



Geneticizing Disease

Implications for Racial Health Disparities

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Abstract

Today's dialogue in medical journals and the mainstream press on health disparities in American society increasingly focuses on individuals' genetic predispositions to disease. More and more, race is interjected into this dialogue as scientists link genes of certain racial groups to medical conditions while pharmaceutical companies increasingly seek to medicate those conditions. Unfortunately, during this process the focus on preventing racial health disparities—which in large part can be attributed to social determinants—becomes obscured.

The debate about whether to include race in medical research has a long and troubled history. Yet the implications of including government-defined, socially constructed racial categories into the geneticizing of disease are worryingly reminiscent of scientific racism. This paper will address the use of race in the move to geneticize—or perhaps more accurately to racialize—disease and then refocus the discussion of health disparities to the known social determinants that disproportionately and negatively affect the health of people of color.

Note to reader: The authors recognize the difficulty in defining race, ethnicity, ancestry, descent, and population groups, and will use the terms they determine most appropriate for each segment of the paper. The emphasis in this paper on racial health disparities includes a critical examination of the misplaced use of race in the U.S. Food and Drug Administration's recent approval of the first race-based medicine, specifically targeted for African Americans with hypertension.

Introduction and Summary

Today it is almost impossible to pick up a newspaper or open a Web browser without finding an article that links a specific gene to a certain medical condition. In fact, a simple Google search of “gene linked” in November last year pulled up hits with genes linked to depression risk, restless leg syndrome, autism, breast cancer, childhood asthma, and type 1 diabetes in children. This is only on the first page of results from a total of 30,600,000 hits.

Increasingly, genes are being linked in the mainstream press, on the Web and also in prestigious medical journals not only to medical conditions but also to behavioral conditions such as narcissism, aggressiveness, and in some instances to voting behavior. Linking disease to specific genes is becoming progressively more common among the American public, too. The increasing perception is that an individual’s genes are the main cause of disease.

The “geneticizing” of disease is used most appropriately in those instances where we know that genes or gene variants alone can cause disease—such as Tay-Sachs disease, which is prevalent among the descendants of Eastern European Jews but not just this one ethnic group, or sickle cell anemia, which is common among Africans and African Americans but also in other ethnic groups that have faced the scourge of malaria over countless generations. Yet that is a real stretch in other instances when genes are linked to health conditions that become labeled as race specific, since this has the potential to distort the discussion on racial health disparities.

The implication in the press is that race is the determining factor in these and other possibly “race-based” diseases. Health professionals and the public must be wary of oversimplifying the idea that “x” gene equals “y” medical condition since millions of genetic variations may exist and identifying them all, and how genes interact with one another, has yet to be determined.

Indeed, researchers within the medical industry are wary of the oversimplification of geneticizing disease. Consider the growing concern among a consortium of scientists that genes are operating in a much more complex way than previously believed. Findings from the National Human Genome Research Institute, for example, suggest that it may be inaccurate to say that a gene can be linked to a single function like a predisposition to heart disease.¹ This is critical information since the portrayal of genetic research and disease within the mass media often presents this information as mostly based on simple genetic predispositions.

If one examines the research on genes, race, and disease more closely, most research points only to a correlation of genes to disease, which is significantly different from a gene-based disease. Genes may predispose a person to certain health ailments, but health conditions are a combination of environment, lifestyle impositions, personal decisions, and access to affordable, quality health care. As geneticist Francis Collins observes, “associations often made between race and disease only occasionally have anything to do with DNA [and] most diseases are not single-locus genetic diseases and often are quite complex, involving many genetic loci as well as environmental factors.”²

In short, it has been well documented that disease is a combination of nature and nurture.³ Health care policymakers must ensure that a *correlation* between a gene pattern and a medical condition does not become a proxy for the *causation* of that medical condition as some in the medical and pharmaceutical industries move toward geneticizing and racializing disease.

Perhaps the issue of most concern in this shift to geneticize disease is the inclusion of race into the research and development of medications in an attempt to combat health disparities. The inclusion of race into medical research is not novel, nor is the controversy surrounding it. In fact, opposing sides of the debate use the same argument—those in favor of eliminating racial categories and those in favor of using racial categories in medical research argue that such a move is problematic. Yet both sides of the debate express legitimate concerns on whether to include race in medical research.

The problem with including race in gene-based medical research is that recent

scientific developments undermine the notion that race as a *biological fact* is still in question. While a lively debate about the biological underpinnings of race ensues under projects such as the HapMap project, a partnership of scientists and funding agencies from around the world to help researchers find genes associated with human disease that respond to pharmaceuticals, elsewhere world renowned geneticists such as Craig Venter and Francis Collins declare that race is not biological. Craig Venter, who along with Collins helped map the human genome, states that “skin colour as a surrogate for race is a social concept not a scientific one.”⁴

Still, some scientists rely on biological theories that oversimplify genetic variation between groups of people and confuse this with socially defined races. For example, if you ask three different scientists to define race, you will most likely get three different answers.⁵

This misconception about race has taken hold due to the tendency to racially categorize people based upon physical appearance, in most instances skin color and hair-type (the “I know it when I see it,” or phenotypical, reasoning). To date, however, the variations known as races are best explained by genetic drift, or the subtle changes within culturally breeding subpopulations over geologic time, and gene flow, or asymmetrical exchanges that are the byproducts of conquest between human subpopulations. Due to genetic drift and gene flow the existence of races is today a “social reality,”⁶ one which public policies, discussed later in this paper, reinforce.

This social reality is scientifically misleading, yet these socially constructed racial categories can be used to measure health

disparities between different racial groups to determine the health status of different populations. It is well documented, for example, that people of color suffer from health disparities such as shorter life spans, higher infant mortality rates, and higher prevalence rates of many chronic conditions compared with their white counterparts. But using race to measure health disparities is very different from using unproven genetic differences to account for these same health disparities.

Problems arise when race as a social reality and race as a scientific “fact” are conflated in medical research. These efforts to geneticize or racialize disease have several dangerous implications:

- They may skew research by placing individuals on a short list of socially constructed, government-defined racial categories, thereby increasing the risk of perpetuating health disparities.
- They may compromise the health of people of color by eliminating from medical consideration the social determinants of health problems.
- They may contribute to the reemergence of scientific racism through an emphasis on linking genes to disease and race.

The dangers implicit in all three of these efforts to racialize disease require health professionals to come to grips with the reasons for health disparities due to race

as a social reality and the misconceptions about health disparities due to race as a scientific myth.

This paper will briefly detail some of the health disparities experienced by people of color in the United States before turning to the emergence of race-based medicine and the threat it poses to effective health care. The paper will then examine the evolution of racial categories in the United States, and how current research finds that race is not genetically real. The paper will detail how known social determinants, such as residential segregation and other inequities, have continued to marginalize the status of people of color in the health care system and perpetuate health disparities. In closing, the paper will address the dangerous implications associated with an overemphasis on the role of race and genes on health disparities.

