Over the past decades the mortality rate in the United States has decreased and life expectancy has increased. Yet a number of recent studies have drawn Americans’ attention to the fact that racial and ethnic disparities persist in health care. It is clear that the U.S. health care system is not only flawed for many reasons including basic injustices, but may be the cause of both injury and death for members of racial and ethnic minorities.

In 2002, an Institute of Medicine (IOM) report requested by Congress listed more than 100 studies documenting a wide range of disparities in the United States health care system. This report found that people belonging to racial and ethnic minorities often receive lower quality of health care than do people of European descent, even when their medical insurance coverage and income levels are the same as that of the latter. A second study, whose results appeared in the New England Journal of Medicine, found that although African Americans and members of other ethnic minorities make up a growing percentage of Americans infected with the virus that causes Acquired Immunodeficiency Syndrome (AIDS), they are seriously underrepresented in clinical trials of new treatments for the disease. African Americans and Hispanics, the researchers discovered, were roughly half as likely as whites to participate in HIV treatment trials and about half as likely to receive experimental medicines. This occurs at a time when HIV is spreading among African Americans at a higher rate than among whites.

A third study, in the Archives of Internal Medicine, found that African Americans were far less trusting than whites of the medical establishment, and of medical researchers in particular. African Americans were 79.2% more likely to believe that someone like them would be used as a guinea pig without his or her consent, versus 51.9% of whites surveyed. This study also found that 62.8% of African Americans (versus 38.4% of whites) believe that physicians often prescribed medication as a way of experimenting on people without consent.

These studies only confirmed what many in the minority community had known for years — that racism, whether explicit or subtle, is alive and well by some members in the medical profession. It is clear that a subtle, perhaps unconscious form of racism is just as harmful as expressed hatred and bigotry, because it affects the medical care of human beings. Although the IOM study found that most health care providers were well intentioned, the study cited “indirect evidence” that physicians’ decisions were influenced by their perceptions of race.

As a result of these studies, new initiatives were proposed and immediate action was taken to address these serious racial and ethnic disparities. Progress has been made in several areas since the original 2002 report. However, five years later, the 2007 National Healthcare Disparities Report (NHDR) reported that overall, disparities in quality and access for minority groups and poor populations have not been reduced since the original report. The three key themes that have emerged from this report are the following: (1) overall, disparities in health care quality and access are not getting smaller; (2) progress is being made, but many of the biggest gaps in quality and access have not

Peter A. Clark, S.J., Ph.D., is the Director of the Institute of Catholic Bioethics and a Professor of Medical Ethics at Saint Joseph’s University in Philadelphia, Pennsylvania.
been reduced; (3) and, the problem of persistent uninsurance is a major barrier to reducing disparities.6

Unless measures are taken to address this racism, unless a new sense of trust is established between the medical professionals and racial and ethnic minorities, these injustices will continue to deepen and expand, and more lives will be placed in jeopardy. This paper advocates for a comprehensive, multi-level, culturally relevant strategy that contains interventions that target individuals, communities, and the nation as a whole. This entails understanding the causes of racism that exist by some in the medical profession, identifying practical interventions that address racism in individuals, communities, and the nation as a whole, and forming partnerships that will work to develop a new sense of trust between members of the medical establishment and the minority communities.

The purpose of this article is fourfold: first, to give a historical context to this sense of mistrust for the medical establishment by racial and ethnic minorities, with focus on the African American community; second, to show the impact of the historical context on the present-day situation; third, to give an ethical analysis of why these injustices in the medical profession must be addressed and corrected; and fourth, to present some practical strategies and reforms on how to address the present racial and ethnic disparities in health care.

Historical Context
The Conspiracy Motif
The oral folklore tradition is deeply rooted in the African American heritage. For generations, a wide variety of negative stories have circulated within the community about the medical profession and public health programs. In 1972, when the tragedy of the Tuskegee Syphilis Study was revealed publically, news spread rapidly throughout the African American community.7 The truth was bad enough, but the problem was compounded as this information spread by word of mouth, and exaggerations and rumors intertwined with the truth. Today, in the African American community, and many other minority communities, the Tuskegee story is a major part of childhood folklore passed down by family members for the purpose of preparing present and future generations to deal with the harsh realities of life. By contrast, in the white community, very few have heard of the Tuskegee Syphilis Study, and even fewer have been affected by it.

Those who study folklore make a distinction between rumor and legend. A rumor is “a specific proposition for belief, passed along from person to person, usually by word of mouth without secure standards of evidence being present.”8 A legend “is a narrative account set in the recent past and containing traditional motifs that is told as true.”9 Since certain accounts incorporate modern motifs as well as traditional ones, most folklorists and social scientists now use the designation “contemporary legend” to describe “unsubstantiated narratives with traditional themes and modern motifs that circulate orally (and sometimes in print) in multiple versions and that are told as if they are true or at least plausible.”10 Drawing a clear distinction between rumor and contemporary legend is not always possible.11 This article attempts to make this distinction and demonstrate the ways in which rumors and contemporary legends have affected, first, the oral folklore tradition of the African American community and, second, its relationship to the medical establishment.

