

VIEWPOINT

Ensuring Equity and Justice in the Care and Outcomes of Patients With Cancer

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Supplemental
content

In 1966, Rev Martin Luther King Jr told the Medical Committee for Human Rights, "Of all the forms of inequality, injustice in health is the most shocking and the most inhuman...." The problem of health inequity rings especially true for cancer. In 1980, all women in Chicago had the same cancer mortality rate: there was no disparity. By 2007, black women were substantially more likely than white women to die from breast cancer and metastatic colon cancer, even as, or perhaps because, therapies improved. Historical shifts have produced the wide racial gaps in survival seen today for many cancers, and this injustice has been exacerbated by government inaction.

While exact data on unnecessary deaths from cancer care disparities are not precisely documented, an estimated 134 000, or 22% of the 610 000 individuals in the United States who died of cancer in 2018, could have lived if they had the health care access, quality, treatment, and outcomes of college-educated individuals.¹ For all this profound inequity, addressing cancer injustice does not require a technological solution. This is known because some communities have reduced racial disparities, whereas others have eliminated them altogether. The biological, psychosocial, and socioeconomic complexity

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of cancer disparities are important, but that complexity cannot deter the United States from enacting proven policy measures to rectify racial inequities.

Elected leaders with the courage to act have the tools to address the injustice related to cancer outcomes. Highlighting these initiatives is important to give tangible examples for what is possible when policy makers commit to cancer justice. If policy action can reduce cancer inequity, the converse also holds true. The persistence of racial disparities across parts of the United States is attributable, at least in part, to government inaction.

Historical Aspects of Cancer Disparities

Throughout the 20th century, US cancer mortality rates increased, peaked in 1991, and then declined 26% from 1991 to 2015.¹ But shifts in mortality have differed markedly among racial populations. Although the US black population experiences higher cancer mortality outcomes today, this was not always the case. Until the late 1950s, the US black population actually had lower cancer mortality rates than the US white population.² Throughout the latter half of the 20th century, cancer mortality in the black population increased substan-

tially, whereas cancer mortality in the white population remained nearly flat. Systemic factors, namely early detection and quality treatment inequities, have been identified as primary drivers of these racial differences in cancer outcomes, which form the basis for the substantial racial gap that continues to this day.

From the 1990s to 2015 (the last year for which data are available), cancer mortality rates have declined for most racial groups, although this decline has been inconsistent, varying substantially by region. Three-quarters of US counties show racial disparities in breast cancer mortality. Even worse, across 35 of the 41 largest US cities, breast cancer mortality disparities actually increased.³ Yet, in other localities, the disparities have been reduced. With racial disparities in mortality increasing in many jurisdictions and declining in others, the importance of regional policies that implicate access to early preventive services and quality treatment cannot be overstated.

Cancer injustice today is related to disparate mortality rates for 3 major cancers—female breast cancer, prostate cancer, and all-gender colorectal cancer (Figure in the Supplement). For these 3 cancers, the annual age-adjusted mortality rates per 100 000 persons in 2015 (the most recent year available) for the black population compared with the white population were 27.6 vs 19.8 for female breast cancer, 37.5 vs 17.8 for prostate cancer, and 18.6 vs 13.7 for colorectal cancer.⁴ For these cancers, scientific progress has enabled low-cost early detection and effective therapies; but crucially, these medical advances are not yet available to all patients. Addressing cancer disparities, therefore, does not require new screening or treatment methods, it simply requires action that equalizes access to and utilization of high-quality care. In other words, cancer injustice is not a science problem, a technology problem, or a genetics problem. It is a policy problem.

Model Policy Responses to Cancer Injustice

Health policy is made in many ways. Insurers set policy with coverage decisions. Foundations and universities set policy in deciding what studies to fund. This Viewpoint focuses on one key locus of health—state and local policy action—because there are few health care–related areas in which government has failed communities of color more than in cancer mortality.

