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RACISM
and **PUBLIC**
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CONFERENCE PAPER

Race, Health Care and the Law

Regulating Racial Discrimination
in Health Care

Vernellia R. Randall



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Race, Health Care and the Law:

Regulating Racial Discrimination in Health Care

Vernellia R. Randall

Paper prepared for the United Nations Research Institute for Social Development (UNRISD)
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Even though socially constructed, race, like geopolitical constructions, conveys both privilege and deprivation. We live in a world marked by poverty and underdevelopment. Eighty percent of the world's population live in countries that have access to less than twenty percent of the world's resources; while the other twenty percent live in the luxury of more than eighty percent of these resources. Similar disparities in resource distribution occurs within countries. Slavery, colonization, neo-colonialism, cultural imperialism and exploitation of the resources of the developing world (predominantly non-white) has resulted in the wealth of the developed world (predominantly white). Even within societies the distribution of valuable resources tracks race, with one group being privileged and the other groups deprived.

That is why this paper refers to “racially privileged” and “racially disadvantaged” groups and countries. I use these terms to highlight the point that both countries and peoples are privileged and disadvantaged based on race. In addition, the question of which group is privileged or disadvantaged will vary from country to country; and the groups that are disadvantaged are not necessarily the numerical minority. Finally, I do not at all intend to assert or imply that there is any biological explanation for the privilege or disadvantage. All privilege or disadvantage related to race is socially constructed from a past and present built on slavery, colonization, neo-colonialism, cultural imperialism and/or racism (both individual and institutional).

The World Health Organization defines health as “. . . a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”^[45] However, for “racially disadvantaged” groups that definition has little validity. Colonialization, slavery, neo-colonialism and racism has assured that the developing world lags behind the developed world and that “racially disadvantaged” groups lag behind “racially privileged” groups.^[11] The problem of racism and racial discrimination is evident not only in health status, but also in health care and in health care research. The pervasive nature of racism affects individuals at all economic levels, thus, there cannot be “complete . . . mental and social well-being”^[57,45] for “racially disadvantaged” groups until the problem of racism is addressed and resolved.

The first part of this paper will review data on racial disparities in health status in countries afflicted by racial divisions. The second part will discuss racial discrimination in health care, paying special focus on the United States where the issue of discrimination has been systematically studied by public health analysts. Part three will examine racialized conduct in health care research highlighting a few case studies: the Tuskegee syphilis study, the maternal-fetal HIV transmission prevention trials, and bioethics/legal principle of informed consent. Part four will discuss the legal responses to racial discrimination in health care and health research. And part five will conclude the study by calling on governments to take a pro-active role in uncovering and dealing with institutionalized racism, and by emphasizing the need for routine and systematic collection of health status and health care data that is disaggregated according to race, gender and socioeconomic positions.

Racial Disparity in Health Status

Equal access to quality health care is a crucial issue facing “racially disadvantaged” groups. The need to focus specific attention on the racism inherent in the institutions and structures of health care is overwhelming. “racially disadvantaged” groups are sicker and dying at significantly higher rates than the majority populations of their countries. Furthermore, people in developing countries are sicker than people in developed countries and these disparities tracks racial lines.

There are many examples of disparities in health status between racial/ethnic groups. In the United Kingdom, Black people tend to have a greater incidence of high blood pressure than white people.^[68] In Brazil, the infant mortality rate for children under 12 months is 62.3 per 1000 for Black and Brown children compared to 37.3 for White.^[69] The life expectancy in the United States is 26 years longer than life expectancy in Haiti.^[70] In Australia, life expectancy at birth is 56.9 years for Indigenous men and 61.7 years for Indigenous women, compared with 75.2 years and 81.1 years, respectively, for non-Indigenous men and women.^[71] The American Indian death rate from diabetes is 27.8 per 100,000, compared with 7.3 for Whites--380 percent higher.^[45] In the United States, Black women are three times more likely to die while pregnant than White women, and four times more likely to die in childbirth. The maternal mortality rate for Hispanic women is 23 percent higher than for non-Hispanic women. Disparity occurs at all income-level.^[45] The mortality stratum for all of Africa is either high or very high Child /Adult, while all of Europe is either low or very low child and most of Europe is low or very low adult. Only Estonia, Hungary, Kazakhstan, Lithuania, Moldova, Russia and Ukraine have high adult.^[72] By any standard, “racially disadvantaged” groups fail to have “a state of complete physical, mental and social well-being”^[65] and that failure is tied to race and not merely wealth.^[59,48]

The current health disparity issues are not isolated health system problems. In fact, the health disparity is the cumulative result of both past and current racism. For instance, because of institutional racism, in general “racially disadvantaged” groups have less education and fewer educational opportunities; “racially disadvantaged” groups are disproportionately homeless and have significantly poorer housing options; and “racially disadvantaged” groups disproportionately work in lowest pay and high health risk occupations.

