle-class white woman from Georgetown? We should view obtaining anyone's cells, DNA, or tissue for research without consent as ethically problematic. Any solution to the ethical issues raised by the book should explore whether the system developed to oversee human research can meet the ethical challenges of "biobanking" in the face of health disparities.

Skloot does not share my view on the need for a systemic approach to the problems her book addresses. Instead, she offers her readers an opportunity for what fundraisers call a "commercial coventure": she will donate a portion of the proceeds from every sale of her book to the Henrietta Lacks Foundation, which she has set up to, in her own words, "provide financial assistance in the forms of scholarships to the descendants of Henrietta Lacks; it will also work to provide the Lacks family aid in covering the costs of health insurance." Given Skloot's critique of others' ethics, I would have expected her to disclose to her readers/donors that legally, the Henrietta Lacks Foundation cannot be used solely to support the Lacks family. The foundation, which combines commerce and charity, makes a good marketing

device. It allows Skloot to increase sales of her book while sensationalizing the problem of race and health disparities.

Skloot believes that Henrietta Lacks' descendants deserve charitable support solely because of their biological connection to Henrietta. I find it ironic that in a time of great debate about national health reform, the policy solution Skloot offers is what I call "private reparations" and is limited to those she finds worthy of her charity.

Henrietta and her children were not the only blacks who were denied education and access to health care in the 1950s. Their situation was typical of the vast majority of blacks. While Henrietta sought treatment at Johns Hopkins Hospital, groups of blacks in Virginia and elsewhere were

trying to persuade the U.S. Supreme Court to overturn the then-legal doctrine of "separate but equal" that had, with a few minor exceptions, fostered deplorable conditions in black schools. After the 1954 *Brown v. Board of Education* decision, some states, Virginia among them, even

passed legislation closing public schools until those laws were declared unconstitutional in 1964. In 2004, the Virginia legislature and governor recognized the wrongs these laws had done to children and established a scholarship fund for students denied an education because they were unable to attend schools closed to avoid desegregation. I confess I prefer the Virginia solution to Skloot's foundation because the legislation is a collective societal mechanism designed to repair harms to particular individuals: a form of *public* reparation—and recognition—for a legal harm. These individuals' connections to a shameful period of our social history justify their scholarships, rather than their genealogies.

The disparities in education and health status that many blacks continue to experience today require serious attention and radical changes. I, for one, would rather pay one hundred dollars more in taxes so that more people of whatever race or family background have improved access to health care and good science education than "give" the same amount to Skloot's foundation. I find it disheartening that even bioethicists do not see Skloot's private charity option as a way of diverting public discourse away from the deep structural problem of health disparities.

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Distracting us from the solutions we need.
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