Ultimately, the goal of this paper is to educate health care policymakers, advocates, and the public on how some research in genetics and biomedicine is accompanied by risks that could further undermine the health of people of color, reify race, and shift resources away from improving social determinants that contribute to health disparities. With our medical industry increasingly captivated by genetic links to disease, the health of all people, and particularly people of color who continue to suffer the most from health disparities, is at risk.

Racial Health Disparities in the United States

While the causal claims for health disparities have changed over time, the existence of a correlation between race and health status has become increasingly apparent. Consider life expectancy statistics across race. In 1900, life expectancy in the United States was 47.3 years for whites. For nonwhites, the majority of whom were black, life expectancy was 33.0 years. Yet by 2004, the comparable numbers were 78.3 years for whites and 73.1 years for blacks, illustrating that while the gap may have closed, the disparity persists.⁷ There remains a similar disparity in infant mortality: African-American babies are 2.5 times more likely to die than white babies, and American-Indian babies are 1.5 times more likely to die than white babies.⁸

The existence of health disparities is also evident in the prevalence of chronic disease and mortality rates between races. For instance, at least 1 in 5 Americans, regardless of race, has hypertension. If a person is American Indian or Native Hawaiian however, their chances of having hypertension increase to 1 in 4, and if a person is African American then the chances increase to 1 in 3.⁹

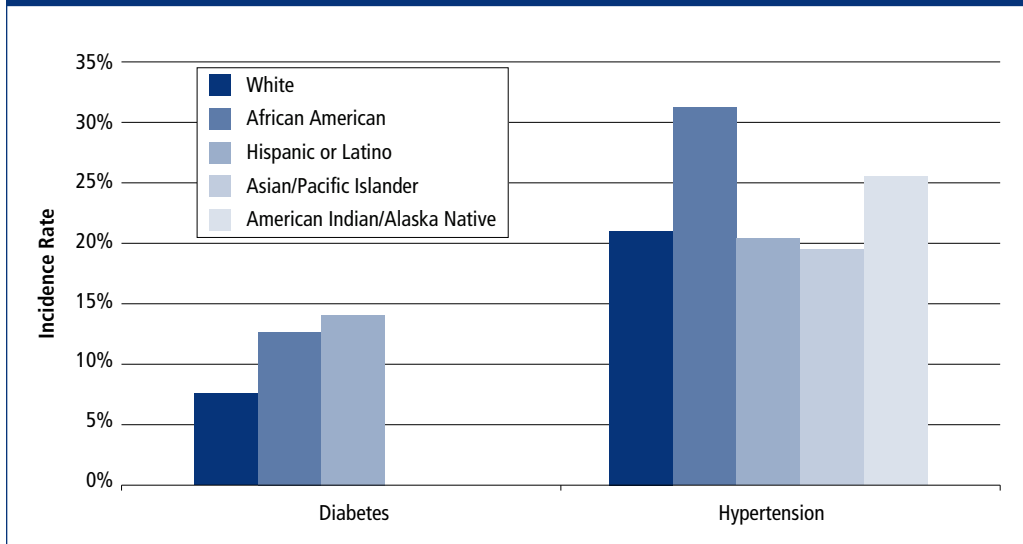
Similarly, over the past 15 years, the number of people with diabetes has doubled, and 1 in 3 people born in 2000 can expect to have diabetes in her lifetime.¹⁰ Yet again, the picture is starker for racial and ethnic minorities. Of individuals over 20 years of age, Mexican Americans are 67 percent more likely and African Americans are 60 percent more likely to have diabetes than their white counterparts and are also more likely to die from the disease.¹¹

One disease in particular illustrates this point: heart disease. Heart disease is the leading cause of death in the United States, accounting for nearly 40 percent of deaths each year—one person every 36 seconds dies from it. While African Americans are 15 percent less likely than whites to suffer from heart disease, 67 more African Americans per 100,000 died in 2005 from the disease than whites.¹²

Figures 1 and 2 divide the incidence and death rate of selected chronic conditions experienced by broadly constructed racial and ethnic categories. Collecting data by these categories, however, does not provide a full picture of health disparities. Each of these racial categories contains various subcategories.

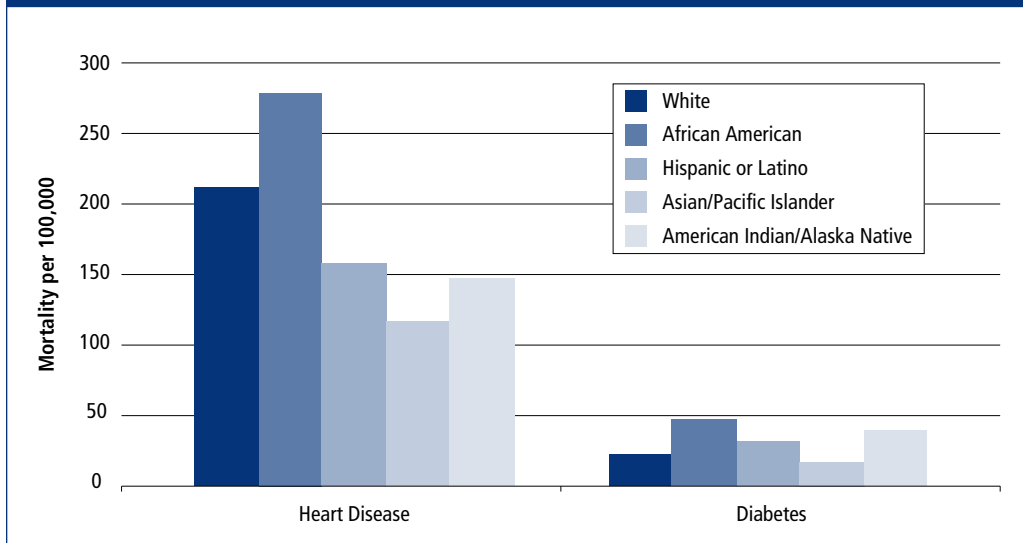
For instance, the health status data available regarding the Asian/Pacific Islander racial category does not capture the various health differences experienced by Asian/Pacific Islander subgroups such as Koreans and Filipinos. These two subgroups have higher

FIGURE 1: INCIDENCE RATE OF DIABETES AND HYPERTENSION AMONG RACIAL AND ETHNIC MINORITIES



Source: Diabetes rate for individuals 20 years of age and over, 2001–2004 data of diagnosed and undiagnosed patients. *Health, United States, 2006*. Hypertension rate for adults, 2005 data, *National Health Interview Survey: Summary, 2005*.

FIGURE 2: MORTALITY RATE OF HEART DISEASE AND DIABETES AMONG RACIAL AND ETHNIC MINORITIES



Source: 2004 data, *Health, United States, 2006*.

rates of breast and cervical cancer that are not depicted by the general Asian/Pacific Islander category statistic. This is not just a specific experience that occurs within the Asian/Pacific Islander group—every racial category has different sub-

groups that bear a different burden of a particular chronic condition.

The disparities presented in the tables exist (at varying levels) regardless of income, education level, geographical location, or

other socioeconomic factors. What remains constant is race—racial and ethnic minorities bear the burden of poor health and health outcomes at a much higher rate than whites in the United States. The danger, though, lies in extrapolating from these facts that race as a genetic factor has something to do with health disparities.