Another aspect of the health status disparity is between the “racially privileged” countries and “racially disadvantaged”. There is a significant economic gap between the so-called developing world and the developed world. And that economic gap is traceably in significant part to colonialization, slavery and neo-colonial policies and practices. An important aspect of the economic gap is the huge disparity in the health conditions. Furthermore, the physical and economic burdens of diseases affect peoples in the “racially privileged” countries more significantly than they do those in “racially disadvantaged” countries. In its 1999 World Health Report, the World Health Organization (WHO) stated that “[d]espite the long list of success in health achieved globally during the 20th century, the balance sheet is indelibly stained by the avoidable burden of disease and malnutrition that the world's disadvantaged populations continue to bear.”^[66] What WHO doesn't comment on is how that disadvantaged is tied, for the most part, to racism.

In general, overall health status has improved in many “racially disadvantaged” countries as life expectancies increase and infant mortality rates decrease. However, the disparities between life expectancy and infant mortality for the “racially privileged” and “racially disadvantaged” is still very significant.^[66] In fact, in some aspects, health status is getting worse. HIV/AIDS crisis is spreading and deepening,^[58] water-borne diseases such as cholera continue to cause illness and death,^[52] and bacterial based illnesses such as malaria, pneumonia and tuberculosis are developing significant resistance to antibacterial drugs.^[66]

Furthermore, despite significant health status disparities, individuals are denied equal access to quality health care on the basis of race. For instance, in the United Kingdom, Caribbean men are less likely to be registered with a general practitioner than white.^[73] Whites are three times more likely to undergo bypass surgery than non-Whites.^[74] Non-White patients seeking admission to nursing homes experience longer delays before placement than White patients.^[45] Doctors are less likely to recommend breast cancer screening for Hispanic women than for White women.^[74] Non-White pneumonia patients receive fewer hospital services than White patients.^[74] Finally, poor urban Black and Hispanic neighborhoods average 24 physicians per 100,000 people, compared to 69 physicians per 100,000 for poor White communities.^[74]

This denial of health care does not occur only as overt racism, but also as a result of institutional racism. This institutional racism is the result of the disparate impact of practices and policies, inadequate laws and regulations and ineffective enforcement of existing laws and regulations, cultural incompetence of health care providers and institutions, and socioeconomic inequities that are disproportionately distributed along racial lines. These factors contribute to “racially disadvantaged” groups having disparities in health status, unequal access to health care services, insufficient participation in health research or exploitation in health research and insufficient receipt of health care financing.

Racial Discrimination in Health Care

Racial discrimination is both overt and covert and it takes two closely-related forms:

individuals from “racially privileged” groups acting against individuals from “racially disadvantaged” groups, and acts by “racially privileged” community or country against “racially disadvantaged” community or country which has the intent of maintaining privilege;

policies, practices, regulations and laws that , when implemented, have a disparate negative impact on individuals from “racially disadvantaged” groups, communities or countries.

These constitute 'individual racism and institutional racism'. Individual racism consists of overt acts which causes death, physical, mental or economic injury or the destruction of property. Institutional racism is less overt, or more subtle, less identifiable in terms of specific individuals or countries committing the acts. But, it is no less destructive. Institutional racism originates in the operation of established and respected forces in the society or world and is instrumental in maintaining privilege, and thus receives far less public condemnation than individual racism.

When white terrorists bombed a black church and killed 5 black children, that is an act of individual racism, widely deplored by most segments of the society. But, . . . [when] black babies die each year because of the lack of proper food, shelter, and medical facilities, and thousands more are destroyed and maimed physically, emotionally, and intellectually because of conditions of poverty and discrimination in the black community, that is the function of institutional racism.^[14]

Individuals from “racially disadvantaged” groups are sicker than individuals from “racially privileged” groups. Knowing that does not explain why and it certainly does not indicate the presence of institutional racism. To understand the role of institutional racism in health status requires an understanding of how health status is determined.^[45] Clearly, many things affect health status. An individual's personal lifestyle choices affect health status because they affect an individual's personal behavior and psycho-social health, which affect his or her health. Physical environment and biology also affect health status. Health care institutions affect health status because both personal behavior and human biology are affected by an individual's access to health care, and by the quality of health care the individual receives from health care institutions.^[31,45]

Class or Poverty theory maintains that the primary factor affecting differences in health care status between racial groups is socio-economic.^{i[45]} According to the class theory, poverty affects life-style, psycho-social behavior, personal behavior, human biology, physical environment, access to health care, and the behavior of the system and its institutions toward the individual. According to the class theory, it is lack of money, not racism, that explains the disparity in health.

