HEALTH CARE AND CIVIL RIGHTS: AN INTRODUCTION

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This article offers a brief history of healthcare civil rights, describes a range of healthcare issues that have a civil rights component, and discusses the need for an expanded civil rights framework to guide the provision of health care. Unequal health care based on race and ethnicity has received renewed attention over the past several years, but healthcare discrimination based on socioeconomic status, disability, age, and gender also deserve careful attention. (*Ethn Dis*. 2005;15[suppl 2]:S2-27–S2-30)

Key Words: Civil Rights, Health Care, Healthcare Discrimination, Health Law

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INTRODUCTION

Considering healthcare issues from a civil rights perspective raises many difficult and sensitive legal and social issues, including: racism and other forms of prejudice and discrimination; the appropriate scope of individual legal rights; and the manner in which the country has chosen to organize the financing and delivery of its health care. For example, *Unequal Treatment,* the Institute of Medicine's landmark report on racial and ethnic health disparities, discussed many issues with civil rights overtones.[1] Yet, unequal health care based on race and ethnicity is by no means the only area in health care today that involves important civil rights questions; healthcare discrimination based on socioeconomic status (SES), disability, age, and gender also deserve careful attention. The discriminatory legacy of the US healthcare system and the ease with which the system can perpetuate discriminatory practices of various types argue for an expanded civil rights framework to guide the provision of health care.

This article explores several aspects of the discipline of healthcare civil rights, an area of study that has attracted renewed attention over the past several years.[2] It begins with a short overview of the history of healthcare civil rights in the United States and then describes a range of issues that raise civil rights concerns. Finally, it sets out a series of topics that should be part of any discussion concerning an expanded role for civil rights law in American health care.

A BRIEF HISTORY OF HEALTHCARE CIVIL RIGHTS IN AMERICA

Martin Luther King, Jr. once remarked that "Of all forms of inequality, injustice in health care is the most shocking and inhumane."[3] Yet, prior to the Civil Rights Movement in the 1960s, healthcare injustice was commonplace in this country. Racially segregated health care dates to slavery times, when major plantations had on-site facilities to care for slave laborers.[4] After the First Reconstruction ended in the late 1870s, Jim Crow laws ushered in a new era of discriminatory healthcare access and delivery through separate hospitals and physician practices, separate medical, nursing, and dental schools, and separate professional medical societies.

These dual health systems for patients and providers alike, and the *de jure* legal system underpinning them, existed through much of the 20th century. One example is the Hill-Burton Act of 1946, which provided federal money to states to build new hospitals and refurbish old ones in the aftermath of World War II. The Hill-Burton Act subsidized the construction of 40% of US hospital beds between 1946 and 1976.[5] However, Hill-Burton is also well known for its less altruistic provisions, including one—unique in federal law in the 20th century—explicitly permitting federal underwriting of racially exclusionary practices:

> a hospital will be made available to all persons residing in [its] territorial area . . . , without discrimination on account of race, creed, or color, but an exception shall be made in cases where separate hospital facilities are provided for sepa-

> rate population groups, if the plan makes equitable provision on the basis of need for facilities and services of like quality for each such group.[6]

It would be 17 years before this provision was ruled unconstitutional in the seminal case of *Simkins v. Moses H. Cone Memorial Hospital,*[7] which has been referred to as the "Brown v. Board of Education" of health care.[8]

Following closely on the heels of the *Simkins* case was passage of the Civil Rights Act of 1964, the most far-reaching civil rights legislation of the 20th century. Of major importance to the healthcare field is Title VI of the Civil Rights Act, which prohibits discrimination on the basis of race, color, or national origin by programs and activities that receive federal financial assistance.[9] Federal regulations implementing the law extend beyond acts of intentional discrimination, which are prohibited on the face of the Title VI statute, and reach conduct and practices that, even if facially neutral, have a disproportionate adverse impact on members of minority groups. A year after the Civil Rights Act, the Medicare and Medicaid programs were enacted; these greatly amplified the importance of Title VI, given their infusion of federal dollars into the healthcare system.

