

Political Discourse and the Framing of Health Equity

Cancer and Race: What They Tell Us about the Emerging Focus of Health Equity

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Abstract This article examines the history of concepts and frames (such as “equity” or “disparities”) and how these frames have guided public policies and explanations about differences in health across the population. Considering the emblematic case of cancer, which has stimulated long and heated debate over social, economic, and biological causes, the article argues that the vocabularies of health reform are both semantic and also deeply political—framing different reform agendas. The article describes the evolving US debate over the biological, social, or environmental origins of differential cancer mortality along lines of social difference and race, tracing important shifts and reversal over time. Through this analysis, the article explains how and why equity concerns have figured (sometimes implicitly, sometimes explicitly) in health reform discussions, often in tension with other frames. It examines how Americans have used these frameworks to justify different kinds of action and inaction, concluding with a discussion of how these frameworks of “disparities” and “equity” should be understood today in scientific, political, and policy discourse.¹

Keywords race, health equity, cancer, health disparities

Recently, the focus of many reform-minded scholars, funders, and some policy makers has shifted from disparities—reducing inequalities in mortality, incidence, and survival across groups—to equity, defined as focusing on “those disparities that can be traced to unequal, systemic, economic, and social conditions” (McNeill Ransom et al. 2011: 94). The shift in terminology is not merely semantic, but represents (at its heart) a

1. This reflection essay draws heavily on my book, *How Cancer Crossed the Color Line* (Oxford University Press, 2010).

new programmatic vision—it aims to focus on unjust structural conditions that shape health outcomes. In other words, while disparities (in health outcomes) might have many roots, from social class to biology and environment, the focus on inequities seeks to call attention to differences that are created by malleable social circumstances.

There is both a rhetorical and political strategy at the heart of this shift in language—narrowing the scope and target of reform while honing in on the health effects linked to social status and environment. Equity-focused scholars and reformers ask, why should zip code and the social circumstances of one's birth, upbringing, and life make such a difference in health outcomes? Championing this new approach, for example, the Robert Wood Johnson Foundation has insisted that many disparities in health are rooted in disparities in structural opportunity. "When it comes to health across cities," commented Catherine Malone and Dwayne Proctor, "zip codes are unequal and so are health outcomes. . . . Our goal is greater health equity in America." According to this ideal, if health equity is achieved, "the end result should be decreased health disparities."² Embracing this new call to action, as one reform-minded group of scholars have put it: "The goal of health equity will not immediately eliminate all health disparities, but [it] will provide a foundation for moving closer to that goal" (Health Equity).³

As policy frames, terms like "equity" and "disparities" are calls to action—highlighting achievable goals. Since at least the early 1970s, for example, reducing cancer disparities has focused epidemiologists, public health officials, scholars, and others on expanding cancer screening, ensuring access to prompt diagnosis and treatment, and evening out chances of survival. The inequalities are stark. Black women with lower incidence of breast cancer than white women were experiencing higher mortality, why? Such disparities in cancer incidence, mortality, and survival had their origins in differential access to care, reformers argued. Narrowing the gap became the crucial measure of progress. But skeptics promoted another contention—that some disparities could be rooted in differences in biology and genetic risk—and, as such, were not as easily "fixed" or

2. Catherine Malone and Dwayne Proctor, "Shaking Up Systems to Achieve Health Equity," (May 17, 2016). www.rwjf.org/en/culture-of-health/2016/03/shaking-up-systems.html.