Certainly, access to health care services is related to the financial capabilities of an individual or a country. The class theory, however, oversimplifies the issue and completely ignores the independent role of racial discrimination and neocolonialism that is based on racism.^[18,41,45,64] Racial discrimination influences not only life-style, personal behavior, psycho-social behavior, physical environment, and biology, but also economics. Thus, racism has a double influence.

Racial discrimination establishes separate and independent barriers to health care institutions and to health care. To understand the impact of racial discrimination on health and health care there must be a developed knowledge base. The country with the most developed body of knowledge related to race and health care is the United States. The research from the United States clearly demonstrates that within a country, racial barriers to quality health care may manifest themselves in a number of ways:

¹*Lack of Economic Access to Health Care.* Over 42 million Americans are uninsured with no economic access to health care. As access to health insurance in the United States is most often tied to employment, racial stratification of the economy due to other forms of discrimination has resulted in a concentration of “racially disadvantaged” groups in low wage jobs. These jobs are almost always without insurance benefits. As a result, disproportionate numbers of individuals from “racially disadvantaged” groups are uninsured with no economic access to health care.

²*Barriers to Hospitals and Health Care Institutions.* The institutional/structural racism that exists in the United States hospitals and health care institutions manifests itself in (1) the adoption, administration, and implementation of policies that restrict admission; (2) the closure, relocation or privatization of hospitals that primarily serve “racially disadvantaged” communities; and (3) the continued transfer of unwanted patients (known as “patient dumping”) by hospitals and institutions to underfunded and over burdened public care facilities. Such practices have a disproportionate effect on “racially disadvantaged” groups; banishing them to distinctly substandard institutions or to no care at all.

³*Barriers to Physicians and Other Providers.* Areas that are heavily populated by “racially disadvantaged” groups tend to be medically undeserved.^[45] Disproportionately few physicians from “racially privileged” groups have their practices located in “racially disadvantaged” communities. In fact, physicians from “racially disadvantaged” groups are significantly more likely to practice in “racially disadvantaged” communities, making the education and training of individuals from “racially disadvantaged” groups crucial. Yet, due to discrimination in post-secondary education, racial biases in testing and quality of life issues affecting school performance, “racially disadvantaged” groups are seriously under represented in health care professions.^[45] The shortage of professionals from “racially disadvantaged” groups affects not only access to health care but also access to the power and resources to structure the health care system, leaving its control almost exclusively in hands of individuals from “racially privileged” groups. The result is a system that benefits the “racially privileged” at the expense of others.

ⁱ When individuals are separated into different racial population groups, there is general recognition of a health disparity between them. The explanation usually given for this disparity is that differences exist in socioeconomic status or class.

⁴*Disparities in Medical Treatment.* Differences in health status can also reflect inequities in preventive care and treatment. For instance, in the United States, African Americans are more likely to require health care services than European Americans, but are less likely to receive them.^[45] In fact, racial disparity in treatment has been well documented. Studies have shown racial disparity in both quality and availability of treatment in AIDS,^[19] cardiology,^[50] cardiac surgery,^[40] kidney disease,^[22] organ transplantation,^[27] internal medicine,^[67] obstetrics,^[61] prescription drugs,^[30] treatment for mental illness,^[60] and hospital care.^[12]

In the United States, there are marked differences in time spent, quality of care and quantity of doctor's office visits between whites and blacks. Even when controlling for income, education, and ability to pay, Whites are more likely to receive more and more thorough diagnostic work and better treatment and care than people of color. Furthermore, researchers have concluded that doctors are less aggressive when treating patients from "racially disadvantaged" groups.^[45] At least one study indicated a combined affect of race and gender resulting in significantly different health care for African American women than white women and men.^[45]

Certainly, difference in treatment is based on a number of different factors including clinical characteristics, income, medical or biological differences. Nevertheless, race plays an independent role,^[29] and of all the influences on the health of "racially disadvantaged" groups, it is imperative that health care systems be free of racial discrimination - both individual and institutional.^[45]

⁵*Discriminatory Policies and Practices.* In the United States, discriminatory policies and practices can take the form of "medical redlining",ⁱⁱ excessive wait times, unequal access to emergency care, deposit requirements as a prerequisite to care, and lack of continuity of care. Discriminatory practices and policies often appear racially neutral but disproportionately affect "racially disadvantaged" groups.