The ethnologist Patricia A. Turner identifies two distinct but recurrent “motifs of danger” that have influenced the African American community in its distrust of the medical establishment and public health programs. The first is what she calls the conspiracy motif. The conspiracy motif suggests the existence of an organized plot by the “powers that be” against African Americans — a plot that first threatens individual black persons and then is translated into animosity toward the whole race and minorities in general. Turner traces the history of the conspiracy theory from the European involvement in the slave trade of black Africans to the contemporary “powers that be,” including the Federal Bureau of Investigation (FBI), the Central Intelligence Agency (CIA), the
Food and Drug Administration (FDA), the Centers for Disease Control (CDC), various branches of the armed services, commercial interests, and the medical and health establishments. This motif was dominant from the beginning of slavery in the United States through the late 19th century, but it also appeared in subtle ways during the past century, starting with the Tuskegee Syphilis Study.\(^\text{12}\)

Turner’s second motif of danger is the contamination motif, which she sees as dominant in the 20th century and continuing into the early years of the 21st century. Turner uses “contamination” to refer to “any item in which the physical well-being of individual black bodies is being manipulated for racist reasons.”\(^\text{13}\) This motif can be seen in some black views of contemporary medical and public health efforts; at times the motif coincides with the themes of genocide and conspiracy as discussed later in the article. An examination of these two motifs in an historical context will reveal why suspicion and distrust of the medical establishment and public health programs is reasonable on the part of African Americans. In many ways these two motifs focus on the trust issue from two different perspectives. The conspiracy motif’s perspective focuses on the perceptions of African Americans, and the contamination motif’s perspective focuses on actual disparities and on the behavior of physicians. Both perspectives lead to misinformation and misperceptions, which has caused ambiguity about and confusion and even mistrust of the medical profession. Such suspicion and distrust is the basis of African Americans’ reluctance — and sometimes outright refusal — to participate in new clinical drug trials for AIDS and other experimental treatments.

Medicine has never been an entirely value-free discipline. It has inevitably reflected and reinforced the beliefs, values, and power dynamics of the society at large. As such, it has been influenced by race and racism directly and in subtle ways.\(^\text{14}\) Evidence of this fact can be seen in the use of medical theories to justify slavery. Physicians in slaveholding cultures believed that black people possessed peculiar physiological and anatomical features that justified their enslavement. These medical theories not only reinforced the societal attitudes that black people were inferior — something less than human — but also justified the use of blacks for medical experimentation and dissection.\(^\text{15}\) This is not to say that poor whites were not abused in the United States; rather, the point is that blacks were used more often and with greater disregard because of their race.\(^\text{16}\)

In the antebellum South, black bodies were used by medical schools for teaching purposes. As the ideas of the “Paris school” of hospital medicine reached the United States, physicians who ran medical schools began to realize that they had to have human specimens.\(^\text{17}\) Medical students need living people to study in order to learn anatomy, recognize and diagnose diseases, treat conditions requiring surgery, and try out new ideas and techniques. They also need dead bodies to perform the autopsies that help them confirm diagnoses and understand the effects of disease on the human body.\(^\text{18}\) In the 30 years preceding the Civil War, southern medical schools fiercely competed with each other for new students, which put additional pressure on the schools to have an abundant supply of clinical materials.\(^\text{19}\) This need for human specimens, both living and dead, was first met by placing various advertisements in local newspapers. The following ad, for example, which appeared in the Charleston Mercury between 1837 and 1839, announced the establishment of a special clinic for the treatment of blacks:

Surgery of the Medical College of South Carolina, Queen Street — The faculty inform their professional brethren, and the public that they have established a Surgery, at the Old College, Queen Street, For The Treatment of negroes, which will continue during the session of the College, say from first November to the fifteenth of March ensuing. The object of the faculty, in opening this Surgery, is to collect as many interesting cases, as possible, for the benefit and instruction of their pupils — at the same time they indulge the hope, that it may not only prove an accommodation, but also a matter of economy to the public. They would respectfully call the attention of planters living in the vicinity of the city, to this subject; particularly such as may have servants laboring under Surgical diseases. Such persons of color as may not be able to pay for Medical advice, will be attended to gratis, at stated hours, as often as may be necessary. The faculty takes this opportunity of soliciting the co-operation of such of their professional brethren, as are favorable to their subjects.\(^\text{20}\)

Such advertisements led both blacks and poor whites to fear mistreatment in southern hospitals.\(^\text{21}\) They believed that, if admitted to such institutions, they would either be treated as experimental guinea pigs or allowed to die so that autopsies could be conducted on them. The evidence that this fear contributed to blacks and poor whites being mistreated in southern hospitals proves that this situation was real and not imagined.

After the Civil War, the absence of anatomical laws providing for the legal acquisition of human bodies led the medical profession to resort to illegal means
The oral folklore tradition of “night doctors” and the unethical practice of medical schools in obtaining cadavers for autopsies and bodies for experimentation not only fostered a fear of the medical establishment among African Americans that has been handed down through the centuries, but also reinforced societal attitudes toward racism.

The oral folklore tradition of “night doctors” and the unethical practice of medical schools in obtaining cadavers for autopsies and bodies for experimentation not only fostered a fear of the medical establishment among African Americans that has been handed down through the centuries, but also reinforced societal attitudes toward racism. From 1619 until the early 1900s, it appears that the “powers that be” in the United States were often involved in a form of conspiracy against African Americans, both individually and corporately. African Americans were degraded, threatened, and physically and emotionally abused by many in the medical profession. As a result, many African Americans today, aware of what occurred in previous times through oral folklore, have an innate mistrust of the medical establishment. With the advent of the 20th century, the influence of racism on the attitudes and values of medical professionals did not end, but became more subtle. The motif of conspiracy was replaced, for the most part, by the motif of contamination. Issues of trust and mistrust became intertwined with issues of bias and prejudice. The focus changed from the perceptions of African Americans to actual disparities and the behavior of physicians and the medical profession.