3. The idea of equity has attracted increasing interest—coming into wider use among health scholars and reformers over the past decade or so, and framing an old challenge (the problem of addressing population-wide health inequalities and disparities) from a new perspective—not by trying to lower the gaps in mortality between groups but by looking at each group and attempting to achieve the highest level of health possible, bearing in mind different socioeconomic conditions. Where disparities research focused on reducing differences in outcomes, the new focus on inequities focuses on a related, yet distinct, problem—fixing avoidable or unjust differences in health.

remedied. Unlike those health disparities rooted in social and economic inequalities, some disparities might never go away, they contended. For the last few decades, this biological claim has deviled those who seek to reduce cancer disparities. The inequity argument can be seen as a new chapter in this ongoing debate, sidestepping the biology question by refocusing not on striving for equality but for equal opportunity and on injustice.⁴

Tensions in the vocabulary of health reform (equity, disparities, socioeconomic roots, genetic, and so on) have guided public policy interventions for decades. In what follows, I consider the history of how cancer differences have been framed—an emblematic case of how frameworks have mattered in policy and society. To look at cancer is to see shifts and tensions in the unfolding debate over the origins of differential health. The recent focus on “equity” is merely the latest chapter in this century-long debate. Yet, the focus on equity is not fundamentally new; the concept, even if not the word itself, has often figured in health reform and justified different kinds of political reform.

Framing of Cancer and Difference: Before Disparities

Before Americans began focusing on cancer disparities in the 1960s and 1970s, how did they frame inequalities in mortality across the population? One hundred years ago, most health experts believed that health disparities were natural—part of a normal fabric of the social and biological order. Few experts would have championed a cause or call to reduce cancer disparities because any disparities were seen as defined by different bodies and different biological risks. It was, for example, a disease associated simultaneously with longevity, biology, and social circumstances. The longer you lived and the more you were able to avoid mortality from the dominant infectious diseases of the time (such as tuberculosis), the more

4. In 2016, for example, when the Susan G. Komen Foundation announced a new \$27 million “health equity” initiative to reduce breast cancer deaths in African American communities, they threw their weight behind the idea that it was not biology but “local programs like screening, treatment assistance, emergency financial aid, medical supplies, and living expenses” that determined death and survival. “Susan G. Komen Announces \$27 Million Health Equity Initiative to Reduce Breast Cancer Deaths in African-American Community—10-City Initiative Complements Komen’s Decades-long Service to Medically Underserved,” “African American women are almost 40 percent more likely to die of breast cancer than white women in the U.S. and in some cities, that number is as high as 74 percent. That makes this a public health crisis that must be addressed immediately,” said Komen President and CEO Dr. Judith A. Salerno. “We are deeply appreciative of friends and partners who are working with us to do so.” [ww5.komen.org/News/Susan-G-Komen-Announces-\\$27-Million-Health-Equity-Initiative-To-Reduce-Breast-Cancer-Deaths-In-African-American-Community.html](http://ww5.komen.org/News/Susan-G-Komen-Announces-$27-Million-Health-Equity-Initiative-To-Reduce-Breast-Cancer-Deaths-In-African-American-Community.html).

likely you (and your social group) were to die from cancer. Tuberculosis was a disease of the underprivileged; cancer was a disease of the longer lived and well-to-do.

Racial biology, so called, also figured prominently in this framing of mortality differences with white people seen as carrying higher risks. “Without exception,” wrote the influential Prudential Life Insurance company statistician, Frederick Hoffman, “the general cancer mortality is higher for the white population than the Negro” (Hoffman 1915). Racial behavior, in experts’ view, also explained differential rates of venereal disease, tuberculosis, and infectious disease. Hoffman and many other health experts saw these differences as outgrowths of natural differences in the way white and black Americans lived. For experts, these differences in lifestyle and social circumstances were not biological, but largely social.