For example, refusal to admit patients who do not have a physician with admitting privileges at that hospital, exclusion of Medicaidⁱⁱⁱ patients from facilities, and failure to provide interpreters and translations of materials, to name a few.^{»[45]} One significant example, is the United States federal Medicaid "racially neutral" policy that limits the number of beds a nursing home can allocate to Medicaid recipients. The indirect effect of the policy is to encourage these facilities to move existing patients who have spent all their assets and are now newly eligible for Medicaid into "Medicaid beds" as they become available.

It is mostly middle-class white women who have the assets to afford long term care without Medicaid, live long enough to spend down those assets, and become eligible for Medicaid. Thus, unintended effect of this policy is that there are fewer resources spent on "racially disadvantaged" populations for nursing home care even though they represent a larger portion of the Medicaid population and have more illness. In Medicaid, it is the combination of over-representation of individuals from "racially disadvantaged" groups in the program coupled with the government under-spending that is yet another example of the kind of structural and institutional racial discrimination that can persist unnoticed and uncorrected in many areas of a health care system.

⁶*Lack of Language and Culturally Competent Care.* A key challenge in a non-homogeneous society is to establish clear standards for culturally competent health care. Culturally competent care is defined as care that is "sensitive to issues related to culture, race, gender, and sexual orientation."

ⁱⁱ Medical redlining is the excluding of key medical services from predominantly communities whose members are from "racially disadvantaged" groups and concentrating them in the communities of the "racially privileged".

ⁱⁱⁱ Medicaid is the a United States government health insurance program for the poor and disabled.

Cultural competency involves ensuring that all health care providers can function effectively in a culturally diverse setting; it involves understanding and respecting cultural differences.^[45]

One example of institutional barriers to culturally competent care is the prevalence of linguistic barriers and the failure to use bilingual staff.^[45] The failure to use bilingual, professionally and culturally competent staff in patient/client contact positions results in lack of access, miscommunication and mistreatment for those with limited proficiency in the dominant language. This includes not providing education or information at the appropriate literacy level. Furthermore, laws that restrict access to public services to those with proficiency in the dominant language -- also have acute and racially disproportionate impact on “racially disadvantaged” groups.

⁷*Impact of the Intersection of Race and Gender.* The unique experiences of the women from “racially disadvantaged” groups have been largely ignored. These women share many of the problems experienced by “racially disadvantaged” groups, in general, and women, as a whole. However, race discrimination and sex discrimination intersect to magnify the barriers women from “racially disadvantaged” groups face in gaining equal access to quality health care.^[45] This intersection or "magnified impact" affects provision of treatments, access to medical care and inclusion in research. This is partly the result of different expectations of medical care between men and women and of gender bias among health care providers. Furthermore, these barriers are exacerbated in the case of gender-specific illnesses.^[45]

Policies and practices that increase government surveillance and control of women from “racially disadvantaged” groups are also a key factor in health status. Women from “racially disadvantaged” groups are less likely to receive sympathetic intervention by law enforcement in the case of domestic violence. For instance, in the United States, there are numerous cases of women who, after calling upon police for help in such cases, are victims of both domestic violence and police violence.

In the United States, family planning is another area where public policy has had a negative impact on health status and life choices of women from “racially disadvantaged” groups. These women do not have equal access to preventive medicine or the full range of birth control. Barriers include lack of family planning services or facilities in their communities; lack of coverage of certain services, medications or procedures by other publicly funded health insurance programs; and disproportionately higher prescription of medically risky or unnecessary procedures such as contraceptive implants or forced sterilization. State and local policies are more likely to be discriminatory than federal policies. However, there are few standards for ensuring equal access and equal treatment at this level of government. In the United States, jurisdiction over the family planning area is increasingly devolving to the state and local level, which means that there is a critical need for a clear regulatory infrastructure that provides redress for these barriers and remedies and consequences for policies and practices with discriminatory outcomes. Such regulatory infrastructure does not exist.

⁸*Lack of Data and Standardized Collection Methods.* There is a temptation not to criticize the data collection system of the United States since it is hands down the best when it comes to disaggregating data so that the impact of racial discrimination can be identified and tracked. Nevertheless, the current data collection efforts in the United States are inadequate and fail to capture the diversity of racial and ethnic communities.