Case in point: This higher death rate due to heart disease experienced by African

Americans has led some in the medical industry to focus on remedies for heart disease for this racial group. Specifically, the pharmaceutical company NitroMed Inc. created BiDil®, the first race-specific drug targeted to African Americans suffering from hypertension, a precursor to heart disease. BiDil, however, highlights the many controversies involving race, medicine, and disease.

Race, Medicine, and Disease

In June of 2005, the U.S. Food and Drug Administration approved its first race-based drug, BiDil, amid much controversy. The drug is designed to treat heart failure among African Americans in an effort to eliminate the health disparity in mortality rates between African Americans and whites. NitroMed, the manufacturers of BiDil, marketed the drug to African Americans: “The African American community is affected at a greater rate by higher heart failure than that of the corresponding Caucasian population.”

BiDil was initially hailed by the NAACP and the Association of Black Cardiologists, among others, as a victory for African Americans in the fight to eliminate health disparities. But soon thereafter, the FDA’s approval of the drug sparked controversy due to:

- The manner in which the research was conducted
- The overlooked epidemiological studies pointing to social determinants, which increase rates of hypertension leading to heart disease and other diseases for people of color
- Questions surrounding the financial support of organizations that supported the medicine and the pharmaceutical company that developed it

In July, 2007, Clyde W. Yancy, M.D., on behalf of the Association of Black Cardiologists, retreated from the association’s initial overwhelming approval by stating that “none of us are comfortable with race as a descriptor for drug efficacy.”¹³

Why the about-face, at least by the Association of Black Cardiologists? NitroMed initially sought a patent to use the drug in all patients regardless of race. This patent was denied, and then NitroMed went back through the research, conducted another study and requested another patent by the FDA to market BiDil to African Americans specifically. Targeting African Americans for this medication overlooked epidemiological research that had proven that social conditions contribute to higher rates of hypertension among African Americans.

For example, Dr. Michael Klag, a prominent epidemiologist, conducted a study showing that in general, the darker the skin color, the higher the rate of hypertension for African Americans.¹⁴ The difference in rates is attributed to the higher levels of stress associ-

ated with darker skin in trying to obtain valued social goods such as employment, education, and housing.

Furthermore, the rates of hypertension in people of African descent that live in the Caribbean and Great Britain are 2 to 3 times lower than they are in the United States, and the highest rates of hypertension in the world are among those of German descent in Germany.¹⁵ The study illuminates that the hypertension health disparity suffered *by* blacks and even *within* the black population compared with white Americans has social origins and biological effects.

But more disturbing still is how the second BiDil study was not conducted in a scientifically accurate way. Instead of testing the drug on African Americans and other racial groups then comparing the results for the different groups, it was tested only within a self-identified African-American cohort. Furthermore, BiDil is no more than a combination of two generic medications available on the market at a much cheaper rate, raising questions around the interests in maintaining the patent for BiDil.

Once the drug had been approved, the NAACP took issue with the fact that Medicare would not pay for BiDil. Medicare asserted it would not cover BiDil because it is a combination of the much cheaper generics they *do* cover. Expert groups, including the American Heart Association and the American College of Cardiology, deny that there is evidence that the medication, which costs insurers roughly \$1,400 to \$2,800 per year per patient, works any better than its two generic parts—isosorbide dinitrate and hydralazine—taken separately.¹⁶ Jay Cohn, the original holder of both BiDil patents, stated that he prescribes BiDil to

his white patients when other drugs are not working and said, “I actually think everybody should be using it.”¹⁷

Finally, the financial links between groups that supported BiDil and NitroMed, the company that makes it, were highlighted in the media. *The Wall Street Journal* reported earlier that same year that the NAACP and NitroMed formed a three-year, \$1.5 million partnership to help address health care disparities in a “health justice campaign.”¹⁸ Likewise, the American Association of Black Cardiologists received \$200,000 to organize the clinical research for the trials.¹⁹

Jonathan Kahn, a professor at Hamline University, highlighted the risks and implications of the FDA’s approval of BiDil best. He critiqued the efficacy of the drug in African Americans in the *Yale Journal of Health Policy, Law and Ethics*:

Doctors use race as a surrogate to get at biology and marketers use biology as a surrogate to get at race. The pharmaceutical industry is trying to create new ethnic markets to sell drugs and generate profit from two generic drugs.

Kahn went on to state that the federal government’s support of BiDil was like a stamp of approval to use race as a biological category.

The pursuit of race-based medicine boasts implications for others besides African Americans. This case is a dangerous opening for those working in the biotech community to continue down this path of conflating race with biology via race-based medicine. Ultimately, this has important social and political implications, in addition to biomedical consequences.

Misconceptions of Race-Linked Disease

Misconceptions of a genetic link to race have permeated American society and medical research. Those who seek to employ the use of race in medical research rely on studies that show genetic diseases and variations in humans can be clustered into groups based on geographic region and then link this to groups based on race and ethnicity. In the past, people referenced the disproportionate rates of sickle cell anemia in African Americans and Tay-Sachs in Ashkenazi Jews as proof of the efficacy of this approach, yet when this inference was examined closely, it fell apart as proof that biologically different races exist.

Take sickle cell anemia, which does occur in large numbers of African Americans. Sickle cell anemia is an autosomal recessive disorder and appears in offspring only when both parents contribute the variant that causes the disorder. The sickle cell variant provides individuals in malaria-prevalent areas with a better chance of surviving the disease, and these individuals in turn can pass the trait onto their children. It is most likely that the development of the variant occurred independently in several populations and that the common factor in its distribution is malaria, not African ancestry.²⁰

This explains why sickle hemoglobin also occurs in parts of Southern Italy, Northern Greece, Southern Turkey, the Middle East, Saudi Arabia, and much of Central India. This is further substantiated by the fact that Kenyans, who still reside on the African continent, do not have a high frequency of sickle cell anemia because they live at higher altitudes where the incidence of malaria, and therefore sickle cell, is very low.²¹

Interestingly enough, the highest rates of sickle cell occur in a small Greek population (at double the rate it is found in African Americans).²² While sickle cell is prominent in African Americans, this can be ascribed to the closed-population phenomenon where individuals developed sickle cells to combat malaria and were producing offspring with other individuals who also had developed the cells in response to malaria.²³

The same holds true for Tay-Sachs disease, which is usually associated mainly with Ashkenazi Jewish populations from Northern and Eastern Europe. Tay-Sachs, like sickle cell disease, is an autosomal recessive disorder that (also like sickle cell) occurs in populations other than the population group with which it is commonly associated. The National Tay-Sachs and Allied Disease Association suggests that carrier testing is vital for individuals in high-risk populations such as French Canadians, Louisiana Cajuns, and Pennsylvania Dutch populations.²⁴

Similar to sickle cell disease, the high prevalence of the gene found in Ashkenazi Jewish populations can be explained by the closed population phenomenon. These diseases, which may be viewed as race-specific (or in this case, ethnicity-specific) actually result from the combination of ancestral migration and geographic location.

