

Keith Wailoo. *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health.* Chapel Hill: University of North Carolina Press, 2001. ix + 360 pp. \$50.00, cloth, ISBN 978-0-8078-2584-6.



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Disease and African-American History

In the twenty-first century, as Americans learn each week about new developments for treating diseases, it is difficult to recall that only seventy years ago, most diseases and infections baffled the best researchers. Keith Wailoo's insightful *Dying in the City of the Blues* uses sickle cell anemia to document the changes in our comprehension and treatment of disease from the early twentieth century to the present. Within the main theme of a disease's shift from invisibility to visibility, Wailoo includes subthemes of the politicization of diseases, the changes in healthcare in the United States, and racism that frames understanding and treating African Americans. To Wailoo, understanding the cultural and social context of a disease is as important as uncovering its causes and treatment because it defines awareness, funding, and patient care.

Wailoo centers the story of sickle cell anemia in Memphis not only because Memphis included rural African Americans migrating from Mississippi, Missouri, Arkansas, and Tennessee, but also because Memphis became a center for health care

by the early twentieth century. Initially known as a city of moderation for professional African Americans, by 1940 more black agricultural workers moved to Memphis as the boll weevil, agricultural mechanization, and lack of educational opportunities drove blacks, as well as many whites, to urban centers in the North and South. Their numbers in Memphis allowed them to occasionally manipulate Mayor E. H. Crump's Democratic political machine to their benefit. Still, health care for African Americans remained poor and segregated. Aided by New Deal funds, philanthropy, and city bonds, John Gaston Hospital opened in the mid-1930s to provide health care for the poor. This facility and Memphis General provided researchers like Lemuel Diggs with cases that led them to understand the mechanism of what became known as sickle cell anemia.

Sickle cell anemia's symptoms were known but obscured by attention given to other diseases. Most philanthropic funds and research investigated hookworms, pellagra, tuberculosis, and child mortality in the early decades of the twentieth century. As treatments were announced, reform-

ers were convinced that the South's problems were solved.[1] Even during various public health campaigns for sanitation and disease control, most whites believed black infant mortality and illness were linked to ignorance and black's biological inferiority. Awareness of sickle cell anemia was also concealed because of its similarity to malaria's symptoms--the aches, chills, and pain. Yet public awareness of infant mortality in Memphis and other cities led to significant changes in healthcare. Federal and philanthropic funds made invisible diseases and mortality rates visible resulting in a "complex negotiation, a social, political, and intellectual process that cannot be taken for granted" (p. 82).

Still, as Memphis healthcare benefited from funds to provide for better medical care, pathologist Lemuel Diggs's findings on sickle cell anemia had different results. Diggs, trained in the emerging field of hematology, contended that the diagnosis of sickle cell required different blood tests that few local doctors knew. Most white researchers and the public, influenced by eugenics, regarded this rare blood disease as yet another indication of African-American inferiority.[2] Tainted by impure blood, blacks were assumed since the days of slavery to be "biologically weaker and hereditarily prone to disease" (p. 79).

Yet research, federal health studies, and an increasingly vocal civil rights movement during World War II combined to change health care and public perception of sickle cell anemia. Thanks to pressure from the National Association for the Advancement of Colored People, anthropologists, and liberal whites, the Red Cross stopped labeling blood according to race in 1942. Blacks' "Double-V" campaign marked their determination to equalize American society.

As African Americans demanded better healthcare after World War II, cases of malaria decreased in Memphis. Diggs's studies on sickle cell anemia gained credibility because blacks continued to describe the same symptoms they had

for decades. In yet another discovery, Linus Pauling's research demonstrated that the disease existed within red blood cells at the molecular level. To Wailoo, "Pauling's discovery immediately made sickle cell disease into a researcher's cash crop" (p. 115). Like other diseases, sickle cell anemia's enhanced visibility now made it a commodity at the same time it provided funds for research. In Memphis, where researchers like Diggs had gathered to study this blood disease, a sickle cell center at the University of Tennessee opened. Not only would the center devote its resources to studying the causes and cures for the disease, it also broke the Jim Crow barrier by admitting black patients.

As the 1960s civil rights movement increasingly focused on social, economic, and cultural inequalities between black and white Americans, sickle cell anemia was used to highlight neglect of African Americans and elicit sympathy for them. Now economic and social injustice, not genetics, became reasons for poor health. Magazines including *Jet* and *Ebony* and televisions and film stars like Sidney Poitier and Bill Cosby publicized the plight of African Americans suffering from sickle-cell disease. Yet with publicity and increasing attention came other consequences. "What," Wailoo asks, "was the relationship between the researcher's curiosity about such diseases and the goal of improving the health of 'ordinary' sick people?" (p. 155) The quest for a cure for the disease became a metaphor for erasing African Americans' pain and psychological wounds from hundreds of years of racism. In the swirl of attention given to sickle cell anemia as a visible disease, less attention was given to the patients and their physical pain.