For instance, disaggregated information on subgroups within the five primary racial and ethnic categories is not systematically collected. Further, racial and ethnic classifications are often limited on surveys and other data collection instruments, and “racially disadvantaged” groups are

often wrongly classified on vital statistics records and other surveys and censuses. To fully understand the health status of all individuals as well as to recognize the barriers they face in obtaining quality health care, it is important to collect the most complete data on “racially disadvantaged” groups, and “sub-groups”.^[45] The lack of a uniform data collection method makes obtaining an accurate and specific description of race discrimination in health care difficult, if not impossible. Such data collection has to include collecting data on provider and institutional behavior.

⁹*Inadequate Inclusion in Health Care Research.* Despite volumes of literature suggesting the importance of race, ethnicity, and culture in health, health care, and treatment, a minute percentage of the health care research funds in the United States are allocated to research on issues of particular importance to women and “racially disadvantaged” groups (21.5 percent). Funding of research by women and “racially disadvantaged” group scientists only amounts to .37 or less than one half of one percent. Although several laws have been enacted to ensure that research protocols include a diverse population,^[45] more must be done to address decades of exclusion. The health condition of “racially disadvantaged” groups will continue to suffer until they are appropriately included in all types of health research.^[45]

¹⁰*Commercialization of Health Care.* There is a trend for the health care systems of the world to move steadily toward a system where a corporation intervenes and structures the health care processes after standard business principles. Thus, established national health systems (for example, those in Canada and the United Kingdom) are moving more toward the market model and health care reform in the both the United States and South Africa is being largely confined within a shrinking and weakened public sector while a bloated private sector continues largely unaffected.^[10]

In the United States, this commercialization of health care takes the form of managed care. If there is no proper oversight, managed care can have the tendency over time to place increasingly stringent fiduciary requirements on providers. The impact of these largely financial interventions may include the failure to develop more expensive but culturally appropriate treatment modalities, not allocating the necessary expenditures to develop adequate health care infrastructure for “racially disadvantaged” communities. The potential for discrimination, particularly racial/ethnic discrimination, to occur in the context of managed care is significant. Leading commentators and advocates for civil rights in health care services, financing, and treatment have recognized this risk yet little has been done to protect “racially disadvantaged” groups from this form of discrimination.

Several managed care practices may have disparate effects on “racially disadvantaged” groups. One of the most common ways in which managed care organizations (MCOs) discriminate against “racially disadvantaged” groups is in their selection of providers. A physician or other type of provider that serves mainly poor “racially disadvantaged” groups may not be included in a managed care network because the provider’s patients might be labeled “too costly.” Some plans target the communities of the “racially privileged” while ignoring the communities of the “racially disadvantaged”, a process known as selective marketing. In addition, some MCOs may be limiting the access of Medicaid patients to the full array of providers. They do so by sending these patients provider lists that contain only providers that accept Medicaid resulting in “segregated” provider lists. Other methods MCOs have used to discriminate against Medicaid patients are excluding sections of urban, predominantly “racially disadvantaged” group communities from the MCO’s service area; applying a stricter definition of “necessity”;^{iv} and longer waiting times for new-patient or urgent-care appointments.^[10]

^{iv} The standard used to determine whether a patient will receive a particular test or treatment.

Disintegration of Traditional Medicine. Several authors have argued that one impact of globalization “is a future in which people in developing countries may find themselves in the worst of all possible worlds from a health perspective: they will not have access to Western medical care and standards of public health, and they will have lost their faith in traditional medicine and its cultural underpinnings.”^[24]

Racialized Conduct in Health Care Research

Racial discrimination in health care is one aspect that need concerted efforts by states. The other aspect is the racialized conduct of scientists, professionals and other public figures on matters relating to scientific experiments, clinical trials, industrial products and safety standards. In recent years, there has been a number of cases in which scientists abused their professional codes of conduct and caused harm to populations that look different from themselves. Also, many companies routinely use different raw materials for their products in different countries, evade standards or offer low quality goods to poor countries with weak legal regulations. Finally, there is the additional problem of companies dumping industrial waste in countries and communities that appear different from firm owners and managers.

Whose industries benefit from continuing underdevelopment in the Third World? Whose consumers benefit from primary products that keep African producers just above the bread line? Whose bankers benefit from Third World indebtedness? Whose arms manufacturers benefit from African arms races? Whose delicate consciences are soothed by the giving of modest gifts?^[11]

Notwithstanding the broad range of issues, this paper is limited to looking at the racialized conduct in health care research. Such conduct is tied to the wide disparities among countries and groups in the fields of science and technology, as well as the growing need for solutions to chronic diseases of various types. Racial prejudice, hidden biases and cultural racism may influence the choices of scientist and industrialists in selecting sites, individuals or groups for experiments and clinical trials. The most famous example of unethical conduct of the “racially privileged” against “racially disadvantaged” is the Tuskegee Syphilis Study. The most recent example is the Maternal-Fetal HIV Transmission Prevention Trials.