Experts of this era framed cancer as a disease of civilization, and saw “primitive” societies as relatively protected from its ravages. So too did class differences frame the cancer question. In an era where infectious diseases (tuberculosis, pneumonia, and others) were the leading cause of mortality, poor people lived in worlds where infectious disease, childhood mortality, and early death dominated. By contrast, better-off people who enjoyed longer life spans survived these threats in greater numbers. The consequence of their survival was that they lived long enough to reach the so-called “cancer age”—a dominant view that linked cancer to privilege, aging, and higher social status. If cancer was a disease of privilege, then the absence of cancer in lower-class groups was a point of curiosity for experts. Writing in his book *Cancer: Its Origins, Its Development, and Its Self-Perpetuation*, New York surgeon Willy Meyer wrote that “primitive people . . . in the familiar character of their restful surroundings, would almost seem to be on a par with the fish of the ocean, the life of which is spent in place indifference in the never-changing salt solution and its always equal temperature” (Meyer, 1931: 236). For such experts, cancer disparities were embedded in the different cultures and ways of life of blacks and whites.

In the first half of the century, however, a handful of shrewd dissenters ignored this civilization-primitivism framework, and understood that cancer mortality differences were themselves the product of a society with unequal access to resources. For them, different social factors explained disparate outcomes. As one expert wrote in the *American Journal of Cancer* in 1935, “Cancer appears to be less prevalent in the colored population,” but statistics were notoriously unreliable. “Undoubtedly, differences in diagnostic practice [that is, in access to diagnosis] have

some effect upon our statistics on cancer death rates” (Holmes 1935). In this view, well-to-do people only appeared to have higher cancer rates because they had greater access to diagnostic services and care. For Louis Dublin, insurance access (life insurance) confounded what was known and unknown about cancer. As chief statistician at Metropolitan Life Insurance, he understood that differences in insurance coverage (not only in access to diagnosis) skewed the cancer mortality data—shaping theories about who had cancer and where cancer resided in society. As Dublin wrote in 1928, if there was one serious limitation in the cancer mortality data, it was that “the business is conducted, very largely in the urban areas. . . . The conditions which prevail in the rural South, where a large proportion of the Negroes live, are therefore not closely reflected by the insurance experience” (Dublin 1928). A new idea took root here—the notion that access to health care services influenced the cancer statistics and the mortality trends.

Dublin’s insights were not driven by a concern with equity; rather, his words illustrate a growing sensitivity to the fact that existing frames of primitivism and civilization were inadequate, and did not explain differential cancer mortality. For such observers, the old framework was misguided and deceptive. Nor did the old frame offer a plan of action. Structural questions such as unequal access explained why some died from cancer and others did not. For these critical observers, new frameworks were needed to explain the social origins of these disease differences.

Social Inequities and Health—the Rise of a Modern Frame

New times called for new frameworks. In the context of the Great Depression and the New Deal (and the growing pressure on government to collect evidence and to respond to widespread economic deprivation), the 1930s and 1940s witnessed a more explicit reform focus on the social origins of health outcomes. Expanding New Deal government brought more robust federal and state involvement in reducing the toll of infectious disease mortality and childhood mortality, and reshaped how US society began to grapple with cancer. Programs such as the National Cancer Institute, the US Public Health Service, and Social Security were created as efforts to enhance access, and to reduce inequities across groups. The social welfare agenda of New Deal reform was sweeping, even if at the same time these programs existed within (and continued to promote) a segregated racial society.

Mid-twentieth-century social and economic forces were gradually altering awareness of cancer disparities—shifting not only the idea that cancer was a disease of privilege, but also establishing new views about the social origins of cancer. For example, the migration of black Americans into cities where cancer diagnosis was more common meant an increasing likelihood of diagnosis, albeit in struggling public hospitals and not in white-only or segregated facilities. In the context of migration, old regional differences in access to care were accompanied, and in a way displaced, by new institutional ones. Diagnosis was slowly improving everywhere, but not evenly. But also government programs played a role, as the US Public Health Service initiated new programs such as the Ten Cities Cancer Surveys, pushing government statisticians like Harold Dorn to look at cancer statistics with new eyes. All these trends—in migration, diagnostic science, and government—slowly eradicated the old primitivism-civilization framework of cancer.