The Contamination Motif: A Form of Genocide
In the late 19th and early 20th centuries, many medical and public health journals began to focus on the problem of syphilis among African Americans. Racist assumptions and stereotypes still existed within the medical establishment. Blacks were viewed as inferior, and this continued to justify using black bodies in ways that white bodies would have never been used. The predominantly white medical establishment maintained that “intrinsic racial characteristics such as excessive sexual desire, immorality, and overindulgence caused black people to have high rates of syphilis.... Physicians also pointed to alleged anatomical differences — large penises and small brains — to explain disease rates.”

These racist assumptions became the basis for the initiation of the Tuskegee Study of Untreated Syphilis in the Negro Male

In 1932 the United States Public Health Service initiated a study on African American men with syphilis in Macon County, Alabama, to determine the natural course of untreated, latent syphilis in black males. The study comprised 399 syphilitic men as well as 201 uninfected men who served as the control group.

ern landowners fostered a fear of ‘night doctors’ in the post-Reconstruction period in order to discourage the migration of blacks from rural farming areas to Northern and Southern urban centers.” Her theory appears to be historically well founded after examining the body of evidence from the post-Reconstruction era. However, some evidence indicates that “night doctors” did in fact play a major role in the procurement of black bodies for medical purposes.

The oral folklore tradition of African Americans concerning “night doctors” is widespread, testifying to the influence that this belief in their existence had on blacks during this time. Stories of the “night doctors” are still told in the African American community, and historical research suggests that many may be true. It is estimated that, in those years, about 5,000 cadavers were dissected each year in the United States and that at least a majority were procured illegally. By the 1920s, passage of anatomy acts eliminated body snatching in most parts of the United States, but it did not substantially alter the social origins of the supply of cadavers for medical schools.
These subjects were recruited from churches and clinics throughout Macon County and were led to believe they would receive free meals and “special free treatment” for what was called “bad blood,” in addition to burial insurance. In reality, however, they were enrolled in this study without informed consent. The infected men were neither informed that they had syphilis—a disease known to cause mental illness and death—nor treated for it. In fact, the researchers, in order to study the disease’s natural course, withheld the standard treatment of mercury and arsenic compounds from the infected men. In 1947 when penicillin was determined to be an effective treatment for syphilis, this too was withheld. The treatment these men actively received came in the form of placebos.

The Tuskegee Syphilis Study was a covert medical research study. However, it was widely known in medical circles because articles about it were published in major medical journals, such as the Southern Medical Journal and the Archives of Internal Medicine. As late as 1969, a committee at the federally operated CDC examined the study and agreed to allow it to continue. Not until 1972, when the first accounts of this study appeared in the press, did the Department of Health, Education and Welfare (HEW) terminate the experiment. At that time, 74 of the test subjects were still alive; at least 28, but perhaps more than 100, had died directly from advanced syphilitic lesions. (In 1980 HEW was renamed the Department of Health and Human Services; the CDC was renamed the Centers for Disease Control which, in 1992, then became the Centers for Disease Control and Prevention.) For many in the African American community, news of the study confirmed what they had long suspected: that the medical profession and the federal government used various forms of contamination to commit genocide.

Stories about the motif of contamination, as a form of genocide, continued to spread in the African American community throughout the 20th century. There are many in the African American community who believe that condom distribution was part of a government plan to reduce the number of black births. This belief became more credible when the contraceptive device Norplant became available. Following its legalization, stories began to circulate that inner-city African American women on welfare were being forced to use this contraceptive device. Such stories intensified when various editorial writers and public policymakers began to suggest that “welfare mothers” be required to have the device implanted as a condition for further benefits. Additional fertility-related measures, such as the sterilization statutes adopted by many states in the 1970s, also helped perpetuate this notion of genocide in the African American community. By the late 1920s, two dozen states, led by California, passed laws authorizing the sterilization of habitual prison inmates, and residents of mental institutions. Tending to reinforce the notion is the finding that a direct correlation exists between the race of a patient and the availability of certain procedures. Various medical studies have shown that certain procedures, such as renal transplants, hip and knee replacements, and gastrointestinal endoscopy, are less likely to be performed on blacks. However, blacks are more likely to undergo other procedures such as hysterectomies, bilateral orchietomies, and the amputation of lower limbs. These findings, coming from reputable medical journals, have only increased African American cynicism concerning members of the medical establishment.

Present Day Concerns

Genetic screening and public immunization programs have also raised suspicions in the African American community. The sickle cell anemia screening programs of the 1970s created misinformation, confusion, and fear. Inadequate planning and preparation by the medical profession and public health officials, and a failure to educate the American public on the difference between being a carrier versus having the disease, resulted in unnecessary stigma and discrimination. Ultimately this confusion and misinformation led to great suspicion in the African American community that this was another form of genocide. The same has been true of public immunization campaigns. Especially widespread is the fear that certain drugs may be experimental and thus potentially toxic. Injections have been suspected of being vehicles for the introduc-

It is clear that minority communities in general and the African American community specifically exhibit a general attitude of mistrust toward some members of the medical profession. But there also exists some degree of mistrust of minority communities by physician-researchers.
tion of experimental substances or infectious agents into the minority communities. Even today, health fairs and “immunization days” sponsored by community-based clinics sometimes cause concern among African American and other minority parents. This fear has been fanned by the circulation in minority communities by books such as Curtis Cost’s Vaccines Are Dangerous: A Warning to the Black Community, which describes vaccination as “purposely injecting loathsome filth from a diseased animal directly into the crystal-clear blood streams of our precious children.” As a result of this book, diagnostic tuberculosis (TB) skin testing has often been refused, because it involves injecting tuberculin material directly under the skin. Some believe that the test is intended to give TB rather than detect it. Such misinformation has greatly contributed to the “legacy of mistrust” of some members of the medical establishment in the African American and other minority communities.

