Et in Arcadia ego. Two years ago, I was on a boat in the middle of the river that runs through Brisbane, Australia, with Sarah Winch, a medical ethicist at the University of Queensland. We were talking about the intersection of our professional work and our personal experiences of caregiving. Sarah’s husband, Lincoln, had died at the age of forty-eight, four months after a late-stage diagnosis of kidney cancer. My friend Julia was the same age when she died, on November 18, 2010, after living with breast cancer for seven years. Sarah asked me, “What was it like to write guidelines on end-of-life care while your best friend was dying?”

I am writing this on the third anniversary of Julia’s death. Having agreed to provide some field notes on the experience of directing the consensus process for the 2013 edition of The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life and of coauthoring the book itself with Bruce Jennings and Susan M. Wolf, I am still trying to answer Sarah’s question. What was that experience like? What is it like when work and life overlap so deeply, when one life ends and the work continues?

I dedicated my work on the Guidelines to the memory of Julia, including her motto, et in Arcadia ego, in the book’s dedication. (She chose this monetae mortuus—a reminder of mortality, a motif throughout classical and medieval art and literature—for herself long before she became sick.) She was a letterpress printer who was steeped in English and classical literature, and she wore her learning lightly. When I would try our Guidelines material on her, exploiting both her generosity and her vast experience of what we called “the deep end” of cancer care, she would tell me that something didn’t work by saying, “That’s too clever for me.” Meaning, you’re trying to be too clever. Simplify.

In the last year of Julia’s life, we didn’t talk about the Guidelines much—too close to real life—although her insights and our common experiences continued to inform my thinking in countless ways. Every so often, she’d be frightened: “What, you’re not done yet?”

The book details how researchers took cancerous cervical cells from a poor black woman, without even telling Lacks or her family, and how the cells evolved into the scientifically significant and commercially lucrative HeLa cell line while the family continued their harrowing existence after her 1951 death. As an expert on race and bioethics, I am frequently asked about the book. I have mixed feelings. By bringing the family’s story to a wide audience, the book has prompted necessary discussion about bioethical issues such as informed consent and tissue ownership. But I am not a huge fan.

How can I not love a book that has received stellar reviews and becomes mandatory reading at many colleges? One problem is that it views the history of African Americans in medicine and bioethics exclusively through the lens of exploitation, powerlessness, and victimization. Undeniably, racism is inextricably linked to the development of American medicine, and adversely affects African Americans’ health and lives. The history of medicine demonstrates that the Lacks family’s experience is just one among innumerable examples of what happened when a black person entered the health care system—and what often still happens. In Newport News, Virginia, black patients were housed in the local jail until the 1914 establishment of a black hospital. In November 1931, Juliette Derricotte, a prominent educator, died after being denied hospital care following an automobile accident in Georgia. Unconscious bias plays a role in racial and ethnic inequities in contemporary health care. And yes, there was the United States Public Health Service Syphilis Study at Tuskegee, which subjected African American men to experimental syphilis treatment. The book’s inclusion of the history of the United States Public Health Service Syphilis Study is a reminder that the Lacks family survived harsh racism in Virginia, that several members migrated to Maryland in pursuit of better lives, and that some have entered college. The family’s objections to a German laboratory’s publication last spring of the genome of a HeLa cell line without their permission led to their agreement with the NIH. Their actions make plain that their history should be viewed as one that moves beyond victimization to accommodation. Now, when considering the family’s strengths, my students need look no further than their successful negotiations with the NIH to be granted some control as to how the HeLa genome is used in research.

R ebecca Skloot’s The Immortal Life of Henrietta Lacks received renewed attention in August after the National Institutes for Health reached an agreement with the Lacks family over the use of the HeLa genome. The book details how researchers took cancerous cervical cells from a poor black woman, without even telling Lacks or her family, and how the cells evolved into the scientifically significant and commercially lucrative HeLa cell line while the family continued their harrowing existence after her 1951 death. As an expert on race and bioethics, I am frequently asked about the book. I have mixed feelings. By bringing the family’s story to a wide audience, the book has prompted necessary discussion about bioethical issues such as informed consent and tissue ownership. But I am not a huge fan.

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Beyond that failing, the book at times depicts a stereotypically dysfunctional black family. Skloot spotlights promiscuity, mental illness, and incarceration without any explanation for why these are vital to her larger narrative. And her transcription of family conversations in what she calls “native dialects” contributes to a mistaken picture of an uneducated family unable to make complicated decisions. I encourage my students to think about the Lacks family beyond the prism of exploitation and stereotype. I ask them to do the same for the syphilis study victims, to understand how the unexamined use of the description “poor, uneducated sharecroppers” obscures the individuals’ individuality and resilience. In class, we recognize that the Lacks family survived harsh racism in Virginia, that several members migrated to Maryland in pursuit of better lives, and that some have entered college. The family’s objections to a German laboratory’s publication last spring of the genome of a HeLa cell line without their permission led to their agreement with the NIH. Their actions make plain that their history should be viewed as one that moves beyond victimization to accommodation. Now, when considering the family’s strengths, my students need look no further than their successful negotiations with the NIH to be granted some control as to how the HeLa genome is used in research.