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#### RACIAL DISTINCTIONS IN MEDICINE\*

Charles Sullivan \*\*

### Cognitive dissonance is a wonderful thing. 1

For years, there has been intense concern about racial discrimination in health care -- ranging from the infamous Tuskegee study to questions of equal access to medical care. In the process, enormous amounts of data have been generated about the health and treatment of various segments of the American population, and a range of explanations has been offered for racial or ethnic disparities. These include old-fashioned bias, less culpable but perhaps more ingrained insensitivity to cultural differences, socio-economic factors, and, in some cases, resistance of racial, ethnic or national origin groups to medical interventions.

In the shadow of efforts to explain, and hopefully, ameliorate racial disparities, there is an increasing question whether race *should* be taken into account in some medical decisions. This question necessarily arises from an inquiry into the causes of racial disparities — put simply, are the races genetically different (as opposed to different culturally or socio-economically) in ways that are relevant to health care?

Most of those concerned with equal access proceed (explicitly or implicitly) under what might be called the "equality" hypothesis - all

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<sup>&</sup>lt;sup>1</sup>Cognitive dissonance, originating in Leon Festinger, A Theory of Cognitive Dissonance (1957), argues that humans try to develop consistent belief systems, and that holding inconsistent beliefs – dissonance – leads to discomfort, which in turn leads to efforts, often not fully conscious, to reconcile belief systems. Sometimes that "reconciliation" requires ignoring what would otherwise be plain inconsistencies.

races are the same in almost any way that would matter to health care; current racial differences result from what might be called social construction. That is, the genetic potential for good health for blacks and whites is presumed to be the same. Variations are explained by factors which are exogenous to health per se – economic disparities in access to health care, discrimination by health care providers, cultural differences among subject populations which may result in less healthy lifestyles, and/or less reliance on traditional medical care. Presumably, elimination of these conditions -- whether by subsidy, legislation, or education -- would equalize health outcomes.

There is, however, a "difference" model: blacks are different from whites, such that identical treatment is neither necessary nor appropriate. The difference model could be expressed in a weak form, which is not so different from the equality model. The weak form would merely posit that historical, cultural, and economic factors result in racial groups being, at this point in time, statistically different, even if underlying biology is the same. Under this approach, it may be appropriate to take race into account in various decisions not because there is anything biological involved but because race is a useful proxy for other factors that are relevant to decision making.

The strong form of the difference model is more interesting, and more threatening: it posits that races are different genetically, which differences need to be taken into account in at least some medical decision making.

Analyzing these two models can be extremely complex, as often true of attempts to distinguish between genetic and environmental causes of phenotypes. For example, a recent article by Professor Vernellia Randall on cigarette smoking among blacks — obviously an important "lifestyle" influence on health — states that they have greater nicotine dependence than whites "despite the fact that African-Americans start later in life and smoke fewer cigarettes." <sup>3</sup> She suggests that this greater dependence may be attributable to the brands African Americans tend to smoke (which in turn might be explained by targeted

<sup>&</sup>lt;sup>2</sup>A recent study in the New England Journal of Medicine confirmed disparities in treatment of whites and blacks in terms of whether cardiac catheterization was undertaken, but found no difference in terms of the race of the treating physician.

<sup>&</sup>lt;sup>3</sup>Vernellia R. Randall, Smoking, the African-American Community, and the Proposed National Tobacco Settlement, 29 U. Tol. L. Rev. 677, 688 (1998).

marketing by cigarette companies), but acknowledges that the causes are still to be determined by biomedical research.

Given the tragic history of racism in this country, including "scientific racism" and such disgraceful episodes in modern medicine as Tuskegee, either the weak or strong forms of the difference model need to be addressed carefully. But recent developments suggest that there is an increasing assumption that there are genetic differences that should, at least occasionally, be taken into account.

Some manifestations of this are prime examples of cognitive dissonance. For example, the NIH Revitalization Act of 1993 mandates the inclusion of minorities (as well as women) in clinical trials.<sup>4</sup> The underlying predicate of this must be that minorities are genetically different from whites. Otherwise, there is little point to the inclusion and, given the lack of trust by minority group members, especially African Americans, in medical experimentation, it is not clear why the government should encourage such participation.<sup>5</sup> But this is not directly acknowledged in the Act of by the Office of Minority Health of HHS, nor is there generally federal government recognition of possible genetic racial differences.