In the later part of the 20th century, the contamination theory has also been associated with the AIDS epidemic. Indeed, many believe that AIDS was conceived as a deliberate plot to exterminate African Americans and other minorities. In a 1990 survey conducted by the Southern Christian Leadership Conference, 35% of the 1,056 black church members who responded believed that AIDS was a form of genocide. A rumor found consistently among African Americans is that the AIDS virus was created in the CIA laboratory. According to such rumors, the virus is either a biological warfare experiment that was tried out on African Americans and Haitians or biological warfare intended to diminish the African and Haitian population. These rumors, along with other factors, have contributed to the increase in HIV infections in the African American community. According to the Centers for Disease Control, although African Americans make up only 13% of the United States population, they account for almost half the estimated number of HIV/AIDS diagnoses made during 2006.

In a 2002 study by Dr. Allen Gifford et al., it has been shown that even though African Americans and other minorities make up a growing percentage of Americans infected with HIV/AIDS, these minority groups are underrepresented in clinical trials studying new treatments for this disease. Analysis of the findings of their nationally representative sample found that an estimated 14% of adults receiving care for HIV infection participated in a medical trial or study; 24% had received experimental medications; and 8% had tried and failed to obtain experimental treatment. According to multivariate models, non-Hispanic blacks and Hispanics were less likely to participate in trials than non-Hispanic whites (odds ratio for participation among non-Hispanic blacks, 0.50 [95% confidence interval, 0.28 to 0.91]; odds ratio among Hispanics, 0.58 [95% confidence interval, 0.37 to 0.93]) and to have received experimental medications (odds ratios, 0.41 [95% confidence interval, 0.32 to 0.54] and 0.56 [95% confidence interval, 0.41 and 0.78], respectively). These findings confirm that there are disparities among racial and ethnic groups in the rate of study enrollment, as others have observed in selected populations of patients with HIV or inferred from the racial and ethnic composition of particular cohorts; moreover these findings suggest that such disparities persisted up to four years after the National Institutes of Health issued guidelines for increasing enrollment of members of minority groups. The effects of race or ethnic group were seen even within socioeconomic strata, remained apparent after multivariate adjustment for the level of education, and seemed to be present in all aspects of access to research.

Although the authors did not pinpoint a single reason for the racial disparities, they believe there is less awareness and more widespread negative attitude about clinical research and experimental medications in minority communities. “Black persons may interpret informed consent procedures as ‘liability waivers’ for researchers to do little to protect patients,” they write.

Distrust of the medical professionals by minority groups was further confirmed in another study. In this study, researchers analyzed data from 527 African American and 382 white respondents to a national telephone survey on participation in clinical research. African Americans, this study found, were more likely than white respondents (41.7% to 23.4%) to expect their physicians to give less than a full explanation to research participation; they were also more likely (45.5% to 38.8%) to believe their physicians would expose them to unnecessary risks. African American respondents were in general more distrustful than white respondents.

It is clear that minority communities in general and the African American community specifically exhibit a general attitude of mistrust toward some members of the medical profession. But there also exists some degree of mistrust of minority communities by physician-researchers. Researchers tend to “purposely avoid recruiting marginalized populations (such as members of minority groups, substance abusers, or homeless persons) to clinical trials because they believe that poor compliance is common in these groups.” Some could argue that this avoidance itself may be
a form of racism? Studies have shown that many of these supposed compliance obstacles are probably surmountable and, more important, have not in many cases predicted poor compliance. This lack of trust on the part of researchers, which has a long history, contributes to the disparities seen in the medical care provided to members of racial and ethnic minority groups. If physicians do not believe that the patient will be compliant, then it is less likely that the physician will prescribe the needed drugs. In some cases, physicians see this as a way of not wasting our limited medical resources. Only through the building of trust will patients be involved in care, adhere to recommended treatment, and willingly participate in clinical research increase.

Underrepresentation of minorities in clinical research trials can be a matter of life and death for minority patients. In a study conducted by the Chronic Disease Prevention & Control Research Center at Baylor College of Medicine, Goldberg and Weinberg et al. found that between 1995 and 1999, blacks, Asian-Pacific Islanders, Hispanics, and Native Americans together made up for less than 10% of patients included in new cancer drug trials. “Underrepresentation of this sort leads to results that do not account for a host of factors — genetic, cultural, racial, religious, linguistic, as well as variables related to age and gender — that could have a huge impact on how well new drugs do in the real world.” This report led to numerous discussions about how clinical trials are conducted, but until practical steps are taken to address these issues, the quality of evidence will be undermined.