Tuskegee Syphilis Study

The most well known post-slavery experiment is the Tuskegee Syphilis Experiment which the United States engineered from 1932 through 1972. The Tuskegee Experiment involved four hundred African American men in a government-sponsored study to research the effects of untreated syphilis. While the men were not deliberately exposed to syphilis, as some rumors maintained, they were never told that they were not being treated or that effective treatment was available. Furthermore, even though the experiment was regularly reported over the course of the forty years, there was no outcry from the medical establishment.

The Maternal-Fetal HIV Transmission Prevention Trials

There are approximately 2.3 million HIV-infected women world-wide that give birth each year, thus the problem of maternal-child HIV transmission is significant. The first effective intervention to reduce the peri-natal transmission of HIV was developed in the United States in a clinical trial where HIV-positive pregnant women and their newborn infants were administered AZT (also called zidovudine).^[16] The success of the research protocol was so significant that six months after stopping the study the U.S. Public Health Service recommended the treatment regimen as the standard of care.^[47] The cost of the treatment. The wholesale cost of AZT was estimated to be in excess of \$800 per mother and infant. Based largely on the cost, in an unpublished report, the World

Health Organization concluded that in the developing world, the treatment protocol was not feasible.^[4] In 1997, 16 randomized clinical trials were conducted in Thailand, the Dominican Republic and several African nations in an attempt to find a less costly, effective method of preventing peri-natal transmission of HIV.^[51] Over 17,000 pregnant women were involved; 15 of the trials involved the use of placebos as controls and as a result it has been estimated that over 1000 babies were infected. Of the sixteen studies, nine were funded by the United States Government through the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).^[4,38]

Critics asserted that the placebo studies were unnecessary because research that proved the effectiveness of AZT for pregnant women provided the necessary data for researchers to compare against well-designed shorter regimens.^[39] Others maintain that the trials were unethical because they were exploitative.^[4] At any rate, these studies implicated race because they did not and could not have occurred in any predominantly white society. They implicated bioethics because they used one population in a harmful way for the benefit of other populations. Supporters of the studies maintain that it would benefit the society to have a treatment protocol that was less expensive than full course of AZT. Yet, nothing in the research plans or intervention for studies indicated that even if a less expensive protocol was developed that it would be made available to the people in the study country at a price that they could afford. Yet, it was the bioethical/legal principle of informed consent that was used to justify the study. Which raises the basic question are bioethical principles such as informed consent sufficient to protect populations where there is a serious inequitable distribution of power and resources.

Bioethics/Legal Principle of Informed Consent

While Bioethics lacks a single, accepted methodology,^[4] it has traditionally focused on "mid-level ethical principles," such as autonomy, beneficence, justice, nonmaleficence and informed consent.^[20,13,53,8,46] Furthermore, there are clear international standards that implement these bioethical concepts. The Nuremberg Code establish guidelines which not only require informed consent; but require researchers to forego research if it is too risky in and of itself or in relationship to the benefit to the patient.^[3] The Declaration of Helsinki provides that subjects, including the control group, should not only be assured of the "best proven . . . therapeutic methods"; but also that the "concern for the interests of the subject must always prevail over the interest of science and society".^[3] Finally, the International Covenant on Civil and Political Rights provides that "no one should be subjected without his free consent to medical or scientific experimentation."^[56] These principles are intended to be a regulative guideline, stating conditions of the "permissibility, obligatoriness, rightness, or aspirational quality of actions falling within the scope of the principle[s]." ^[7] However, there a number of problems with traditional bioethics.^[17]

First, Bioethics focuses on the individual, ignoring the interests of others who are intimately affected, such as the family and the community.^[15] This focus on the individual is based on a philosophy that regards the self, and only the self, as the end per se.^[55] However, there are other perspectives which views this reliance on ethical egoism to be misplaced.^[55] Many societies believe that "it takes a whole village" to raise a child, and thus, at a minimum, these societies would view ethical egoism to be contradictory to the raising of healthy children.^[55] Furthermore, even as adults, none of us function as islands; we all must rely on others for, at a minimum, reaffirmation of our self-assessment.^[55]