The most explicit and dramatic manifestation of possible genetic racial difference was the announcement earlier this year of clinical trials for a drug "designed exclusively for African Americans." According to the New York Times, the trials have been authorized by the FDA and sponsored not only by the drug's manufacturer, NitroMed, Inc., but also by the Association of Black Cardiologists, described as a group representing 500 black heart specialists.

NitroMed's clinical trial vividly illustrates the intersection of the two models. There is no doubt about the race gap in heart disease: blacks are far more likely than whites to die from this condition.<sup>7</sup>

<sup>&</sup>lt;sup>4</sup>42 U.S.C.S. § 289a-2 (2001). See also Why African Americans May Not Be Participating in Clinical Trials, JAMA, Oct. 1996.

⁵Id.

<sup>&</sup>lt;sup>6</sup>Week in Review, 4-1, Sunday, May 13, 2001.

<sup>&</sup>lt;sup>7</sup>See Lance E. Becker, et al, *Racial Differences in the Incidence of Cardiac Arrest and Subsequent Survival*, 329 New Eng. J. Med. 600-606 (1993). There are numerous other "racial gaps" in health conditions. See generally, John A. Rich, *The Health of African American Men*, 569 Annals Am. Acad. Pol. & Soc. Sc. 149 (2000).

Further, there seems to be reason to believe that blacks do not react as well as whites to standard hypertension drugs.<sup>8</sup>

An equality model would conclude that the racial gap is explained by dietary or lifestyle habits, as to which education is the solution, or results from unequal access to health care, or less aggressive treatment by the medical profession. There are, in fact, ongoing studies trying to identify more precisely the causes of the racial gap. Equality theorists would have a harder time dealing with the evidence that blacks do not respond as well as whites to current drugs, but that, too, might be explainable by lifestyle factors, including a lower degree of trust among African Americans (and, therefore, perhaps less compliance with prescribed regimens). For a difference theorist, however, the NitroMed clinical trial is a straightforward reaction to the racial gap in heart disease, and strongly indicated by scientific evidence that current drugs are less effective for African Americans. This approach would seek to solve a documented problem, and looks upon resistance to it as misguided at best and its own kind of racism at worst.

But the resistance to such explicit recognition of possible racial differences is fierce. The Times article was headlined, "Shouldn't a Pill be Colorblind?," and recounted critics who questioned the whole concept of race as scientifically meaningless. If there is no such thing as a "black" race, in genetic terms, how can a drug be designed for African Americans? For example, an editorial in the New England Journal of Medicine, entitled "Racial Profiling in Medical Research," attacked a study finding a particular drug as more effective in whites than blacks in treating left ventricular dysfunction.

Where do we go from here? Or, more precisely, where does the law go from here? The NitroMed study was authorized by the FDA. Should it have been? Is this approval of race discrimination? If the NitroMed drug is ultimately approved, and doctors prescribe it to their African Americans and not to their white patients, is this problematic? This is scarcely an academic question in light of FDA approval of

<sup>&</sup>lt;sup>8</sup>Compare DV Exner, Lesser Response to Angiotensim-Converting —Enzyme-Inhibitor Therapy in Black as Compared with White Patients with Left Ventrical Dysfunction, 344 New Engl. J. Med. 1351-57 (2001) with Clyde W. Yancy, and 19 others, Race and Response to Adrenergic Blockade with Carvedilol in Patients with Chronic Heart Failure, 344 New Engl. J. Med. 1358-65 (2001). See generally Shades of Doubt and Fears of Bias in the Doctor's Office, Chron. Of Higher Educ., May 25, 2001, A16.

<sup>&</sup>lt;sup>9</sup>Racial Profiling in Medical Research, 344 New Eng. J. Med. 1392-93 (2001).

drugs which are clearly going to be marketed as more effective for blacks, with FDA approval of, or at least acquiescence in, such marketing.<sup>10</sup>

And, lest we think that there is no harm with an additional drug which appears to do some good for some individuals, recall that most drugs have potential adverse side-effects. Treating an African American with a designer drug is not risk free.

Further, there is the risk that, if racial differences become acceptable bases for treatment in some instances, there will be a tendency to implement more and more race-based treatments. For example, a British team recently reported that black patients required much more of an antirejection drug after renal transplants than did their white counterparts. The study was based on very few patients, but could lead doctors to overprescribe medications to their African American patients.