**Impact of the 2007 National Healthcare Disparities Report**

The March 2002 Institute of Medicine Report showed that racial and ethnic minorities received a lower quality health care than whites, even when their insurance and income were the same as whites. The authors wrote:

Even among the better-controlled studies, the vast majority indicated that minorities are less likely than whites to receive needed services, including clinically necessary procedures. These disparities exist in a number of disease areas, including cancer, cardiovascular disease, HIV/AIDS, diabetes, and mental illness, and are found across a range of procedures, including routine treatments for common health problems.

The study found that patients’ attitudes, such as their preferences for treatment, do not vary greatly according to race and so cannot explain racial and ethnic disparities in health care. In addition, the authors wrote, “There is considerable empirical evidence that well-intentioned white physicians who are not overtly biased and who do not believe that they are prejudiced typically demonstrate unconscious implicit negative racial attitudes and stereotypes. Both implicit and explicit stereotypes significantly shape interpersonal interactions, influencing how information is recalled and guiding expectations and differences in systematic ways.”

Since the original report, some progress has been made in key conditions that disproportionately affect minority populations. However, the 2007 National Healthcare Disparities Report summarizes the many areas where little to no progress has been achieved at reducing disparities. Success has been seen in four core areas:

1. The disparity between black and white hemodialysis patients with adequate dialysis was eliminated in 2005.
2. The disparity between Asians and whites who had a usual primary care provider was eliminated in 2004.
3. The disparity between Hispanic and non-Hispanic whites and between people living in poor communities and people living in high income communities for hospital admissions for perforated appendix was eliminated in 2004.
4. Significant improvements were observed in childhood vaccinations for most priority populations.

Other improvements among core measures include the following: children who received recommended vaccines among blacks, Asians, and Hispanics; new AIDS cases for blacks and Hispanics; tuberculosis treatment for foreign-born Asians; nursing home residents who developed pressure sores; adults who can sometimes or never get care as soon as they wanted and prenatal care for pregnant women; and for the poor, people under the age of 65, with health insurance. These findings show some progress in decreasing disparities, and each racial and ethnic group showed improvements in some areas. However, not all improvements closed the gap between these groups and reference groups. Despite these successes, there remain big disparities in the quality documented since the initial report. These disparities include:

1. Blacks had a rate of new AIDS cases 10 times higher than whites.
2. Asian adults age 65 and over were 50% more likely than whites to lack immunization against pneumonia.
3. American Indians and Alaska Natives were twice as likely to lack prenatal care in the first trimester as whites.
4. Hispanics had a rate of new AIDS cases over 3.5 times higher than that of non-Hispanic whites.
5. Poor children were over 28% more likely than high income children to experience poor communication with their health care providers.62

Besides these areas listed in the 2007 report, there are other areas of concern. Blacks are more likely than whites to suffer severe, untreated, and disabling depression.63 In a retrospective study of Atlanta hospitals between 1998 and 2004, researchers found that uninsured and Medicaid-insured patients, and those from ethnic minorities, had substantially increased risks of presenting with advanced-stage cancers at diagnosis. This means they are more likely to endure excruciating, and often more expensive, treatments, and they are more likely to die from cancer.64

A recent study confirms that black Americans continue to distrust medical research and clinical trials. Powe et al. found that minorities are 200% more likely to perceive harm coming from participating in research. This study provides direct evidence of why fewer blacks participate in cardiovascular prevention trial research. Failure to participate in clinical trials for conditions that affect blacks disproportionately and knowing that blacks often respond differently to medications, will only perpetuate health disparities.65 A National Institutes of Health survey released in 2005 — whose data had been compiled from a range of trials and research over two decades — found that minorities are actually willing to volunteer at the same rate as whites, but are not asked as often. It is interesting to note that an earlier research study by Thomas LaVeist and colleagues at the Johns Hopkins Bloomberg School of Public Health found that few blacks had heard of the Tuskegee experiment, and even fewer knew accurate facts. The researchers argue that the Tuskegee study plays only a modest role in producing distrust. Instead, they contend that the following reasons account for blacks’ low participation in clinical trials: economic barriers, attending lower-quality health care facilities, time off to participate, difficulty getting appointments, negative experiences in the medical system, and the complexity of required procedures such as consent forms.66

Prejudice may play a role in disparities regarding health care for African Americans, but the issue of race and culture may be more important in achieving treatment goals. In another, more recent study by Thomas Sequist et al. in the *Archives of Internal Medicine,* the investigators found that African American patients often had worse outcomes than white patients regarding the treatment for diabetes mellitus. In the review of 4,556 white patients and 2,258 African American patient charts, treated by 90 physicians, researchers found that 57% of white patients were able to control their cholesterol, as compared to only 45% of African American patients; 47% of whites and 39% of African Americans achieved optimal hemoglobin levels. The researchers found that racial discrepancies applied to physicians across the board. They found that 30-40% of the discrepancies could be attributed to differences in patients’ sex, income, insurance, and rates of obesity. However, the majority seemed to stem from the patient-physician relationship. The researchers found that a lot of diabetes care revolves around lifestyle changes, such as in diet and exercise levels. The problem is that physicians tend to promote a one-size-fits-all approach which does not account for individual needs and differences. For example, counseling African American and Latino patients with diabetes to lower carbohydrate intake by cutting rice from their diets may not be a realistic strategy if rice is an important staple for the family. Fruits and vegetables may be a part of one person’s culture but not another’s culture. This study attributed the differences less to overt racism than to a systematic failure to tailor treatments to patient’s cultural norms.67