At mid-century, health was in epidemiological transition in America, and most experts acknowledged that disparities were never static but always evolving. With infectious disease in decline as a major cause of mortality, the death toll from chronic degenerative diseases like cancer rose to take their place. As old disease divisions disappeared, new ones appeared—giving rise to a new face of health differences during the period from 1940 through the 1960s. More and more, cancer was understood as an “equal opportunity disease,” and one that should—in the natural course of things—affect each group equally. To the extent that outcomes differed, experts began to ask why. And it is here (in this society where infectious disease mortality fell across the board, if unevenly) that a modern focus on cancer disparities emerged. And by the 1960s and 1970s, in the context of a rising focus on civil rights and health care reform, the fight against those disparities began to take shape.

Adding further complexity to this epidemiological picture, cancer itself was changing as a result of medical and scientific specialization—the malady no longer being regarded by experts as one singular disease, but as coming in many different types, each of which told a different story about disparities across the population and methods of prevention. In some cancers, behavior (not race or biology per se) seemed to be a major factor when discussing disparities. As one 1950 Congressional Report on the new cancer trends highlighted, breast cancer rates in the US population told the story of higher incidence among whites as compared to nonwhites. Experts theorized that these disparities could be explained by social factors (difference in behaviors such as rates of breastfeeding). Lung cancer, on the

other hand, revealed higher incidence in whites than in nonwhites; but here, studies suggest another social factor (cigarette smoking) played a dominant role in the rising incidence and mortality among white men. By contrast, cervical cancer showed higher incidence among nonwhites, provoking some experts to wonder about the role of sexual behaviors. By the 1950s, then, many observers had developed a behaviorist framework to explain these disparities—theorizing that cancer differences were rooted not in biology, as once believed, or in civilization, but in social differences in increasingly stigmatized behaviors. To fix these disparities, it was said, one needed to address the underlying behaviors—smoking, sex, and practices associated with maternity.

By the years after World War II, a new face of cancer inequality had arisen—one that was far more complicated and confusing than the prewar picture, and one where an active debate about multiple causes and different methods of intervention and prevention had arisen. Disparities came in many shades. By the 1950s, even as some experts linked cervical cancer to behavior, for example, new diagnostic tests like the Pap smear—linking early diagnosis to increased survival—meant that differences in access to diagnosis figured more than ever in mortality differences. With expanding access to testing, such cancers became more clinically and socially visible at earlier stages of development. Yet, it would take another decade before experts would frame these differences in access as questions of equity and social injustice.

The 1960s health care debates over Medicare and Medicaid provoked a quantum shift of framework by squarely associating health outcomes with differences in access to health services, and identified health insurance as the crucial factor separating the haves from the have-nots in society. The World War II environment had seen this new framework slowly unfold, with Americans witnessing the rising cost of health care and the expansion of private health insurance—a set of developments that left behind many in the population (particularly the elderly and poor). Since the 1930s, out-of-pocket payments for health care expenditures had risen steadily, driven by a greater number of tests and therapies. By the late 1940s, private insurers had entered the market (covering growing numbers of Americans, often through their employers), and ensuring access to an expanding market of high-cost goods. Systematically, these trends created the growing gap between those with and without private health insurance. This new political reality explains much about what drove President Truman and other Democrats to push for national health insurance in the late 1940s, it underpinned the establishment of disability provisions in Social Security in

the 1950s under Eisenhower, and it defined the pressures building into the early 1960s to pass Medicare and Medicaid. The central reform ideal of this era became expanding access to those who were most vulnerable, including the disabled, the elderly, and the poor, and to even the playing field in the name of fairness and equity.

Although the term *equity* was not widely used at the time in these debates, a powerful equity-based framework defined these political battles. The unfairness of the emerging health insurance gap was palpable. “Almost everyone realizes that a great mass of the old people do not have the savings, and cannot depend upon their children, to pay for the doctors, hospitals, nursing homes, and drugs which, because they are aging, they need more than do younger people,” wrote Walter Lippman in 1960.⁵ This insurance gap opened a vexing new stage in the American debate—hinging not on whether there were inequities in the emerging health care system, but what to do about such inequalities and injustices.

