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## Race and Healthcare in America: Foreword

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## FOREWORD

Barbara A. Noah<sup>1</sup>

“We hold these truths to be self-evident, that all men are created equal . . . .”<sup>2</sup> As young children in American elementary schools, we have all studied this country’s foundational document. But it is only as we grow older that we begin to question whether being created equal portends equal treatment or equal opportunity. In the context of healthcare, as in so many other fundamental contexts, the ideal of being created equal bears little relationship to the reality as lived.

The last two decades have seen a very welcome increase in attention to the issues of racial disparities in health status and in access to and quality of healthcare. A literature review published nearly twenty years ago demonstrated a surge of academic interest in the subject.<sup>3</sup> Since then, numerous commentators have explored the problem of racial disparities in health from the medical, ethical, and legal perspectives. These combined efforts have led to some governmental action at the state and federal levels to improve the situation, and have drawn the attention of medical educators. Still, evidence continues to demonstrate the existence of disparities in health status<sup>4</sup> and in access to care.<sup>5</sup> In this issue of the Houston

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<sup>2</sup> THE DECLARATION OF INDEPENDENCE para. 2 (U.S. 1776).

<sup>3</sup> See generally BRIAN D. SMEDLEY ET AL., UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE (2003); Trevor A. Sheldon & Hilda Parker, *Race and Ethnicity in Health Research*, 14 J. PUB. HEALTH MED. 104 (1992).

<sup>4</sup> See, e.g., Council on Ethical & Jud. Aff., *Black-White Disparities in Health Care*, 263 JAMA 2344 (1990); Kaiser Fam. Found., KEY FACTS: RACE, ETHNICITY & MEDICAL CARE, (Jan. 2007), <http://www.kff.org/minorityhealth/upload/6069-02.pdf>.

Journal of Health Law and Policy, five authors examine equality of access and treatment in our healthcare system. This symposium issue is particularly timely as the nation's attention is focused on healthcare reform and particularly the implementation of President Obama's legislation.<sup>6</sup>

Professor Dayna Bowen Matthew tackles the problems facing undocumented immigrants who seek access to health services in *The Social Psychology of Limiting Healthcare Benefits for Undocumented Immigrants - Moving Beyond Race, Class, and Nativism*. The author utilizes the Group Identity Model from the field of social psychology to explore the reasons for the resistance to publically funded healthcare for undocumented immigrants. As she explains, the problems that arise from social categorization into in-groups and out-groups include prejudice, discrimination, hatred, and stereotyping.

In the context of access to healthcare, Professor Matthew notes that the general trend in recent legislation is to deny publically funded care to undocumented immigrants. Restricting care for this population to basic public healthcare and emergency care risks not only the health of these individuals but also those with whom they come in contact. Professor Matthew argues that the Group Identity Model would improve American immigration policy by elevating the quality of discourse about inclusion/exclusion among citizens and non-citizens, and encourage policymakers to allocate scarce medical resources based on shared needs and benefits rather than immigration status or immutable characteristics, such as national origin.

Next, Professor Elizabeth Pendo considers the impact of the Genetic Information Nondiscrimination Act of 2008 (GINA) on race and sex-based discrimination in her article *Race, Sex and Genes at Work: Uncovering the Lessons of Norman-Bloodsaw*. Focusing on a gap in the literature on genetic discrimination, Professor Pendo considers its impact in the employment context. After providing an overview of the statute, she considers the lessons of the first class action lawsuit

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<sup>5</sup> See generally Barbara A. Noah, *The Invisible Patient*, 2002 UNIV. ILL. L. REV. 121, 124-33 (summarizing and discussing evidence of disparate treatment in multiple health care contexts) (book review).

<sup>6</sup> Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).

claiming genetic and medical discrimination in the workplace. The African-American plaintiffs in this class action were tested without their knowledge or consent for syphilis, other sexually-transmitted diseases, and for the genetic mutation that causes sickle cell anemia. As Professor Pendo explains, the case, along with survey data of employers collected in 2004, demonstrates that genetic testing does occur in the employment context. Thus, GINA is not merely a preemptive statute; it addresses real and current concerns about genetic testing in the workplace.

Perhaps even more importantly, Professor Pendo argues that the collection and use of genetic information perpetuates and worsens already well-established patterns of race and sex discrimination in the employment context. Although GINA prohibits employers from obtaining and using employees' genetic information, genetic testing is still permitted as part of medical examinations with the employee's consent and employers can still acquire genetic information from employee medical records if the employee authorizes the release of general medical information. Because genetic information often is not race or gender neutral, the use of such information in the employment context can exacerbate race and sex discrimination. Thus, the author argues that employers should learn from past litigation and take care to avoid using medical information, including genetic information, as a basis for disparate treatment of employees.