Research suggests that health care providers’ diagnostic and treatment decisions, as well as their feelings about patients, are influenced by patients’ race or ethnicity.68 This has led to actual health disparities among minorities, especially the African American community. What is becoming clear is that a link exists between issues of trust, culture, race, and actual disparities in health care. The factual discussion of actual disparities shows that a substantial portion of medical disparities are due to physician bias and prejudice whether explicit or subconscious. However, some of these disparities are also due to the misinformation and mistrust that has been documented in this section. This distrust has had a critical impact on the physician-patient relationship. In many ways these subtle issues of distrust may have a greater impact on medical disparities in the African American community than many would have expected. Little is being done to address issues like cross-cultural education on medical professionals, increasing the number of minority physicians, and addressing the myths and rumors that persist in the African American community. Issues of explicit and subconscious racism among medical professionals, which can be the result
of myths and rumors in the African American community, must be addressed from both a medical and ethical perspective.

**Ethical Analysis**

The evidence is quite compelling that racial and ethnic disparities in health care contribute to disparities in care for minorities in the United States. David Satcher, M.D., the former United States Surgeon General, argues that this evidence correlates with persistent health disparities in the burden of illness and death. Satcher writes,

> Compared with their white counterparts, black babies are twice as likely to die during their first year of life, and American Indian babies are 1.5 times as likely. The rate of diabetes among Native Americans is three to five times higher than the rest of the American population, and among Hispanics it is twice as high as in the majority population. Although constituting only 11% of the total population in 1996, Hispanics accounted for 20% of new tuberculosis cases. Also, women of Vietnamese origin suffer from cervical cancer at nearly five times the rate of white women. Satcher contends that although these disparities result from complex interactions among genetic variations, environmental factors, and specific health behaviors, there is also reason to believe that race and ethnicity play a major role. This is certainly a medical problem, but it is also an ethical problem for all Americans. To allow race and ethnicity and issues of mistrust to play any role in providing health care to our fellow Americans goes against the basic principles of ethics. I will argue that — according to the ethical principles of respect for persons, beneficence/nonmaleficence and justice — action must be taken immediately to address these concerns and counteract any form of racism that may be present in the medical profession, whether explicit or subconscious, and to also address any mistrust that exists in the African American community.

**Respect for Persons**

This principle incorporates two ethical convictions: first, that persons should be treated as autonomous agents; second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy. The physician-patient relation is a covenant that is based on mutual trust. It is a fiduciary relationship that is based on honesty. The bond of trust between a physician and patient is vital to the diagnostic and therapeutic process. Edmund Pellegrino, M.D., and David Thomsma, Ph.D., both of whom have written extensively in this area, argue that among the obligations that arise from the physician-patient relationship is technical competence: “The act of the medical professional is inauthentic and a lie unless it fulfills the expectation of technical competence.” Patients, that is, should be able to expect their physicians to have the technical skills to assess and manage their medical conditions. Unfortunately, as discussed above, racial and ethnic minorities believe their medical conditions are not being assessed or managed by physicians in the same way that the medical conditions of white patients are being assessed and managed. All five Institute of Medicine Reports make it clear that disparities between whites and minorities exist in a number of disease areas. Giselle Corbie-Smith, M.D., and her colleagues found that African Americans were “more likely to believe that their physicians would not explain research fully or would treat them as part of an experiment without their consent.” This was confirmed by research done by Neil Powe, M.D., and his colleagues at Johns Hopkins University Medical Cen-
ter. They found that blacks were more reluctant than whites to take part in medical studies because they feared being improperly used as guinea pigs. Medical abuses have come to light through the oral tradition of minority groups and published reports. Some minority groups believe that their physicians cannot be trusted, that physicians sometimes use them as guinea pigs for experiments, and that they are sometimes not offered the same medical procedures that whites are offered, even though they have the same clinical symptoms. It appears that the technical competence of some physicians is being compromised by the impediment of prejudice and bias.

These concerns directly relate to the issue of informed consent. Patients have the right to be informed about the advantages and disadvantages of any medical treatment, experimental or otherwise, and about any viable alternatives as well. Research has shown that, in many cases, racial and ethnic minorities cannot give informed consent because they have not been informed of all their available treatment options. As stated above, violations of informed consent by medical professionals have been documented and, in some cases, have been widely publicized. In fact, past and present injustices against minorities, both factual and perceived, have sometimes led them to interpret informed consent procedures as “liability waivers” for researchers, doing nothing for the former and freeing the latter from the risk of possible lawsuits. One basic aspect of the principle of respect for persons is that a person should never be treated simply as a means to an end. When a caregiver fails to give his or her patient all relevant information concerning risks and benefits, or inform him or her of all possible treatment options, or purposely withholds “standard of care” treatment, or declines to recruit minorities for medical trials because he or she believes that poor compliance is common among them, then that caregiver is using patients as a means rather than an end. As a result of both explicit and subtle prejudice and bias by some medical professionals, minority patients suffer needlessly. This prejudice clearly violates the ethical principle of respect for persons. Minority patients’ autonomy, the basic respect they deserve as human beings, is being violated because they are allowed to endure pain, suffering, and even death when such hardships could be alleviated.

