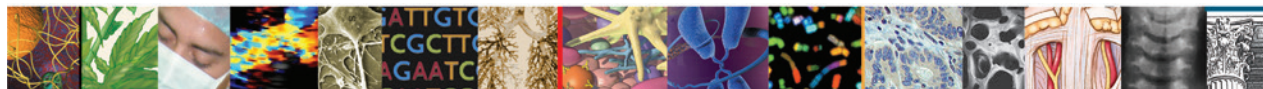


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Structural racism — A 60-Year-Old black woman with breast cancer

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CASE STUDIES IN SOCIAL MEDICINE

Structural Racism — A 60-Year-Old Black Woman with Breast Cancer

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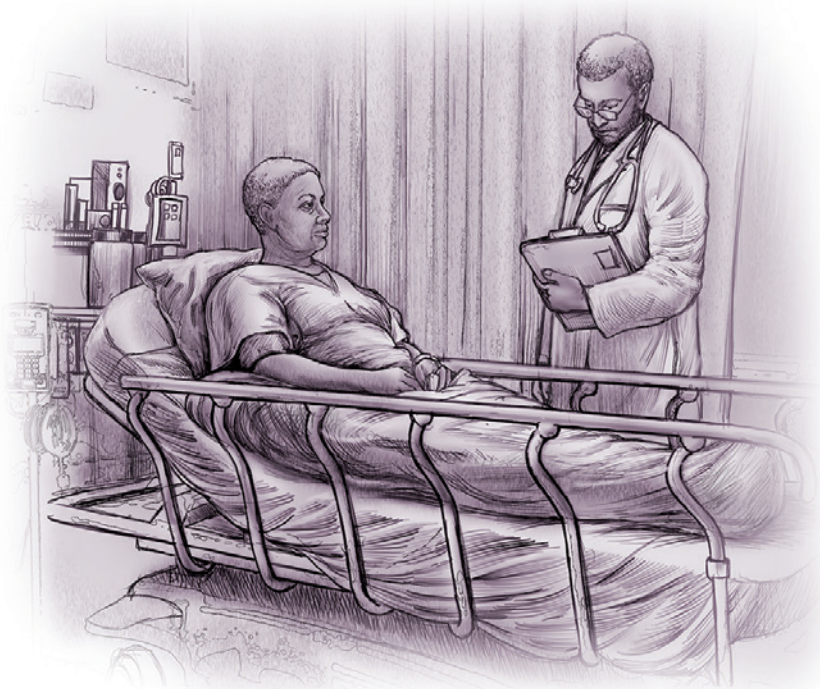
In 2015, Ms. M., a 60-year-old, unemployed, uninsured black woman, presented to the emergency department at a Chicago community hospital with a breast lump. The emergency medicine physician suspected an infection and, without diagnostic testing or planned follow-up, discharged her with a prescription for antibiotics.

When the lump persisted, Ms. M. obtained a mammogram, which revealed potential breast cancer. She was referred to a general surgeon on staff at the community hospital, who excised the cancer and recommended a mastectomy with axillary node dissection. Ms. M. was neither informed of her cancer's stage nor referred to an oncologist.

However, she was then contacted by a navigator who'd been

assigned to the hospital by the non-profit Metropolitan Chicago Breast Cancer Task Force to review abnormal mammograms and guide women into evidence-based treatment. The navigator referred Ms. M. to a breast surgical oncologist at an academic medical center. There, the specialist informed her that she had stage III infiltrating ductal carcinoma, which required a needle biopsy — not an excisional biopsy — and that a mastectomy was unnecessary. This “came just in time to stop me from having my breast cut off,” noted Ms. M.

Many hospitals in Chicago's largely black neighborhoods lack an American College of Surgeons (ACS) Commission on Cancer Center designation.¹ This designation provides a quality framework to



guide cancer care. Of the 12 Chicago hospitals with this designation, only 2 are located on the city's predominantly black South Side. Furthermore, at the South Side community hospitals lacking the ACS designation, mammograms are often read by general radiologists, not mammography specialists. Many of these hospitals are not equipped to perform needle biopsies of suspicious breast masses, which is the standard of care. Hospitals that serve Chicago's minority neighborhoods often face financial constraints that limit the breadth of their cancer care services.

The Metropolitan Chicago Breast Cancer Task Force was established in 2008, when local researchers revealed a growing gap between black women and white women in breast cancer-related mortality.¹ As advances in breast cancer screening, diagnosis, and treatment were adopted, breast

cancer mortality among white women dropped in Chicago and nationwide, whereas breast cancer mortality among black women decreased either less or not at all.