Indirect evidence of this failure comes from observing wide differences in black-white mortality rates by states within the same region and compared with others across the United States. More importantly, there is direct evidence that when ending cancer injustice becomes an explicit government priority, racial disparities decline precipitously or disappear altogether. If some

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governments allow cancer disparities to persist, can their failure to act be attributable to anything other than a conscious decision that other goals are more worthwhile than the fundamental problem of racial injustice?

In 2003, the New York City Department of Health and Mental Hygiene initiated the Citywide Colon Cancer Control Coalition (C5). C5 embarked with 2 objectives: increase colonoscopy screening rates to 80% and eradicate racial disparities. The department enlisted medical professionals to popularize early colonoscopies; facilitated free screening for uninsured populations; developed an open-access system enabling patients to schedule screenings without having to first consult gastroenterologists; and invested in patient navigation to ensure patients understood colon preparation and had transportation to screening. Ten years later, the prevalence of eligible residents who were up to date for colorectal screening increased from 42% to 69%, and screening disparities by race were substantially reduced.⁵ By 2015, the age-adjusted death rates for the black population (12.5 per 100 000) and the white population (13.1 per 100 000) were very similar.⁶

Around the same time, Delaware established a colorectal cancer screening program to eliminate racial disparities. For uninsured individuals, Delaware paid for screening, provided patient navigation, and provided 24 months of quality treatment. From 2001 to 2009, screening disparities declined, the colon cancer mortality rate decreased across the board, and the most recent registry data show minimal mortality disparity by race.⁷ The annualized age-adjusted mortality rate per 100 000 from 2010 to 2014 was 13.5 (95% CI, 12.4-14.6) for the white population vs 15.3 (95% CI, 12.6-18.3) for the black population.⁸ The Delaware program costs \$1 million per year and yields annual savings of \$8.5 million.

In 2007, black women in Chicago were 62% more likely to die from breast cancer compared with white women.⁹ Studies showed

that black women were less likely than white women to receive mammographic screening, and those who did were more likely to receive poor-quality screening. Black women diagnosed with breast cancer were more likely to receive poor-quality treatment. In response, a community-based organization, the Metropolitan Chicago Breast Cancer Task Force, implemented quality-improvement projects and navigation programs and advocated policy changes to the improvements. The result was a 39% decline in death rate over 9 years.⁹ Indeed, Chicago has had the largest breast cancer mortality decline among black women of any major US city.⁹

These examples share several themes. First, policymakers made affirmative commitments to eliminate racial disparities. Second, partnership with medical and advocacy communities facilitated comprehensive public health solutions. Third, sustained investments in high-quality screening and patient navigation involving high-quality referrals empowered disadvantaged patients throughout the complex continuum of care. Collectively, these case studies illustrate the promise of policy action.

However, these successful experiments do not diminish the concurrent potential of other programs, including quality education and a robust social safety net to alleviate inequities. Practical hurdles faced by political entities working to achieve cancer justice must also be addressed, including the need to commit funds.¹⁰

Society should not regard the goal of curbing cancer injustice as more complicated than it really is. If policymakers tolerate cancer disparities in the communities they serve because of competing priorities, they should state truthfully that they have knowingly chosen to do so. What should no longer be tolerated is the misguided belief that the problem is too difficult to solve, cannot be solved, or that it is due to the affected person's genes or inaction. Public health evidence to the contrary is too compelling, and condoning such excuses violates fundamental principles of equality.

ARTICLE INFORMATION

Published Online: April 8, 2019.

doi:10.1001/jama.2019.4266

Conflict of Interest Disclosures: Dr Brawley reports receipt of a grant from the National Cancer Institute during the conduct of the study and personal fees (for book royalties) from St Martin's Press. No other disclosures were reported.

Additional Contributions: The contributions of Matt K. Nguyen, BA, JD candidate, Yale University Law School, and Eugene Rusyn, JD senior fellow, Solomon Center, Yale University Law School, were critical to the development of this article. We also want to thank Anne Marie Murphy, PhD, Executive Director of the Metropolitan Chicago Breast Cancer Task Force, for her editorial help. These individuals were not compensated in association with their contributions to this article.

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