Beneficence/Nonmaleficence

The principle of beneficence involves the obligation to prevent, remove, or minimize harm and risks and to promote and enhance the good of a person. Beneficence includes nonmaleficence, which prohibits the infliction of harm, injury, or death upon others. In medical ethics this principle has been closely associated with the maxim *Primum non nocere* (“Above all do no harm”). Allowing a person to endure pain and suffering that could be managed and relieved violates the principle of beneficence, because one is not preventing harm and, therefore, not acting in the best interest of the patient. The duty to act in the patient’s best interest must override a physician’s or researcher’s self-interest. Clinical researchers are aware that their work should involve diverse populations of patients. “Race, sex, and other socio-demographic factors can influence the course of disease, the response to treatment, the types of toxic effects, and health related behavior, and the degree of diversity can therefore affect the generalizability of the results,” write A. L. Gifford and colleagues, the researchers in a study showing that African Americans and Hispanics were half as likely as whites to participate in HIV treatments trials and about half as likely to receive experimental medicines. This lack of participation is caused by, first, minority’s distrust of some medical professionals, and, second, the tendency of physician-researchers to avoid recruiting minorities because they believe poor compliance is common in these groups. As a result, blacks have, in absolute numbers, outnumbered whites in new AIDS diagnoses and deaths since 1996; since 1998, they outnumbered whites in people living with AIDS. Because of their failure to become involved in clinical trials for new treatments, blacks and Hispanics have long been disproportionately affected by the AIDS epidemic. This has been suggested to be the basis of a cause/effect relationship regarding the spread of HIV/AIDS in the African American community. The stereotyping by researchers and physicians of racial and ethnic minorities (assuming, for example, that they are more likely to abuse drugs, comply properly with treatment, and neglect follow-up care) may contribute to higher death rates and lower survival rates among minorities than among whites suffering from illnesses of comparable severity.

The recent 2008 Johns Hopkins University study by Powe and colleagues confirms this earlier research.

1. 24% of black Americans reported that their doctors would not fully explain research participation to them, versus 13% of whites.
2. 72% of black Americans said doctors would use them as guinea pigs without their consent, versus 49% of whites.
3. 35% of black Americans said doctors would ask them to participate in research even if it could harm them, versus only 16% of whites.
4. 8% of black Americans more often believed they could less freely ask questions of doctors, compared to 2% of whites.
5. 58% of black Americans said doctors had previously experimented on them without consent, compared with 25% of whites.80

Physicians have, as moral agents, an ethical responsibility to treat their patients in a way that will maximize benefits and minimize harms. Failure to adequately assess and manage medical conditions, for whatever reason, is not in the best interest of the patient.

Statistics from the American Cancer Society show that regardless of their insurance status, black and Hispanic patients still had an increased risk of having advanced-stage disease — typically, stage III or IV — at diagnosis when compared with white patients. African American patients were less likely than white patients to receive therapy for cancers of the lung, breast, colon, and prostate regardless of the stage of their cancer.81 Blacks are over 10 times as likely as whites to be diagnosed with AIDS and 15% less likely than whites to being admitted to the hospital for pediatric gastroenteritis. Uninsured black women were also less likely to have a mammogram in the past 2 years (44.2% compared with 76.3% for privately insured black women).82

It is clear, after reviewing these statistics and identifying the biases and stereotyping that exists among some medical professionals, that disparities in U.S. health care expose minority patients to unnecessary risks, including possible injury and death. Physicians have a moral responsibility to do what is good for their patients. Should a physician be impeded in the exercise of his or her reason and free will because of prejudice or bias, then that physician has an ethical responsibility to overcome said impediment or transfer the patient to another physician, one who will do what is demanded by the basic precepts of medicine — that is, to seek the patient’s good. It is also important that if mistrust due to rumor and myth is the cause of medical disparities, then leaders in the minority communities have an ethical responsibility to address this information. Correct information about vaccinations, HIV/AIDS, clinical trials for cancer, etc., must be disseminated in the minority communities. Allowing ignorance about these issues to prevail can become a matter of life and death. Failure to recognize prejudices, biases, and cultural differences and to address misinformation and distrust is a failure not only of the test of beneficence, but may also be a failure of the test of nonmaleficence.

Justice
This principle recognizes that each person should be treated fairly and equitably, and be given his or her due. The principle of justice can be applied to this situation in two ways. First, inequality concerning adequate health care for all Americans is well documented. For years this inequality was attributed to socioeconomic causes which led to a lack of access to health care. With the publication of the IOM reports, it is apparent that subtle racial and ethnic prejudice and differences in quality of health plans are also among the reasons why even insured members of minorities receive inferior care. Prejudice and negative racial and ethnic stereotypes may be misleading physicians, medical researchers, and other health care professionals. Whether such bias is explicit or unconscious, it is a violation of the principle of justice. It has been documented that members of minority groups are not receiving the same standard of care that whites are receiving, even when they have the same symptoms. This is a blatant disregard of the principle of justice.

Second, the principle of justice also pertains to the fair and equitable allocation of resources. It has been documented that members of minorities are less likely than whites to be given appropriate cardiac medicines or undergo coronary bypass surgery. They are less likely to receive kidney transplants or the best diagnostic tests and treatments for cancer. They are also less apt to receive the most sophisticated treatments for HIV. Americans espouse the belief that

Correct information about vaccinations, HIV/AIDS, clinical trials for cancer, etc. must be disseminated in the minority communities. Allowing ignorance about these issues to prevail can become a matter of life and death. Failure to recognize prejudices, biases, and cultural differences and to address misinformation and distrust is a failure not only of the test of beneficence, but may also be a failure of the test of nonmaleficence.
all men and women are equal. If we truly believe it, then we should insist that all men and women must, whatever their race or ethnicity, receive equal medical treatments and resources. Denying certain minorities these medical treatments — when whites receive them as standard care — is an unjust allocation of resources and violates a basic tenet of justice. Physicians and medical researchers have an ethical obligation to use available resources fairly and to distribute them equitably. Failure to do so is ethically irresponsible and morally objectionable. To compromise the basic ethical foundations upon which medicine stands is not only destructive for minority patients but for society as a whole.