Community concern about the growing disparity led to a call to action. Physicians, community leaders, and public health advocates convened to form a task force with workgroups to examine the causes. The task force, initially funded by the Avon Foundation, identified variation in access to mammography and gaps in the quality of breast cancer diagnosis and treatment, rather than biologic differences, as reasons for the disparate outcomes. Black women in Chicago were almost 40% less likely than white women to receive breast care at a breast imaging center of excellence. Furthermore, they were more likely to have their cancer missed on screening mammograms.²

Identifying inequality in the geographic distribution of high-quality care as a root cause of the mortality disparity, the task force established a consortium to improve the quality of breast cancer care. Data from this effort revealed that many safety-net hospitals in Chicago's minority neighborhoods performed poorly on standardized measures of breast care. The task force initiated quality-improvement efforts, such as technician training, physician workshops, operational process improvements, and standardized data collection, and it assigned navigators to lower-quality, underresourced hospitals to guide women with breast cancer toward hospitals that had the ACS designation.¹ These interventions disrupted the invisible, structural roots of inadequate breast cancer care provided by community hospitals serving segregated neighborhoods.

Social Analysis Concept: Structural Racism

Racism is often assumed to mean interpersonal discrimination, which has well-documented negative health effects. Yet racial disparities in breast cancer mortality can be exacerbated by “structural racism” — a manifestation of historical and contemporary “structural violence,” whereby a social structure or institution creates harm by preventing people from meeting their basic needs (see box).³ Structural racism is the embedding of socially and culturally enforced racial hierarchies in societal norms, institutional practices, and laws; it is often not explicitly identified as race-based and is perpetuated

in the implicit assumptions that guide everyday institutional practices, such as clinical resource allocation and decision making in a segregated health care system.³ In this case, structural racism is a root cause of the unequal distribution of breast cancer resources.

Historical patterns of racism and disinvestment have left segregated neighborhoods of concentrated poverty without the same health care resources as affluent neighborhoods.⁴ In the case of breast cancer mortality, these social forces manifest themselves at the institutional level through resource allocation, accreditation, and the availability of cancer-specific specialists, including mammographers and oncologists. At the community level, maldistribution of resources makes obtaining high-quality care more difficult for women in primarily minority neighborhoods than for women in other neighborhoods. The task force demonstrated that safety-net hospitals in Chicago’s minority neighborhoods often provided substandard breast cancer care.⁵ The fact that few hospitals in predominantly black neighborhoods have ACS-accredited cancer programs illustrates the insidious nature of structural racism. Other data show that though racial disparities in breast cancer mortality are a national problem,

they vary among cities, which suggests that differences in local care delivery, not just biologic differences, contribute to the gap.^{1,5}

Race is a social construct, not a biologic category. Definitions of race vary dramatically by place and time, and neither the races delineated in the U.S. census nor those considered in biomedical research protocols are distinguishable on the basis of genetic markers. Racial disparities in health usually result from unequal distribution of power and resources — not genetics.

Structural racism is one root cause of health inequities between blacks and whites in the United States, in outcomes ranging from infant mortality to homicide. Structural racism challenges the epistemological assumptions of health research, which values concepts that can be measured with validity and reliability at the individual level. It calls for clinicians to address deeper, insidious causes of health inequity beyond behavioral and biologic determinants of health. Structural racism compounds the health effects of poverty and other forms of oppression by concentrating poverty in black communities within racially segregated neighborhoods with limited health care options (for additional readings, see the Supplementary Appendix, available at nejm.org).

“Structural racism” refers to the ways in which historical and contemporary racial inequities in outcomes are perpetuated by social, economic, and political systems, including mutually reinforcing systems of health care, education, housing, employment, the media, and criminal justice. It results in systemic variation in opportunity according to race or ethnic background — for example, in racial differentials in access to health care.

Clinical Implications: Ending Structural Racism in Health Care

We propose three critical strategies for addressing structural racism in health care. These strategies hinge on shifting the focus of work on racial differ-

ences in health outcomes from biologic or behavioral problems to the design of health care organizations and other social institutions.

1. Clinicians can make the invisible visible. They can begin by examining health disparities in their practice. Using the data on patient-level quality measures that most

physicians are now given, they can examine clinical outcomes on routine measures of health according to patient race, ethnic background, gender, insurance status, and neighborhood to assess health care equity at their institution or practice.

In the case of breast cancer, the task force used well-established quality metrics from the American College of Radiology and the Commission on Cancer to measure variation among institutions in screening, diagnostic, and treatment practices. By comparing the findings with established quality benchmarks, they showed that hospitals in Chicago's black neighborhoods largely failed to meet mammography quality standards.

Since structural racism operates within and among institutions, measuring quality outcomes according to self-reported patient race, gender, insurance, access, and neighborhood will illuminate opportunities to mitigate inequities in care delivery that might result in outcome differences for patients within individual practices. When racial differences are found, clinicians can seek to understand the social and structural

factors at play and determine the extent to which structural racism, rather than

“race,” is the fundamental cause of the disparity.