Second, bioethics embraces Kantian ethics, which require universal norms and an impartial perspective, which is inattentive to relationships and community.^[62] Kantianism privileges abstract reasoning over virtue, character, and moral emotions.^[62] Kantian ethics maintain that the only way we can morally constitute ourselves is by free and rational choice.^[55] It is the exclusivity of that claim that

is troubling. Many societies believe that we morally constitute ourselves not only through free and rational choice but also through our parents and our community.^[54]

Third, bioethics tends to view the patient or research subject generically, without attention to race, gender, or ability to pay.^[62] Yet, the development of laws and bioethical principles, discourse, and practices are informed by the values and beliefs of one group: White, middle-class, western males.^[26,62,63]

Finally, bioethical principles such as autonomy, beneficence, and informed consent do not have the same force when viewed through a perspective of distrust and disadvantage.

In the "Poplar Tree Narrative" Dr. Dick, a conscientious physician, applies the prima facie principles of beneficence, autonomy, justice and informed consent in such a way that castration of his black male patient is construed as a morally justifiable act, in substance and as a procedure [It kept the male] from getting into "trouble" [It made the male] . . . a better slave. . . . [He protected the male patient's autonomy] by getting what he construes to be [the patient's] informed consent.^[44,32]

These principles leave considerable room for individual judgment by health care practitioners and researchers.^[7] The flaw of a principle-based paradigm is that very judgment. The application of the principles will be subject to other values held by the society. In a world burdened by the legacy of slavery, colonialism, neo-colonialism and racism, the judgment is often exercised in a manner that discriminates based on race.

Thus, bioethics has adopted rules and has applied them with little, if any, concern for how race or other characteristics affect the working of the rules.^[62] In fact, as evidenced in the HIV Transmission Trial research there is a disparity between the bioethical concepts, the practice and the needs of the "racially disadvantaged" group. For instance, one justification given for the Maternal-Fetal Trial was to find a more affordable treatment option for "developing" countries. Yet, the cost of the short course for exceeds the per capita health care expenditure of many countries.^[28] Furthermore, no commitment was made by the governments, the international community, or researchers to assure that the short course would be made available. Thus, similar to the hepatitis B vaccine study of the 1980s it is highly likely that the "racially disadvantaged" countries will not benefit from the results.^[34] This is exploitation.

Bioethics fail to protect deprived groups because bioethicists "believe, first, that people behave in ways that can so far be predicted a priori that empirical evidence about their behavior is superfluous and, second, that people think and act rationalistically, seeking always to maximize and exercise autonomy."^[49] However, the reality is very different.^[6] People act in ways that are more consistent with the values they hold, rather than following any particular bioethical principles.^[23] And racism is a strongly held value.

"Racially disadvantaged" groups have been experimented on without consent, thus violating the principle of autonomy.^[5] For instance, in the Thailand Maternal-Fetal Trials it can hardly be said that informed consent was obtained when the Thai and English version of the consent form differed significantly. In the Thai version the subject was told that they would receive a comparison drug. While in the English version they were told that they would receive a placebo which was defined as a sugar pill. No where in the Thai version did they use the words "inactive substance", "Placebo" or "sugar Pill" even though Thai words or concepts exists.^[56]

"Racially privileged" researchers and providers have treated and experimented on others in ways which have caused harm, thus violating the principles of nonmaleficence^[7] and beneficence.^[7] They have given "racially disadvantaged" groups different treatment and provided them different

access to health care, thus violating the principle of justice.^[7] At best, the judgment in applying the articulated principles has been exercised fairly consistently in a manner which disadvantages and harms the racially disenfranchized group.

The implication is the failure of bioethical problem-solving to take into consideration those factors important to solving problems for racially disadvantaged communities. Most of the problem-solving has been at odds with the affirmation of the individual and the community. In fact, for the most part, mainstream bioethicists have consistently neglected to comment on the social ills or injustices such as colonialization, slavery, neocolonialism and cultural imperialism; the injustices and discrimination suffered, the stereotyping of language and culture, and the disadvantaged economic, political, educational, and health status."^[21]

Legal Response to Racial Discrimination in Health Care and Health Research.

Clearly, there must be laws which ban racial discrimination. But such laws will not be sufficient if they are not carefully structured to address the reality of discrimination in health care. To be so structured, a state must:

Collect health status and health care data disaggregated by race, facilities and providers in order to be able to evaluate the effectiveness of law enforcement;

Provide funds for health care research and development which includes “racially disadvantaged” groups;

Provide for specific definitions of prohibited discrimination and acceptable remedial action with specific attention on including disparate impact discrimination. Such definitions must not excuse disparate impact discrimination based on business necessity. In fact, justifiable discrimination must be very limited if it is allowed at all.