There are legal and ethical questions emerging due to the move to geneticize and racialize disease. Most importantly, the use of “race” in research is not inherently wrong, but there is a difference between using race to measure health disparities and using assumed and unproven genetic differences in race to account for health disparities. The risks of the latter are of great concern.

Race in the United States

Historically, the concept of “race” has varied over time and by culture and has been controversial scientifically as well as socially and politically.²⁵ But generally, the term “race” distinguishes populations from one another based on various phenotypic characteristics, such as skin color, facial features, hair texture, and common ancestry.

Physical variation in particular has led to arbitrary delineation of races in the human species. According to the American Anthropological Association, physical variation of any trait (or gene drift, in genetic science parlance) occurs gradually rather than abruptly over geographic areas, and the presence of one trait does not ensure the presence of another. The Association’s official statement on race says:

Physical traits are inherited independently of one another... knowing the range of one trait does not predict the presence of others. For example, skin color varies largely from light in the temperate areas in the north to dark in the tropical areas in the south; its intensity is not related to nose shape or hair texture. Dark skin may be associated with frizzy or kinky hair or curly or wavy or straight hair, all of which are found among different indigenous peoples in tropical regions.²⁶

For these reasons, many anthropologists argue that while features upon which racial categorizations are made may be based on genetic factors, the idea of race itself is arbitrary and subjective. Yet it remains a pervasive idea in American society.²⁷

In American society, race over the past three centuries has been constructed by societal norms that operate under the notion of racial inferiority of individuals with darker skin. Local, state, and federal government laws under which African Americans were treated as second-class citizens crafted societal practices. Most notable of these laws were the Jim Crow segregation laws in the South that perpetuated the black race as inferior and reaffirmed practices of racial inequality. With societal norms focusing on subordinating the black race, existing power relationships were viewed as natural. Race became the primary factor for identifying who had access to resources, opportunity, and therefore upward mobility.

As these practices continued, efforts were made to develop a scientific justification for these acts of racism. Eventually race devastatingly became a proxy for biology. Once the proxy was in place it was used to justify the oppression and exploitation of people considered “biologically inferior.” Many refer to this advocacy as scientific racism (see sidebar on The History of Scientific Racism, page 13).

Yet American society found it difficult to maintain distinct racial lines. Figure 3 details how racial categories in the United States Census have changed over time. Before 1960, the Bureau of the Census instructed households to complete the race question by choosing the race that the general public perceived it as. In other words, an individual was the race that the average man understood him or her to be. This had no scientific, biological, or genetic basis. It was based purely on

phenotypic expressions, which as noted earlier, can vary widely.

In the 1960 census, however, individuals could for the first time self-identify, or choose one's own race. Oftentimes these rigid racial categories forced individuals of multiple ancestral backgrounds to choose just one race. It was not until the 2000 census that individuals could self-identify in more than one racial or ethnic category.²⁸

History of Scientific Racism

Scientific racism's roots can be tracked back to social Darwinism,²⁹ the quasi-scientific belief that biological changes and adaptations can be applied in the social realm to competition between groups of individuals, nations, and societies, with the ultimate end being "survival of the fittest."³⁰ Proponents of social Darwinism in the late 19th century used the theory to define racial hegemony so that individuals with lighter skin pigmentation were ranked at the top, which in America and Europe reinforced the absolute dominance of whites in society at the time.

Outlandish scientific fields developed because of social Darwinism, including the now discredited field of study known as anthropometrics, which is the practice of measuring the shape and sizes of the skull and then linking the measurements to variations in brain capacity and intelligence among racial groups. At its worst, this system justified the eugenics movement in the early part of the 20th century, in which 64,000 individuals in the United States were forcibly sterilized for their perceived shortcomings, be they race, mental condition, or sexual inclination.³¹

Scientific racism, however, is a recurring theme in American history which pre-dates social Darwinism. The ideology was used, for example, to explain how certain races were afflicted with race-specific diseases. Case in point: Benjamin Rush, a prominent 18th century physician who signed the Declaration of Independence, was the Dean of the Medical School at the University of Pennsylvania, and is today considered the "Father of American Psychiatry." He asserted that Negroes suffered from an affliction called Negritude, which was thought to be a mild form of leprosy.³²

Another example is a condition called drapetomania. This discredited antebellum psychiatric "disorder" was assigned to

slaves who wanted to flee and seek freedom because they were not adhering to their "natural state of servitude." Further, it was argued that this diagnosis was indeed treatable.³³

Still another occurrence of scientific racism was the Tuskegee Experiment. This experiment was conducted by the U.S. government at the Tuskegee Institute, where from 1932 to 1972 experiments were conducted on 399 black men in the late stages of syphilis with no intention of curing them nor telling them about their medical condition. They were used as laboratories for science. One of the doctors involved in the experiment said, "As I see it, we have no further interests in these patients until they die."³⁴

In recent history, the most notable example of scientific racism is the best-selling book *The Bell Curve*, published in 1994, which suggested differences in IQ were genetic and discussed the implication of a racial divide in intelligence.³⁵ Although this study was thoroughly debunked, most notably in Stephen Jay Gould's *The Mismeasure of Man*, authors Richard Herrnstein and Charles Murray of *The Bell Curve* received much media attention through cover stories in publications such as in *Newsweek*, *The New Republic* and *The New York Times Book Review*.

Even in the 21st century, scientific racism is alive and well. Geneticist James Watson, a Nobel Prize winner for his part in the discovery of the structure of DNA, recently stated that Africans were less intelligent than whites and that the genetic proof would be available within the decade.³⁶ Although he immediately recanted his statements,³⁷ other scientists across the world responded, saying Watson's comments were "baseless, unscientific, and extremely offensive."³⁸ Yet these comments are a reminder that these attitudes remain.

FIGURE 3: U.S. CENSUS RACIAL CATEGORIES, 1890, 1960, AND 2000

1890 U.S. CENSUS	1960 U.S. CENSUS	2000 U.S. CENSUS
White	White	White alone
Black, defined as individuals with “three-fourths or more black blood”	Negro, defined as individuals of “Negro or mixed Negro and white descent and persons of mixed American Indian and Negro descent unless the American ancestry predominates”	African-American or black alone
Mulatto, defined as individuals with “three-eighths to five-eighths black blood”		
Quadroon, defined as individuals with “one-fourth black blood”		
Octoroon, defined as individuals with “one-eighth black blood”		
Indian	American Indians, defined as individuals of “white and Indian blood, enrolled in a tribe, or regarded as Indians in their community”	American Indian or Alaska Native alone
		Asian alone
Chinese, Japanese	“Japanese, Chinese, and Filipino, etc., are based largely on country or area of origin, and not necessarily on biological stock”	Native Hawaiian or Other Pacific Islander alone
		Some Other Race alone
		Two or More Races
		Hispanic (yes/no)

Source: U.S. Census Bureau, *Measuring America: The Decennial Censuses from 1790 to 2000*. Washington, DC: U.S. Government Printing Office, 1990; *United States Census Population 1960: Subject Reports. Nonwhite Population by Race*, Washington, DC: Bureau of the Census, 1963; and 2000 Census, Data on Race and Hispanic Origin, viewed at <http://www.census.gov/mso/www/rst/racedata/sld001.htm> on 8/17/07.