2. *Health care organizations can engage the community in an effort to*

change the accepted explanatory narrative. The Chicago task force organized community forums to gather input from minority women on their experiences related to breast health. At community meetings, data were presented supporting the hypothesis that racial disparities are caused by structural racism that leads to variations in care delivery. In addition, the task force engaged public relations firms to synthesize epidemiologic data into talking points and press releases. The media integrated the message about structural racism and quality improvement into their reporting, which led to legislative advocacy, research, and front-page news stories. As a result, the Chicago Department of Public Health made the reduction of racial disparity in breast cancer mortality part of its public health plan. In these ways, the narrative of breast cancer mortality among black women was changed from a story of biologic or behavioral inevitability to the story of a symptom of a pathological social system that could be improved.⁵

3. *Institutions can make systemic changes to eliminate structural racism.* Eliminating racism requires strategies that go beyond health care. Within health care, the task force found substandard screening, diagnostic, and treatment practices at some Chicago hospitals serving minority neighborhoods.⁵ They engaged hospitals in quality-improvement efforts, updating the technical skills of breast-imaging

staff, establishing standardized systems for follow-up of abnormal results, and placing navigators at low-performing hospitals to steer women with suspected breast cancer to accredited centers. Facilities that participated in these efforts showed gradual improvement, though gaps remain, particularly in safety-net institutions. Helping women seek diagnosis and treatment at higher-quality institutions remains a critical improvement strategy, but since the task force's inception, the racial disparity in breast cancer mortality in Chicago has decreased by 20% — a result not observed in the nine other U.S. cities with the largest black populations.⁵

Although the precise reasons for this advance are unclear, it has highlighted the effectiveness of quality improvement in mitigating structural racism in health care. But much more than a one-disease-at-a-time approach is required to eliminate structural racism as a root cause of health inequities. Beyond health care, the task force's findings point to the need for equity in other social systems that affect health outcomes. Clinicians can become civically active and join national efforts to promote universal health care and to end poverty, while working against structural racism in housing, schools, and incarceration in addition to health care.



An audio interview with Dr. Ansell is available at [NEJM.org](https://www.nejm.org)

Case Follow-up

At an academic medical center, Ms. M. received appropriate treatment for stage III infiltrating ductal

carcinoma: induction chemotherapy, a wider excision of the lumpectomy site, and radiation

treatment. At last contact 6 months after diagnosis, she remained cancer-free.

The editors of the Case Studies in Social Medicine are Scott D. Stonington, M.D., Ph.D., Seth M. Holmes, Ph.D., M.D., Helena Hansen, M.D., Ph.D., Jeremy A. Greene, M.D., Ph.D., Keith A. Wailoo, Ph.D., Debra Malina, Ph.D., Stephen Morrissey, Ph.D., Paul E. Farmer, M.D., Ph.D., and Michael G. Marmot, M.B., B.S., Ph.D.

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A Belmont Report for Health Data

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Legal safeguards for health data are limited in scope in the United States. The Health Insurance Portability and Accountability Act (HIPAA) covers identifiable health information held or transmitted by health plans, health care providers and clearinghouses, and their business associates. However, HIPAA doesn't apply to various other companies or products that regularly store and handle customer health information, including social-media platforms, health and wellness apps, smartphones, life insurers, retailers, credit-card companies, and Internet search engines; HIPAA also places no limits on the use of deidentified data, regardless of who controls the information.¹ Beyond coverage limitations, HIPAA doesn't mandate ethics review for data collection or downstream use. Rather, ethics review is required only if other laws are triggered — specifically, in cases of research on living humans that falls under the Common Rule or research intended

to support medical product applications to the Food and Drug Administration. Yet much of contemporary data analytics falls outside these areas — and thus outside mandatory ethical oversight.

The large swaths of data held by digital health pioneers raise a host of ethical concerns related to the reporting of incidental findings, misuse of private information, reidentification of deidentified data, discrimination, and health profiling. Last year, Facebook sought to purchase deidentified patient records, match the records with its identifiable user data, and create digital health profiles of Facebook users — a practice not precluded by HIPAA. Life insurers are transitioning to contracts that instruct policyholders to wear products that continuously monitor their health; companies can increase a customer's premiums on the basis of information gained from this surveillance, but they have no obligation to provide health

warnings. Concerns about data use can affect clinical care, particularly when patients seeking to protect their privacy either avoid care or withhold relevant health information from their provider.²

Just as indignities common in research in living people led to the articulation of ethical principles in the Belmont Report 40 years ago, we believe contemporary concerns about data use call for stakeholders to promulgate ethical guidance for health data.

Regulations regarding protection of personal data — including the recently enacted General Data Protection Regulation (GDPR) in the European Union and the California Consumer Privacy Act — emphasize notification, consent, and deletion rights. But notice and consent, although essential components of data ethics, are insufficient for ensuring ethical use of data. Even under the GDPR's robust protections, research suggests that most Europeans generally click “OK” to accept a company's privacy