Even so, few could have predicted the impact that Medicare, in particular, would have on healthcare civil rights. Since healthcare providers receiving federal Medicare dollars were required to comply with Title VI, then-President Lyndon Johnson had an opportunity to effectively dismantle hospital-based racial segregation. With perhaps unprecedented speed and organization, the Johnson Administration did just that, desegregating hospital wards across the country through a concerted Medicare Title VI certification effort.[8] By the time Medicare was officially launched in July 1966, more than 1,000 hospitals had integrated all components of their operations.[10] Worth noting, however, is that although the Johnson Administration was protecting equal hospital access for racial minorities, it looked the other way when it came to individual physicians under Medicare. In order to secure Medicare's enactment despite opposition from Southern congressional leadership, the Administration exempted physicians from Title VI by classifying Medicare Part B payments as direct assistance to individuals, rather than as federal financial assistance to physicians.[8] Furthermore, nursing homes subsidized by the federal government have not been held to the intensive Title VI compliance and monitoring effort as was required of hospitals.

By 1968, the focus on healthcare civil rights was waning. Several factors led to this decline, including the country's and the Johnson Administration's overall retreat from an activist civil rights agenda. More specifically deflating to healthcare civil rights, however, was the notion that so much had been accomplished: the most obvious vestiges of Jim Crow had been removed from the healthcare landscape by Title VI; Medicare and Medicaid had been enacted; and the Community Health Centers movement, first funded by the federal government as part of the War on Poverty in the mid-1960s, led to the provision of affordable health care to low-income families in rural and urban medically underserved communities and introduced community board governance over the practice of medicine.

Far less understood by the general public, however, but equally damaging to civil rights enforcement in health care, was the separation in the federal Department of Health, Education and Welfare ([HEW], now the Department of Health and Human Services [HHS]) of civil rights enforcement efforts from the agencies directly administering federally financed programs. This division had a devastating impact on the ability of the newly created HEW Office for Civil Rights (OCR) to do its job.[8,11] In fact, the decision to remove civil rights enforcement from day-to-day program administration amounted to a deliberate attempt on the part of some members of Congress to eviscerate civil rights enforcement efforts and, over time, has had precisely its intended effect.[11]

CIVIL RIGHTS CONCERNS IN THE MODERN US HEALTHCARE SYSTEM

Historically, healthcare discrimination has been defined by exclusionary treatment of people based on race. And, without question, racial and ethnic health disparities remain a problem.[1,12] At the same time, the existence of healthcare discrimination on the basis of SES, disability, age, and gender also raise troubling questions. The following section briefly describes examples of ongoing healthcare discrimination in each of these areas.

Socioeconomic Status Discrimination

Compared to racial inequality in health care, health disparities based on class gain little attention. Yet, class is independently associated with health status: those in higher socioeconomic classes live longer and healthier lives than those in lower classes, as demonstrated by an inverse relationship between socioeconomic status and premature death.[13] One potential cause of these economic disparities is the practice of redlining, which refers to discrimination based on geographic location when providing insurance coverage or other services. Although insufficient data exist to know the extent of the redlining problem in health care, the home health, pharmaceutical, and managed care industries have all been singled out as trouble areas.[14]

Physical and Mental Disability Discrimination

Like racial discrimination, healthcare discrimination based on disability has a

long history in the United States, which to this day resonates in our healthcare system's skewing of treatment opportunities for the disabled toward institutional, rather than community settings, and in disease-specific limitations in health insurance. However, the 1990 passage of the Americans with Disabilities Act (ADA) has helped to alleviate at least the former concern in two ways. First, the ADA's overarching goal is to extend to persons with disabilities the maximum opportunity for community integration across broad sectors of society. Second, the ADA vastly expanded the concept of "places of public accommodation" to include private healthcare providers and hospitals.[15] As to the latter concern, courts have consistently ruled that the ADA is not violated by arbitrary service limits tied to certain conditions.[5]