The shifting definitions of race highlight how the categorization of people into racial groups reflects societal beliefs at any given time. In essence, the government refined the idea or construct of race so well that racial categories became biologically legitimate.

Misconceptions About Biological Human Races

Research to date has shown that the genetic make-up of humans is nearly identical. The Human Genome Project and the privately funded operation Celera Human Genome Project discovered that the human genome contains 3164.7 million chemical nucleotide bases (A, C, T, and G), the total number of genes is estimated at about 30,000, and that almost all nucleotide bases are exactly the same in all people. In short, they demonstrated

at the genetic level that all human beings are 99.99 percent alike—despite the fact that the outward physical characteristics of people vary widely.³⁹

In September of last year, Craig Venter went on to announce that he had mapped and released his own personal genome—making it publicly available. With this release, the previously believed 0.01 percent of difference was expanded to about 0.05 percent of difference between individual human beings.⁴⁰ While this is a larger percentage than was previously thought, neither Venter nor Collins have reversed their previous statements that race is not a biological fact.

This 0.05 percent similarity can be explained by the fact that humans are a relatively young species who have not had the time to accumulate genetic variation to the extent other species on earth

have been able to do. In conjunction with this information, it has been widely documented that the greatest genetic variation, within 0.01 percent⁴¹ of difference, actually happens within populations that are closely located, such as the Hmong in Southeast Asia, not between races as the science would seem to show if biological races actually exist.

With the mapping of the human genome, some researchers began to look closely at the 0.01 percent of genes that differ between individuals—and the pursuit of personalized medicine was born. The ideal of personalized medicine is to specifically tailor each person's medical regimen to their genetic make-up. This pursuit, "would end the reductionist practice of using the 132 pounds, 35-year-old white male in research and applying those results to all humans," according to Dr. Bernadine Healy, former director of the National Institutes of Health.⁴²

Included within the genomic framework and the pursuit of personalized medicine is the use of race. And just as *The Bell Curve*—which suggested genetic IQ differences on racial grounds—received wide-

spread media coverage, today genomic scientists are receiving media attention when they discuss how meaningful race is in determining health conditions. Ironically, many of them also state that race is a social construct.⁴³

This perplexing rhetoric is largely inescapable because although all current concrete evidence points to race as socially constructed, it remains an important construct in which all Americans operate. As we head down unprecedented roads of discovery and understanding of disease and medical conditions with the mapping of the human genome leading the way, the framer of the discovered research is of utmost importance.

It is already apparent that some scientists and researchers are using the revelation of our genetic make-up to prove that health disparities exist in part due to our genetic racial differences. Yet because race is a marker for differential exposure to negative health-determining social factors, health disparities should not only be understood in terms of individual characteristics but also in terms of racial inequalities throughout a society.

Determinants of Health

Individual health is a combination of both nature and nurture. The nurture component is directly related to the environment in which one lives—a combination of both societal impositions and personal decisions. Race in the United States, for example, has played a key role in determining access to resources and opportunity, which in turn determine how an individual will perform in society. In regard to health, the correlations between race and residential segregation and race and inequities in the health care system have proven to be decisive factors of an individual's overall health.

Residential Segregation

According to David Williams, a renowned sociologist and health disparities expert, ideas of racial inferiority have had a substantial effect on health and well-being, namely through the perpetuation of racial segregation and its effect on educational and economic attainment, environmental conditions, and the delivery of health care services (see segregation's impact on health care services delivery in "The Health Care System" section).⁴⁴

Williams and other researchers agree that residential segregation, both de facto and de jure, more so than any other policy premised on the inferiority of certain racial groups, has been the most detrimental to the health of racial and ethnic minorities, especially African Americans.⁴⁵ For instance, a 1997 study found that the elimination of residential segregation would completely erase black-white differences in earnings, high school graduation rates, and employment—all factors that directly or indirectly affect health—for young African Americans making the transition from school to work.⁴⁶

Impact on Income and Wealth: Evidence suggests that income affects health through various pathways. Income determines an individual's access to health care services, nutritional and exercise habits, and insurance status to name a few. Income levels determine whether an individual can afford the increasing costs of medical care; researchers estimate that nearly half of individuals who file for bankruptcy do so because of medical debt. And even more startling, 75 percent of those who declare bankruptcy for medical reasons had health coverage at the onset of their illness.⁴⁷

Yet because of the long reach of segregation, middle-class blacks at the turn of the 21st century predominantly lived in poorer areas than whites of similar income levels.⁴⁸ Even more startling is the segregation experienced by affluent African Americans;

they experience higher levels of residential segregation than the poorest Latinos and Asians.⁴⁹

This phenomenon can be traced to federal housing policies of the 1940s. The GI Bill of Rights of 1944 offered home-loan subsidies to nearly eight million World War II veterans, which resulted in significant suburban housing construction. Yet, discrimination in the housing market prevented African Americans from taking advantage of the subsidies and accumulating wealth in the form of home equity. Between 1934 and 1962 the federal government underwrote \$120 billion in new housing, yet less than two percent of these subsidies went to people of color.⁵⁰ Today, home equity is the greatest source of individual wealth in the United States.⁵¹

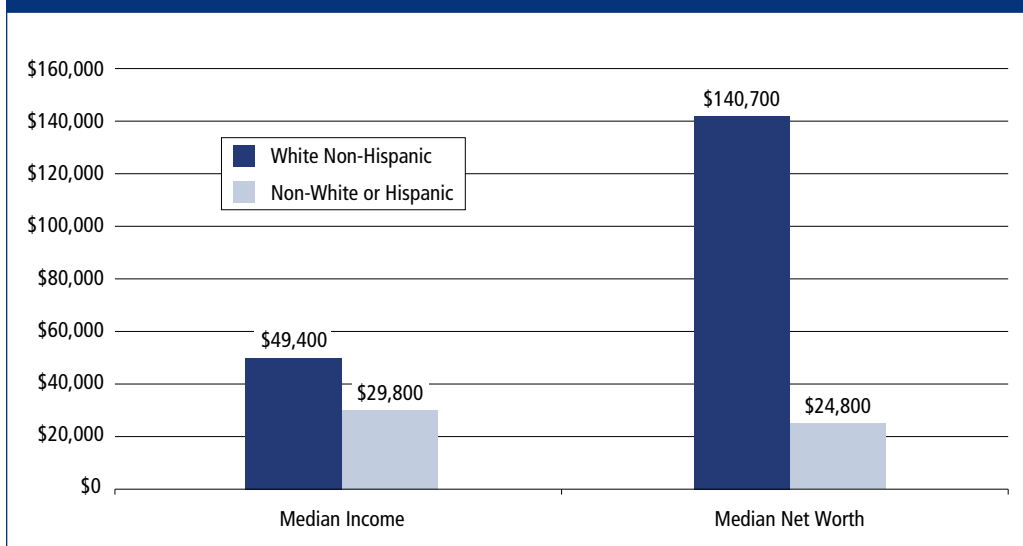
The impact of this policy is best exemplified by the disparity between whites and non-whites in regard to net-worth. In 2004 median net-worth for whites was

more than 5 times higher than that of non-whites (see Figure 4). Discriminatory housing practices relegated African Americans to urban, inner cities where the concentration of poverty was notably higher, which in turn left many of them vulnerable to an unstable home life, lack of employment opportunity, and environmental disadvantages.