In the years leading up to the passage of Medicare and Medicaid in 1965 (and coinciding with the peak of civil rights legislation), the inherent unfairness of the US health care system circumscribed every discussion about health and society in America. It was widely assumed that structural injustice led to disparate health outcomes—cutting along lines of race, class, and age. This insistence fueled programmatic innovations in government and social services, and spurred a decades-long debate that carries over into our own era. Today’s framework for thinking about equity owes much to this era of activism and political reform. Yet, this earlier era also produced something else in its wake: a new “disparities” framework focusing on reducing epidemiological gaps and seeking equality in disease outcomes (such as cancer) across groups.

The Discovery of Racial Health Disparities

The passage of Medicare drew millions of elderly Americans into what Louis Dublin had called the “insurance experience,” and thus also into the medical care system and, as a consequence, provided more comparable access across lines of class and race to the elderly (Dublin 1928). Yet, new gaps in health experience across the population began to appear even as old gaps persisted. With expanding access through private and public insurance, for example, the data on cancer incidence and mortality began to shift. Seven years after Medicare’s passage, health statisticians marveled at

5. Walter Lippman, “Medical Care for the Aged,” *New York Herald Tribune*, June 16, 1960, 20.

an apparent inversion of the old theory of race and cancer. Where early twentieth-century experts had labeled cancer as a white disease, new studies in the early 1970s observed that cancer “was not just a white disease” anymore (Slater 1979). As *Newsweek* reported the findings of an influential Howard University study:

The death rate from cancer in the U.S. has been rising steadily since the beginning of the century, due in part to the control of such major killers as tuberculosis and pneumonia. But recently, epidemiologists have discerned a striking new feature of this trend . . . a sudden, sharp rise in cancer deaths among Negroes. (“Cancer in Negroes,” 1979)

The Howard study observed that, from 1950 to 1967, mortality had risen from 147 per 100,000 to 177 per 100,000 for African Americans while the rate had stabilized at 150 for whites. Epidemiologists, cancer specialists, and society at large had discovered a new face of cancer disparities. Cancer had mysteriously crossed the color line. Narrowing this worrisome gap became an epidemiological and a political concern.

The early 1970s marked the beginning of a decades-long focus on racial health disparities—with the explicit aim of determining why the gap had grown—and attempting to reduce those gaps. The National Cancer Institute created a new SEER program (Surveillance, Epidemiology, and End-Results) to track these inequalities along multiple axes: cancer diagnosis, treatment, outcomes, and survival. Over the next four decades, the drive for reduced health inequalities seemed only common sense—especially given the recent discovery of the “alarming increase” in cancer deaths and the vital need to reverse these historical trends. For the next generation in this post-Civil Rights/post-Medicare era, few, if any, spoke of health inequities; the new watchword, the potent framework for reform, was attacking “disparities.”

But the “disparities” focus also invited, by the 1980s, a skeptical response—the contention that disparities in population health had many origins, and that resolving them by aiming for equivalence in health outcomes across groups was too ambitious. The agenda of health equality ignored the complex social, biological, behavioral, dietary, and economic origins of disease differences across the population. Skepticism took both epidemiological and political form. If the dream of health equality rested on the liberal, reform-oriented idea that an activist government could address these challenges, this insistence gave way to conservative skepticism in the late 1970s and 1980s. “In this present crisis, government,” President Ronald Reagan announced in his 1981 inaugural address, “is not

the solution to our problem. Government *is* the problem” (Reagan 1981). With the rise of a less active federal government and with the declining commitment to 1960s civil rights agendas (and as the US political climate became more conservative and wary of government activism), the focus on health care injustice waned—and the commitment to addressing disparities faced powerful headwinds. At the same time, a new scientific skepticism appeared—the growing conceit that genetic and biological differences might explain some cancer disparities. An old biological fatalism (akin with the early twentieth century’s primitivism-civilization framework) had reemerged. This genetic perspective resonated with the political climate—both cautioning against liberal intervention and the pursuit of equality.