In *La Caja de Pandora: Improving Access to Hospice Care Among Hispanic and African-American Patients*, Professors Alina Perez and Kathy Cerminara consider the problems surrounding access to and utilization of hospice care by patients of color. Because Medicare, Medicaid, and many private insurers require patients to abandon therapeutic treatment in order to become eligible for coverage for hospice care, many patients who rely on reimbursement from these sources to pay for the palliative services of hospice wait too long to seek such care. Patients of color, who already suffer disproportionately higher rates of some types of chronic and terminal illness, also utilize hospice services at a disproportionately lower rate. The reasons for this phenomenon are complex and difficult to isolate and address.

The authors suggest that a combination of factors, including the too-rigid dichotomy between therapeutic and palliative care, payer

rules, the lack of racial and ethnic diversity in the medical professions, and poor understanding of cultural influences on end of life decision-making, among other things, contribute heavily to the under-utilization and disparate access to hospice care for racial minorities. The authors offer several carefully considered and achievable suggestions to improve the situation. First, they recommend research to determine whether adjustments to the current hospice system might increase utilization of hospice care by Latino and African-American patients. They also urge more attention to palliative care transition programs and suggest that legislators and policymakers reconsider state Medicaid rules that require patients to forego therapeutic care in order to qualify for hospice benefits. Finally, they urge healthcare professionals and the institutions that train them to pay more attention to cultural sensitivity training in order to facilitate meaningful communication between dying patients and their healthcare providers about individual choices, fears, and questions relating to hospice care.

Finally, in her article *Screen, Stabilize & Ship: EMTALA, U.S. Hospitals & Undocumented Immigrants (International Patient Dumping)*, Professor Jennifer Smith considers the impact and limitations of the Emergency Medical Treatment and Labor Act of 1986 (EMTALA) on improving access to emergency care for the poor and uninsured. She describes and criticizes a significant gap in EMTALA's reach—its failure to mandate emergency care for undocumented immigrants and the disturbing phenomenon of “forced repatriations” of such patients to their home countries. A combination of lack of financial resources and inadequate medical facilities in these countries often means that such repatriated individuals die of illnesses and injuries that would be treatable in the United States. Because no state or federal legislation expressly forbids the deportation of sick or injured immigrants back to their home countries, the pattern of international patient dumping continues unabated.

Using a case study of an undocumented immigrant from Guatemala who worked as a gardener in Florida, Professor Smith deftly illustrates the plight of both the injured worker (severely injured and in a vegetative state after being hit by an uninsured drunk driver) and the hospital and long-term care facility that cared for him. Although the nonprofit hospital and an attorney

representing the victim tried to arrange for his continued care and rehabilitation with the Guatemalan government, the government itself admitted that it lacked the facilities necessary. Nevertheless, the victim was transported to his native country and remains there, receiving woefully inadequate care. Professor Smith observes that, although hospitals are required to comply with the provisions of EMTALA that forbid dumping medically unstable patients, these hospitals are nevertheless hiring private planes in order to return patients to their native countries when their care imposes a significant financial burden on the institution. Undocumented immigrants have little recourse in such situations. Professor Smith persuasively argues that the U.S. government must do more to enforce EMTALA and other statutes requiring the provision of uncompensated care in order to do what is morally right for undocumented immigrants who, though politically voiceless, contribute so much to the economy of this country.

In all four of the articles that form this Symposium, the authors identify troubling disparities and injustices in our healthcare system and suggest strategies to ameliorate these problems. Sadly, the reforms of the Obama administration will probably do little to address these issues directly. The mandated insurance coverage requirement, for example, applies to U.S. citizens and legal residents, but not, unsurprisingly, to undocumented immigrants.<sup>7</sup> Similarly, the legislation expands public programs but does nothing directly to support the burden of EMTALA's unfunded mandate on hospitals. And, as the evidence has long demonstrated, insurance coverage alone fails to guarantee equal medical treatment.<sup>8</sup> The problem of racial disparities in healthcare remain systemically part of the larger problem of race relations in the United States—politically charged, difficult to isolate from the surrounding complexities of our woefully inefficient healthcare payment and delivery “system,”

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<sup>7</sup> See generally Patient Protection and Affordability Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).

<sup>8</sup> See, e.g., Marian E. Gornick et al., *Effects of Race and Income on Mortality and Use of Services Among Medicare Beneficiaries*, 335 NEW ENG. J. MED. 791 (1996) (reviewing Medicare data for more than twenty-six million beneficiaries, controlling for income variations, and documenting significant disparities in the utilization of various covered health services between white and African American patients).

underappreciated in significance, and often lost in favor of the latest media blitz about a cutting edge cure for a rare disease or a “miracle” recovery from a devastating injury. The authors of these symposium articles very effectively draw attention to these racial disparities. Let’s hope that everyone pays more attention, thinks harder about their values and motivations, and then acts.