Residential segregation has had a profoundly negative effect on individual earning power and employment opportunities. Documentation shows how out-migration of whites and some middle-class blacks from urban areas—where most blacks reside—to the suburbs over the last few decades has been accompanied by the movement of high-pay, low-skill jobs to the suburbs. These practices have negatively affected work opportunities for African Americans, thereby affecting their access to job-based health insurance and an income high enough to afford to purchase health insurance.

FIGURE 4: RACIAL WEALTH DISPARITIES ARE MORE SEVERE THAN RACIAL INCOME DISPARITIES

Median Income and Median Net Worth by Race/Ethnicity, 2004



Source: Diabetes rate for individuals 20 years of age and over, 2001-2004 data of diagnosed and undiagnosed patients. *Health, United States, 2006*. Hypertension rate for adults, 2005 data, *National Health Interview Survey: Summary, 2005*.

Impact on Educational Attainment: Perhaps most notable is the effect residential segregation has had on the quality of primary and secondary education that people of color receive. An individual's capability to navigate the health care system is directly related to this factor. Health literacy—the capacity to obtain, process, and understand basic health information and services needed to make informed health decisions—is the measurement used to access this ability.⁵²

In 2003, the National Center for Education Statistics found that white and Asian adults had higher average health literacy than black, Hispanic, American Indian, and Alaska Native, and multiracial adults. The disparity in health literacy test scores was greatest for blacks and Hispanics in comparison to whites. On average, blacks scored 15 percent lower and Hispanics scored 23 percent lower on health literacy tests administered in that year.⁵³ This lack of literacy makes racial minorities vulnerable in their attempts to navigate the health care system.

More than 50 years after *Brown v. the Board of Education*, elementary and high school education in the United States is still highly segregated and unequal. For example, graduation rates in schools where the majority of the students are racial and ethnic minorities remain significantly lower than predominantly white schools.⁵⁴ Additionally, the majority of funding for public schools remains tied to local property taxes, which are inevitably higher in suburban, predominantly white school districts.⁵⁵

While there is nothing inherently negative with having most of one's fellow classmates being members of minority groups, there exists strong correlation between the

racial minority percentage of school composition and poverty—and its consequences—in primary and secondary education.⁵⁶

Impact on Environment: Exposure to environmental “toxins,” including lead, air pollutions, cockroach excrement, violent crime, alcohol stores, and cigarette and smoking advertisements, are directly linked to the correlation between race and residential segregation.⁵⁷ Experts warn that when fetuses and newborns come into contact with various toxic substances, their organ growth and functions can be skewed through a process called fetal programming. This programming can impact not only that child, making them susceptible to diseases later in life, but also could affect the progeny of that child as well.⁵⁸

This is of utmost concern for racial minorities. The *LA Times* reported on April 12, 2007 that California had the highest concentration of minorities living near hazardous waste facilities, and that Los Angeles topped the nation with 1.2 million people living less than 2 miles from 17 such facilities. Ninety one percent of these people were minorities. These hazardous waste sites can release toxins into the air that cause gene mutations, or changes in gene structure which can leave one's offspring susceptible to cancer and other medical conditions. California is not alone. The seminal study, “Toxic Wastes and Race,” conducted on the location of toxic waste facilities, found that the number one factor in determining the location of these facilities is race, and that African Americans, Latinos, and Native Americans are the communities most likely to be situated close to a harmful facility.⁵⁹

But “toxins” are not the only problem for communities of color. The lack of a safe physical environment in highly segre-

gated areas also negatively affects health. Rates of unhealthy behaviors, including inadequate physical activity, tobacco use, and poor diet, are more prevalent among persons of low socioeconomic status and therefore, minorities.⁶⁰ A lack of community resources takes away the “choice” individuals have in maintaining their health. Without resources to access fresh fruits and vegetables and green space to exercise, individuals are more likely to adopt negative health behaviors that affect their rate of morbidity.⁶¹

The Health Care System

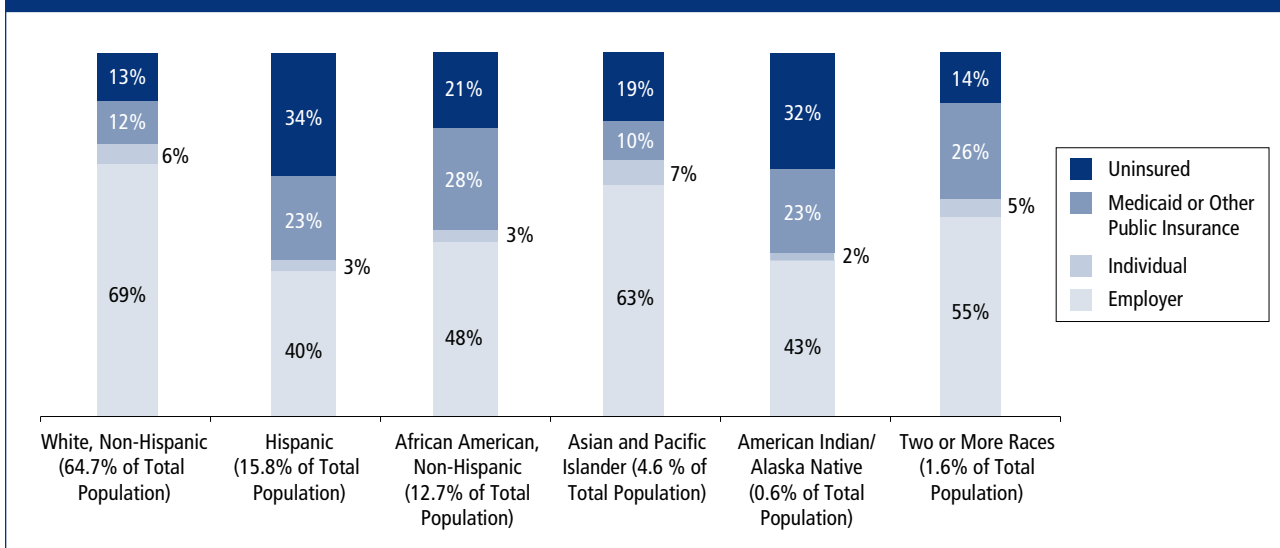
Studies have documented the role of the health care system in perpetuating racial health disparities.⁶² Namely, health insurance status, health insurance type, and the delivery of health care services both independently and jointly influence the quality of care people of color receive and ultimately the health and well-being of these communities.