By the 1970s, research for cures of high-profile diseases became a high-stakes, competitive market for universities and institutions as the federal government and the National Institutes of Health offered grants. President Nixon's allocation of federal funds included sickle cell anemia as

well as his declaration of war on cancer. Universities with medical research centers fought for economic prizes. Diseases became politicized in yet a different way. Those that generated the most publicity received more funds. Politicians like Memphis Republican Congressman Dan Kuykendall promoted additional research in sickle cell anemia to appease his black constituency. On May 18, 1972, President Nixon signed the Sickle Cell Anemia Control Act, making the University of Tennessee one of ten federally funded clinics.

Americans became increasingly aware of the disease, but this awareness came with a price. Genetic counseling echoed arguments about African American inferiority that had dominated their history since slavery. Others argued that sickle cell anemia demonstrated the protective power of evolutionary biology because the sickle cell apparently evolved to guard Africans against malaria. More importantly, "even black Americans wondered why" this disease should be the focus of so much research when other health problems like hypertension "were even more important in black communities" (p. 192). Thus, "the story of sickle cell anemia was but one high-profile example among many of the ways in which patients' advocates, physicians and researchers, and consumer groups organized specific disease campaigns, put diseases on stage, and shaped federal health policy" (p. 195). Here Wailoo succinctly states one of the central problems of modern medical research. The price of visibility means aggressive competition in the market for philanthropic and federal funds. Some diseases that gain public notoriety like sickle cell anemia win the cash prize; others fall through the cracks.

One of Wailoo's strengths in the book is how he contrasts Western medicine's approach to the disease to West African perception. In areas like Ghana, the disease had been known for centuries and named because of the chronic pain associated with it. While West African medicine focused on pain and the patient's condition, Western

medicine examined blood cells and molecules. Wailoo's implication is clear. While Western medicine has accomplished much by searching for origins of diseases and their cures, the patient's needs are neglected.

Dying in the City of Blues combines an extraordinary array of sources from blues lyrics to medical journals to politicians' papers and more to illustrate the dilemmas of naming and publicizing diseases. As a disease becomes identified, lives may be saved or improved. Publicity and media reports garner resources for studies. Often, however, the process of discovery, naming, and defining a disease makes the illness a commodity. What is lost is the attention to patients and their welfare. The contemporary debate about prescription drugs and HMOs illustrates this problem and concludes the book's focus on the politics of health-care.

Wailoo provides a striking description of how scientific research, frequently regarded as objective and purely empirical, remains bound by race, class, culture, and social boundaries. The more funds enter the research pot, the more some diseases gain. As some diseases gain celebrity status, they benefit from more research dollars. For example, funds for AIDS research are important, but more Americans die from heart disease and cancer. Even cancer research has its own politics. Breast and prostate cancer research are significant, but so are other cancers that have less visibility.

But Wailoo implies that the politics of health-care is often driven solely by racism. Examples like the infamous Tuskegee Experiment with syphilis add to this, and no one could argue against his point that blacks lacked adequate healthcare before the 1960s. Yet so did many other Americans like poor white southerners, industrial workers in coal mines and textile mills, and women.[3] Many women recall the thalidomide controversy in the 1960s that led thousands to take a drug to prevent miscarriages that caused

birth defects in their children. Only in the last two decades have medical researchers begun to recognize that women's health problems may require different treatments from men's. Racism existed across the nation when it came to healthcare. But the United States can scarcely claim a distinguished record when it comes to healthcare for the poor or many women.

Moreover, it is surprising that Wailoo neglected to interview some individuals with sickle cell anemia who were treated with various experimental drugs or were public images of the sickle cell patient like Marclan Walker or her family. Interviews may be criticized for relying on individual memory, but they often illuminate aspects of the story that personalize history. While Wailoo calls for more attention to patient's needs, interviews would underscore this point.

Still, Wailoo's book is an important contribution to our understanding of the politics of and cultural differences in healthcare. In the race for a cure, all too often the patient and the family are lost in a miasma of potential treatments that debilitate and rob patients of their quality of life. Clinical visibility of a disease has serious consequences for its social visibility, which can often mean labels of inferiority and poor healthcare.

Notes

[1]. William A. Link, *The Paradox of Southern Progressivism, 1880-1930* (Chapel Hill: University of North Carolina Press, 1992); Edward H. Beardsley, *A History of Neglect: Health Care for Blacks and Mill Workers in the Twentieth-Century South* (Knoxville: University of Tennessee Press, 1987).

[2]. Edward J. Larson, *Sex, Race, and Science: Eugenics in the Deep South* (Baltimore: Johns Hopkins University Press, 1995).

[3]. Margaret Hagood, *Mothers of the South: Portraiture of White Tenant Farm Women* (Chapel Hill: University of North Carolina Press, 1939); Rebecca Sharpless, *Fertile Ground, Narrow Choices: Women on Texas Cotton Farms, 1900-1940*

(Chapel Hill: University of North Carolina Press, 1999).

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