Severely limit or eliminate the use of justifiable discrimination exception to racial discrimination; and finally,

Provide for a means for enforcement that goes beyond individual complaints because individuals are often not aware that they have been discriminated against.

Any regulatory scheme is likely to have particular difficulty addressing issues of “unthinking discrimination”^v and institutional discrimination.^{vi} This is a particular problem with the regulatory scheme for racial discrimination based on the intent of perpetrator rather than the impact on the “racially disadvantaged” group.^[1] Such a standard means that few of the discriminatory acts that occur in a health care system can be successfully litigated since most occur from “unthinking” biases or institutional policies and practices.

Furthermore, the health care system presents several additional problems. First, individuals can be totally unaware that the provider or institution has discriminated against them. Second, because of the very specialized knowledge required in medical care, individuals can be totally unaware that they have been injured by the provider . Third, the health care system may have actually built in

^v Unthinking discrimination is discrimination that results from acting on biases and stereotypes and does not involve an overt actual desire to discriminate.

^{vi} Institutional racism or discrimination is discrimination that is the result of the disproportionately negative impact of policies and practices. It is caused by an acceptance of the disproportionate impact as justifiable as long as there was no specific or actual desire to discriminate.

incentives which encourage unconscious or unthinking discrimination.^[36,42,9,35] Fourth, discrimination that is the result of “business necessity” is seen as justifiable discrimination.

Because of these issues, an appropriate legal structure is essential to eliminating racial discrimination. As long as the law requires a conscious discriminatory purpose for liability, individual discrimination claims cannot address the issue of unconscious or unthinking prejudice.^[1] As long as unthinking discrimination and institutional discrimination is allowed to proceed unchecked - health care discrimination will continue.

As to the bio-ethical/legal protection, World Health Organization and the Council for International Organizations of Medical Sciences (CIOMS) have formulated ethical principles to facilitate the formulation of principles in transcultural research. Unfortunately, these guidelines are so vague that almost any method of obtaining consent would satisfy them.^[34] Another contrast are the recently adopted Guidelines for the Conduct of Health Research Involving Human Subjects in Uganda. In these guidelines Uganda, among many other things, adopted local standard of care instead of best standard, individual consent and rejected leader’s permission, rejected written informed consent, allowed for participation of pregnant women in clinical trials involving placebo, and require investigators to provide some form of interventions to participants and the local community.^[37]

In an effective public policy regulating racial discrimination, appropriate laws must be available to eliminate discriminatory practices in health care. Thus, the crux of the problem that each individual state must address is, what is the best way for the legal system to remedy racial disparity in the health care system? At a minimum, the system must require the collection of data disaggregated by race, allow for actions based on institutional discrimination, not allow a defense of justifiable discrimination and allow for action not only by an injured individual but also by the government and nongovernmental organizations.

As to health care research, there needs to be developed strong and clear guidelines for traditional informed consent of the individual, but also for consent and participation of the community. These guidelines must included the mandatory provision of available treatment in research studies and, a mechanism to assure the provision of treatment to the population of the society. The standards need to focus on how to protect subjects from the racism of the researcher and exploitation. The standards need to provide an international mechanism for recovery for breach of the ethical norms.

Summary

Inequality and discrimination will persist as long as domestic and international laws are inadequate for addressing issues of institutional racism, generally, and health care specifically. In general, laws and regulation must address issues of racial discrimination that result from individuals acting on biases and stereotypes or from institutions that implement policies and practices that have a significant disparate impact.

Effective regulation of racial discrimination in health care will require that governments take a pro-active role in uncovering where institutional racism exist. Among the actions that need to be considered include the routine and systematic collection of race, gender and socioeconomic class data related to health status and health care. Such data should not be limited to census and vital statistics but should include data on access and quality (particularly service delivery, diagnosis and treatment, facility availability, provider availability and other related health activities and services). Such data should be publicly available to both researchers and patients. Further, there needs to be a recognition that traditional mechanisms of protecting individuals such as “informed consent” and other bioethical

concepts are inadequate in the face of the racialized conduct of scientists, professionals and other public figures on matters relating to scientific experiments, clinical trials, industrial products and safety standards.

“It might be that . . . [laws and regulations] often go unenforced; it might be that current inequities spring from past prejudice and long standing economic differences that are not entirely reachable by law; or it might be that the laws [and regulations] sometimes fails to reflect, and consequently fails to correct, the barriers faced by people of color.”^[9] But, without systematic evaluation and monitoring who would know.

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