Insurance Status: Insurance status, perhaps more than any other demographic or economic factor, determines the quality and timeliness of health care an individual receives in the United States. Insurance is the ultimate access variable.⁶³ In 2006, 47 million people in the United States lacked health insurance, nearly 9 million of whom were children. Hispanics and American Indians were more than 2.5 times more likely and African Americans were more than 1.5 times more likely to lack health insurance coverage (See Figure 5).⁶⁴

Without health insurance, an individual is less likely to have a usual source of care, more likely to not receive care, or delay needed care due to financial constraints, and therefore more likely to use hospital emergency departments as their primary source of care.⁶⁵

People of color are often employed in low-pay jobs, which may not offer health coverage and may make it difficult to af-

FIGURE 5: HEALTH INSURANCE COVERAGE OF THE NON-ELDERLY BY RACE/ETHNICITY, 2005



Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates, March 2005 Current Population Survey Data.

ford purchasing health insurance. Recently documented immigrants in particular are in a situation where they do not have access to employer or private coverage because of their disproportionate employment in low-wage jobs. At the same time, recent immigrants are ineligible for public health insurance safety net programs.⁶⁶ These policies are creating additional barriers to health coverage access and perpetuating immigrants' marginalized status in the health care system.

Type of Coverage: The type of coverage and cost sharing responsibilities an individual has also affect the ability to get needed medical care. For example, elderly African Americans are more likely than whites to live with heart disease, high blood pressure, and diabetes—67 percent compared to 55 percent. These ailments require extensive monitoring, prescription drugs, and at times, hospitalization.⁶⁷ The vast majority of elderly blacks have Medicare coverage, the federal health insurance program for the elderly, but more than 60 percent of beneficiaries have supplemental coverage. For African Americans, this supplemental coverage is more likely to be Medicaid, the federal and state public health insurance program for low-income Americans.⁶⁸

Reimbursement rates to providers also vary depending upon type of coverage. Medicaid, which often faces inadequate funding depending on federal and state budgets, has a lower reimbursement rate compared to other public and private plans. These rates drastically restrict Medicaid enrollees' ability to access private physicians who often have the resources and time to provide higher quality health care services. Therefore, Medicaid recipients, many of whom were non-white in 2006, are subjected to

largely separate, often segregated systems of hospital and neighborhood clinics.⁶⁹

Delivery of Health Care Services: The legacy of legal segregation and contemporary de facto segregation has significantly affected where racial and ethnic minorities access health care services (see sidebar "Segregation and Medicine"). In turn, the Institute of Medicine's landmark study, "Unequal Treatment," found that where racial and ethnic minorities receive care is a key determinant in the quality of care they receive.⁷⁰

A 2007 Commonwealth Fund study found that safety net institutions, such as community health clinics and public hospitals, play a critical role in ensuring access to care for minority populations.⁷¹ For example, the study found that adult Hispanics are two times more likely and adult African Americans are 1.5 times more likely to use community health centers as their regular source of care compared to whites.⁷²

Yet community health clinics, while crucial to ensuring that vulnerable populations receive needed care, need to improve the quality of care that is delivered. For example, preventive care reminders and cholesterol screening are more common in private doctors' offices than in community health centers or public clinics.⁷³ Public hospitals also serve as a primary source of health care for many minority populations. Research shows that 5 percent of public hospitals cared for nearly 45 percent of all black elderly patients in 2005.⁷⁴

Both community health centers and public hospitals depend on federal, state, and local funding to continue to serve these vulnerable populations, which may not

always be available. For example, hospital closings in New York City over the past 10 years, such as St. Mary's Hospital in Brooklyn, have increased access barriers for hospital inpatient and outpatient services for African Americans. For example, six of the eight hospitals that closed in New York City between 1995 and 2005 were located in or near communities of color, creating increased geographical barriers to access hospital care when needed.⁷⁵ When underfunded hospitals and clinics do remain open, tight resource constraints often lead hospitals and clinics to adopt their own norms of medical

practices, which may jeopardize the quality of care provided at these institutions.⁷⁶

With the high prevalence of chronic conditions in racial and ethnic populations, disease management is critical. According to the Institute of Medicine, effective management of chronic conditions requires the delivery of many services, hand-offs to other specialists, and aggressive follow-up.⁷⁷ While African Americans receive diabetes, blood pressure, and cholesterol screenings at comparable rates to those of whites, the rate of diabetes related end-stage renal disease per

Medicine and Discrimination

The sad pairing of medicine and discrimination is most evident with the practice of segregation in medical facilities, where in the past separate facilities existed to treat the ailments of whites and non-whites. The post-Civil War United States still found African Americans seeking care in segregated hospitals.⁷⁸ The quality of these hospitals was more than subpar, as African Americans were faced with rundown facilities, where medical resources were inadequate.

Low-quality facilities for African Americans continued well into the 20th century and led to medical misdiagnosis. One notable mistreatment is that of African American polio victims in the 1930s.⁷⁹ Medical historian Naomi Rogers reports on the negative health impacts faced by blacks with polio due to medical segregation:

"During the 1930s the systematic neglect of black polio victims had become publicly visible and politically embarrassing. Most conspicuously, the polio rehabilitation center in Warm Springs, Georgia which [Franklin] Roosevelt, himself a polio survivor had founded, accepted only white patients. This policy reflecting the ubiquitous norm of race-segregated health facilities, was sustained by a persuasive scientific argument about polio itself. Blacks, medical experts insisted, were not susceptible to this disease, and therefore research and treatment efforts that focused on black patients were neither medically necessary nor fiscally justified."⁸⁰

Research however, shows that blacks did suffer from polio just as whites did. Yet, due to scientific racism and medical segrega-

tion, blacks often had to travel greater distance to find a facility equipped to treat polio victims that would admit them. Once reaching these facilities, they were faced with inferior medical equipment and treatment.⁸¹

It was not until the passage of the civil rights legislation in 1964 and Medicare and Medicaid legislation in 1965, that health care facilities became accessible to both blacks and whites. While these laws increased access to quality facilities for African Americans, many facilities in black neighborhoods were closed and health care became less geographically convenient since facilities were located in white, more suburban, communities.⁸² Yet even in the 21st century, more than 40 years after medical facility segregation ended, reports abound regarding de facto segregation in hospitals and quality of care provided.⁸³

Even more startling in today's research literature is not only how segregation affects quality of care provided but also how racial biases have consequences on health. The *Boston Globe* recently reported on "How racism hurts—literally," referencing over 100 studies that indicate the effects of racial discrimination on physical health.⁸⁴ The studies found that women who pointed to conscious and unconscious racism as a source of stress in their lives developed more plaque in their carotid arteries, an early sign of heart disease, than those who did not. They were also more likely to develop breast cancer than those who did not.⁸⁵ While the method of discrimination has changed over time, one thing remains the same—discrimination affects the health of people of color.