Into the 1990s, a generation of research had documented the many competing frameworks on health disparities. Looking back across the century, we must understand these contentious frameworks—whether cancer was a social and economic disease, a genetic disease, an environmental ailment, a behavioral malady, or a disease caused by diet, etc.—as a debate in which science remained deeply intertwined with an unfolding political and reform discussion. In light of this enduring competition to control the debate over cancer, the “disparities” framework called attention to the programmatic pursuit of equality even if, by the 1990s, the complexity of that agenda had become clear. The new focus on “inequity” (a term often referring to unfair and avoidable differences linked to injustices such as corruption, exclusion, or governance practices) should be understood in this historical context. In the still-unfolding debate over cancer and health differences, a new focus on inequities shifts us away from the pursuit of equality and away from the biological discussion, and points us toward identifying and addressing the underlying social or structural injustices known to be driving those inequalities. In 1999, for example, the Institute of Medicine drew attention to the “unequal burden of cancer”—noting one example of inequity hidden within cancer disparities: African Americans have lower breast cancer incidence than their white peers (suggesting lower biological risk), yet they have higher mortality and lower survival chance compared to whites (Haynes and Smedley 1999). In the intervening two decades, not much has changed in this epidemiological picture. Examples like these in the cancer world (and in other realms of health) illustrate why and how a new equity-based framework emerged, focusing not on disparities alone but also on injustice, and thereby aiming to restart a stalled political reform agenda.

Framing Health through Equity and Equality

The recent scholarly or reform focus on health equity is thus not fundamentally new, but it represents a kind of circling back to older strategies along the long and winding road of health reform. Bearing in mind the long history of cancer, civilization, behavior, migration, social status, and race, what can we conclude about these shifting vocabularies of health and the rise of a new language of equity?

The focus on equity is a refinement of the previous generation's focus on the pursuit of inequality, a pursuit that has been frustrated and (to some extent) unsuccessful. In retrospect, we can see the quest for equality in cancer outcomes as born from a specific time when the shocking, recent 1960s divergence captured public health attention and cried out for a reversal. Today, some fifty years later, the ideal of achieving health equality across all groups seems unreasonable—especially as we acknowledge just how many complex social, behavioral, biological, and economic factors shape disparate outcomes across groups, and as the drive to achieve health equality has been frustrated by political and biological skepticism.

The focus on health equity turns our attention away from equality per se, avoids the critique leveled at those who aimed toward health equality, and avoids the familiar biological criticisms—pointing instead toward addressing fundamental issues where health differences have demonstrable origins in social justice and fairness. As the history of American cancer discourse highlights, there have always been fierce competing frameworks for characterizing health differences across the population—debates that are at once scientific and political. The call for health equity is the latest chapter in this unfolding drama. It originates in a frustrating space—with an acknowledgment that reducing “disparities” one disease at a time has been a difficult road. It also originates with a powerful hope—that a new agenda focused on addressing those social differences that clearly and demonstrably produce disease differences can bring progress in a challenging and ever-changing political climate. Every framework, of course, has its limits—telling only part of the story of health and health reform. Disparities, in many ways, is the language of striving for epidemiological equivalence and bringing mortality and morbidity statistics into rough alignment; but the idea of closing the gap was, by definition, both grand yet frustrating and limited. By contrast, the striving for health equity injects the language of social justice into the health debate. The pursuit of *equity*, however, has this limitation—it focuses on a goal that is extremely difficult to measure. Looking ahead then, should the goal of cancer reform be

reducing disparities or equity? Clearly, the answer must be not a commitment to one or the other, but to both continuing on the road to reducing disparities and developing measures and a science to support the pursuit of health equity.

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