If the history of discrimination law teaches us anything, it is that "common sense" notions of racial differences are often wholly inaccurate or at least grossly overstated stereotypes, and that even real differences between the races are rarely justifications for treating one worse than another. On the other hand, in the age of the Human Genome Project, it would be foolhardy to restrict science where genetics does play a role. And it is not hard to identify at least a few areas where race-linked genetic background is critical. The two most common examples are Tay-Sachs, which afflicts those with an Eastern European Jewish lineage and sickle-cell anemia, which afflicts African Americans. <sup>12</sup>

Of course, it is a long step from agreeing that a few conditions are race-related to concluding that, genetically, race-linked genes have an appreciable impact on human health. First, many scientists reject the

<sup>&</sup>lt;sup>10</sup>The drug at issue is Travatan, which is used to treat glaucoma. Msnbc.com, March 16, (citation omitted)

<sup>&</sup>lt;sup>11</sup>Peter A. Andres, et al., Racial Variation in Dosage Requirements of Tacrolimus, Letter to the Editor, THE LANCET, Nov. 23, 1996, 348 (9039): 1446,

<sup>&</sup>lt;sup>12</sup>Some may question whether these are "race" linked at all. Each condition is a genetic condition arising from a gene pool whose members are substantially all members of a particular group. Not all African Americans are afflicted with the sickle-cell trait, and not all Jews have Tay-Sachs. Nevertheless, substantially all of those with the trait in question belong to these respective groups. To a large extent, approaching this question takes us back to the fundamental issue of what constitutes a "race."

whole concept of race, claiming that the genetic differences between members of a given race are often greater than the genetic differences between a given member of one race and a given member of the other. Secondly, if race makes sense in some terms, it may not make sense in America, where there has been considerable mixing of previously distinct gene pools. Indeed, the United States census defines race not scientifically but in terms of self-identification. While there are valid political reasons to do so, it scarcely advances a scientific approach to race in medicine. Finally, there are risks in pursuing this inquiry. Much "scientific" work around the turn of the twentieth century was devoted to racial differences, with the (often-acknowledged) goal of proving the superiority of the white race. Nor has this effort ended, as the recent publication of *The Bell Curve* attests.

Nevertheless, as the Times article vividly illustrates, the topic of genetic differences is still with us. Perhaps as importantly, the very predicate of the clinical trial of a new heart drug -- the greater risk African Americans face of heart disease -- suggests that race-based medicine must be considered: whether or not differences in African Americans and whites can be traced to nature or nurture, the very differences between the populations suggest that race may be a useful factor in identifying and perhaps treating certain conditions. Nor are the potential benefits of the use of race limited to African Americans. <sup>13</sup>

From a legal standpoint, the constraints on race differentiation are limited. The first question is whether any racial distinctions constitute "discrimination" under governing principles. Even if the answer is yes, whether the conduct at issue is actionable is problematic. There are three major sources of federal rights, which collectively leave large areas untouched. Obviously, the Equal Protection Clause limits discrimination by the government, and may implicate action by the FDA and decisions by public hospitals or research facilities. Title VI of the Civil Rights Act of 1964 also can be brought to bear on race discrimination in federally-funded programs, which potentially might have a huge impact because of the dominance of Medicare and Medicaid. Finally, 42 U.S.C § 1981, which bars racial discrimination in

<sup>&</sup>lt;sup>13</sup>Lisa Ikemoto, The Fuzzy Logic of Race and Gender in the Mismeasure of Asian American Women's Health Issues, 65 U. CINC. L, REV. 799, 801 (1997) (criticizing "the contradiction between using race and gender to measure health care, but doing so in a way that ignores the social categories in which these categories operate").

contracts even among private individuals, might have some application, although that statute has rarely been invoked in the health care setting, except to challenge discriminatory denials of medical staff privileges.

The obvious question is to what extent, if any, these legal tools should be brought to bear on racial distinctions in health. Any such analysis must address at least five potential uses of race. In ascending order of difficulty, these are (1) race-focused statistical studies; (2) race-related outreach; (3) race-based clinical trials; (4) race-based clinical screening; and (5) race-based treatment.

It may be time to begin a hard look at each of these areas, and to resolve the cognitive dissonance race and science generates by a conscious and rational approach instead of the denial that has characterized discussions of this subject.