100,000 diabetics is roughly 110 percent higher for blacks than for whites.⁸⁶

But even more startling is the disparity regarding hospital admissions for uncontrolled diabetes. Hispanics have admission rates 230 percent higher than whites, and African Americans have admission

rates 461 percent higher than whites. (See Figure 6)

An explanation for this disparity is due to the lack of a primary source of care or insurance coverage to maintain regular visits to the doctor. Figure 6 displays this reality for African Americans and Hispanics.

FIGURE 6: DELIVERY OF SPECIFIED HEALTH CARE SERVICES, REGARDLESS OF INSURANCE STATUS

	WHITE	HISPANIC		AFRICAN AMERICAN	
		Rate	% Difference From White	Rate	% Difference From White
No Usual Source of Care^a	14.6%	30.9%	111.6%	17.9%	22.6%
With Access to Services					
Received blood pressure screening ^b	91.9%	83.2%	-9.5%	92.1%	0.2%
Received cholesterol screening ^c	73.4%	68.4%	-6.8%	75.3%	2.6%
Received 3 recommended diabetes tests (among diabetic adults) ^d	55.1%	37.9%	-31.2%	54.1%	-1.8%
Hospital admissions for uncontrolled diabetes (per 100,000 population) ^e	15.2	50.1	229.6%	85.2	460.5%
Diabetes related end-stage renal disease (per 100,000 diabetics) ^f	222.7 (men) 165.8 (women)	322.2 (men) 259.6 (women)	44.7% (men) 56.6% (women)	470.2 (men) 344.5 (women)	111.1% (men) 107.8% (women)

^a Rate in 2003–2004; Source: *Health, United States, 2006*.

^b Rate in 2003; Source: *National Healthcare Disparities Report, 2005*.

^c Rate in 2003; Source: *National Healthcare Disparities Report, 2005*.

^d Rate in 2002; Source: *National Healthcare Disparities Report, 2005*.

^e Rate in 2002; Source: *National Healthcare Disparities Report, 2005*.

^f Rate in 2002; Centers for Disease Control and Prevention, National Diabetes Surveillance System.

Discussion: Implications of Race and Genes on Health

The implications of geneticizing disease and linking health disparities to race carries with it many risks such as reification of race; belief in genetic inferiority; reaffirming inherent inequity; potentially exploiting people of color due to the market interest in this area of medicine; and the possibility of a loss of funding geared toward the prevention of disease. As was shown with the approval of BiDil, race is given scientific legitimacy and used as a proxy for a health risk even though there remains no substantial evidence that genetic markers correlate directly with racial categories.

Clearly, using race in medicine allows for the tracking of funding, access, equity, and disparities among groups. Yet the controversy arises over the lumping of people into a few broad, socially-constructed racial categories and whether this has any medical value as a shortcut to more detailed genetic analysis.

An over-reliance on gene causation as a frame for the study and treatment of disease has serious racial implications. To operate under the notion that races are genetically different, with no proof to date to verify this, ignores the complexity of population genomics. This results in people using genetics as a proxy for race. The potential downfall of this is the reification of race—taking race out of the social construct in which it was created and placing it within the context of human genetics. By doing this, it gives race a biologic truth or legitimacy which it does not have, thereby distorting the reality of what race actually is.

And while race is being reified, a survey of the biomedical research being conducted shows race is often used as a valid classification. Within the United States, race, ethnicity, ancestry, and culture are used interchangeably. How accurate can “race” be in determining genetic links to disease and health conditions when the definition of race is one that eludes most researchers?

Furthermore, the linking of race, genetics, and disease has a long history. Troy Duster, a prominent sociologist and scholar on genetics and medicine, refers to this process as the “prism of heritability” where disease is linked to individuals because of socially-constructed racial categories. The risk here is that inequality that is already inherent in our social structures, including the health care arena, will be reaffirmed, and the emphasis on social determinants that impact our health will be minimized.

This can have a hegemonic impact on people of color in the United States who may believe that they are genetically inferior in terms of risk of disease and potential health outcomes. This belief in genetic inferiority is nothing new. One can simply look to the doll test conducted in 1951 for the *Brown v. Board of Education* Supreme Court case where black children pointed to white dolls as the nice, smart, kind, fun dolls, and black dolls as the bad, stupid, mean dolls. And while those were dolls being assigned behavioral characteristics by black children, a belief in genetic inferiority is emerging today within the black community.

According to a study detailed in the *American Journal of Health Studies*, African American women, while facing an unequal cancer burden due to known contributors such as stress, diet, sedentary lifestyle, lack of access to health care, and perhaps geographic location and heredity, overestimate the influence of genetics and underestimate the impact of other variables on breast cancer incidence. This is called genetic determinism, and is problematic because it impacts how *much* emphasis African American women place on prevention and detection.⁸⁷

This type of genetic determinism was recently displayed on the world stage when Oprah Winfrey and guest host Memet

Oz perpetuated a thoroughly discredited myth that blacks have higher rates of hypertension due to the fact that they retain more salt because of their need to do so in order to have survived the middle passage to America.⁸⁸

Another concern people, regardless of race, may not even be aware of is the patenting of DNA. Consider that back in 2000 an Australian biotech company headed by Joseph Gutnick secured the exclusive rights to the entire gene pool of the people of Tonga. The purpose of purchasing an entire gene pool is to study population genetics. This company, Autogen Limited, plans to use the DNA of Tongans—who have an extremely closed-population gene pool—to hunt for drugs that can be used to treat major diseases such as diabetes, cardiovascular disease, hypertension, and the like.

If the research proves fruitful in finding links between diseases and specific genes, the company stands to make hundreds of millions dollars through the commercialization of the drugs. Alarming, however, when the deal was closed the population of over 100,000 Tongans had not been told about the deal—presenting ethical implications.⁸⁹ Furthermore, this reinforces the strategy to medicate disease rather than to prevent the social determinants impacting the health of individuals.

Conclusion

Genetic research in medicine is leading us into a new realm of scientific discovery. The mapping of the human genome, and the subsequent research into the role of genes in disease, has the potential to exponentially improve the overall health of individuals through individually tailored disease management. The research to date, however, strongly suggests gene correlation to disease instead of gene causation.

Attempting to geneticize and racialize disease through the findings of genetic research has the potential to increase health disparities. Furthermore, the manner in which the research is pursued, alongside the emphasis given to gene causation in disease due to its novelty and appeal, may compromise the efforts to eliminate the widely documented social determinants that in many instances cause health disparities.

Public policies to eliminate and reduce health disparities should not perceive race-based medicine as a “magic pill.” Nor should the policies focus on medicating disease once individuals are sick. The goal should remain prevention. In order to prevent racial health disparities, public policies should refocus on addressing the known social determinants that negatively affect the health of people of color. One such effort should be to secure affordable, quality health care for all. Furthermore, with less access to health insurance and therefore health care, racial and ethnic minorities may not have access to new treatments.

Ultimately health care policymakers need to think critically about attempts to medicate disease rather than addressing social factors to prevent it. Without doing so, health advocates risk race being accepted as a proxy for a genetic biologic marker to address health disparities with commercial drug development. Health advocates need to ensure that funding toward the elimination of social determinants that impact health disparities is not compromised.

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