Age Discrimination

Across several fronts, modern medicine seems to be biased against the elderly: medical personnel appear to more quickly diagnose particular conditions in younger patients than in older ones; under-treatment by primary care physicians becomes more prevalent as their patients reach 65 years of age; and older patients may not receive needed surgical care because physicians prematurely assume that the patients' chances of recovery are not good.[16] Another issue pertains to some employers' recent attempts to rescind promised health benefits to retired workers, even in the face of negotiated labor contracts providing lifetime healthcare coverage.[17]

Gender Discrimination

As with healthcare bias against elderly populations, health services research also evidences a gender bias against women, particularly in the area of coronary heart disease.[18] This type of bias has potentially serious consequences, since it could lead to disparate medical interventions and delayed diagnoses. However, even recipients of federal financial assistance do not face suit under Title VI for alleged healthcare-related gender discrimination, since Title VI only prohibits discrimination based on race, color, and national origin. Although it appears to be an untested theory, gender-based healthcare discrimination may be actionable under the US Constitution's Equal Protection Clause.[18] However, a successful Equal Protection claim requires proof of "state action" (ie, a sufficient connection between the government and the conduct complained of) and of proximate causation (ie, a cause-and-effect link between the alleged discrimination and the resulting harm), both of which can be difficult to prove.

Summary: Discrimination Concerns

Finally, overlaying all of these discrete types of healthcare discrimination is the concern that the very method by which the country has chosen to finance and deliver individual health care—namely, managed care—may include systemic practices that alone could perpetuate discriminatory conduct. For example, managed care organizations (MCOs) may avoid setting up contracts in particular service areas altogether, or only sell its products to Medicare, but not Medicaid, in certain areas; or, they may maintain segregated provider networks even within a single service area.[19] In fact, some 90% of African-American physicians believe that MCOs discriminate against them in contracting.[14]

CONCLUSION: AN EXPANDED ROLE FOR CIVIL RIGHTS LAW IN AMERICAN HEALTH CARE

There is a critical need for an expanded civil rights role in this nation's healthcare system, particularly when one takes into account the increasing number of immigrants and elderly in our society. Even the federal government, which has never issued much in the way of health-related civil rights guidance,[11] now seems engaged in the issue, as OCR promulgated limited English proficiency standards in 2003 and both the Democrats and Republicans have recently submitted health disparities bills in Congress. An expanded civil rights framework for health care could take several forms.

Increase Data Collection

It is impossible to know the full extent of the health disparities problem, and impossible to devise solutions to it, without far more data. Title VI regulations authorize HHS to require providers and states to collect race and ethnicity data, but HHS has never exercised this authority.[14] Of course, the fact that HHS has not mandated data collection of this type does not mean that providers and states must refrain from collecting the data.

Breathe New Life into Title VI

The potential reach of Title VI has been far from realized: the federal government, as the largest purchaser of private healthcare coverage in the United States, pours tens of billions of dollars each year into the medical care system,[20] yet reported health care Title VI cases are actually quite scarce. And Title VI enforcement has been drastically undercut by the US Supreme Court decision in *Alexander v. Sandoval,*[21] in which a bare majority of the Court held that individuals who allege disproportionate adverse impact discrimination under Title VI have no private cause of action to enforce their rights. This decision thus lays at OCR's door an enormous responsibility: sole responsibility to enforce prohibitions against the type of discrimination most often encountered in today's healthcare system. If history is any guide, this responsibility will not be met.[11] Breathing new life into Title VI should include reinvigorating federal Title VI enforcement, and a Congressional fix to the *Sandoval* decision.[22]

Further Expand the Concept of Public Accommodations

Expanding on the ideas underpinning the ADA, public accommodation obligations could be redrawn to include private healthcare providers of all sorts, regardless of their participation in federally funded programs. In other words, the 1964 Civil Rights Act should be modernized to extend to race the same protections against discrimination in the private healthcare sector that already exist in the area of federal disability policy.[15]

Expand the Healthcare Civil Rights Research Agenda

A broader research agenda and litigation strategy must be established to address all manner of civil rights issues in managed care[14] and in the areas of healthcare discrimination on the basis of age and gender.

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