**Strategies and Reforms**

Racial and ethnic disparities in health care continue to be documented. The root causes are multiple and diverse: a long history of discrimination; lack of access to high-quality, affordable health care; too few educational and professional opportunities; unequal access to safe, clean neighborhoods; and, in some African Americans, a lingering mistrust of the medical community. This problem is not going to disappear. Much has been written about the failure of health care professionals and medical institutions to address this issue, but simple rhetoric without significant reform will accomplish nothing. Immediate changes that address the issues of racial and ethnic disparities directly and concretely are needed. To accomplish this task, we must initiate, and in some cases follow through with, the following initiatives.

*First*, society should undertake research that allows it to understand the causes of racial and ethnic prejudice and the ways that prejudice affects health care. We already know some of the causes: poverty, lack of access to quality health services, environmental hazards in homes and neighborhoods, and scarcity of effective prevention programs tailored to the needs of specific communities. However, we need more research that focuses on the unconscious biases that seem to pervade the medical establishment. An example of such an initiative is the Federal Collaboration in Health Disparities Research (FCHDR) that has been developed by the Centers for Disease Control and Prevention, in collaboration with the Office of Public Health and Science’s Office of Minority Health, and co-sponsored by AHRQ. FCHDR identifies and supports research priorities for cross-agency collaboration to hasten the elimination of health disparities, and identifying priority research topics on health disparities was one of its primary outcomes in 2006. Through FCHDR, federal partners have formed subject matter expert groups around four initial research topic areas for collaboration: obesity, built environment (which includes homes, schools, workplaces, parks and recreation areas, business areas, transportation systems, etc.), mental health care, and comorbidities. These priorities represent opportunities for federal agencies and other partners to collaborate on innovative research.

*Second*, there is a need to educate both medical professionals and patients. Medical professionals need to become more aware of the subtle forms of prejudice that impact their medical decisions. Patients need to learn how to be more active and better informed in their decisions concerning medical treatment. The education of health care professionals on cultural and racial issues should begin in medical school and continue throughout their careers. It should focus on the fact that racial and ethnic disparities exist and on the ways they can be identified and confronted. The IOM has recommended cross-cultural education programs that, first, enhance health care professionals’ awareness of how cultural and social factors influence health care, and, second, provide methods for obtaining, negotiating, and managing this information clinically. “Cross-cultural education can be divided into three conceptual approaches,” write the authors of the IOM report. These approaches focus, respectively, on the following:

- **Attitudes** (cultural sensitivity/awareness approach),
- **Knowledge** (multicultural/categorical approach),
- **Skills** (cross-cultural approach),

and has been taught using a variety of interactive and experiential methodologies. Research to date demonstrates that training is effective in improving provider knowledge of cultural and behavioral aspects of healthcare and building effective communication strategies.

Cross-cultural education can be done in medical schools, for interns and residents during their training, and for attending physicians as continuing medical education courses. On an individual basis, each physician should follow the recommendation of the American Medical Association: “Physicians should examine their own practices to ensure that racial prejudice does not affect clinical judgment in medical care.” Only through self-examination and continuing objective education will medical professionals be able to identify and conquer racial and ethnic bias and prejudice.

To educate the public, real and meaningful partnerships must be created between medical professionals and communities. Partnerships involving schools, churches, faith-based organizations, and civic...
and local groups, are the key to creating trust with the minority communities. But such efforts cannot be seen as one-time events; they must be part of an ongoing process that involves engagement, dialogue, and feedback. Medical professionals must engage target communities through mechanisms such as advisory boards, free medical screening for various illnesses, health fairs, public education lectures, etc. In these engagements they must conduct a dialogue that ensures open and honest communication and mutual respect. Such sessions will, on one hand, allow medical professionals to inform the public about the need for medical screening and clinical research; and, on the other, allow the public to voice its concerns about certain diseases, research protocols, new medications, and other matters.

Dialogue and transparency of this kind will provide the feedback that gives both medical professionals and the public the ability to listen to each other’s concerns through periodic evaluations, reviews, and open forums. Only through honest and effective communication will trust be fostered and patients come to feel that they have some control in their health care decision-making. Hopefully, this honest communication will also help dispel any myths circulating in the minority communities about certain diseases, medications, experiments, and similar issues. Health care professionals must always be seen as advocates for all people. Only then will patients’ involvement in care, adherence to recommended treatment, and willingness to participate in clinical research increase.

Third, there needs to be collaboration and partnerships among interested parties from academia, industry, government, philanthropy, the corporate sector, and the community to reduce racial and ethnic health disparities. The Health Disparities Roundtable, for example, was convened in 2006 under the co-sponsorship of the Office of Minority Health and AHRQ and also in partnership with the Institute of Medicine. Its purpose is to generate action and engage interested parties in a collaboration and partnership that focuses on research and policy discussions. The committee addresses topics such as the following: effective cultural competency techniques and cross-cultural education in health care settings; strategies to expand and strengthen research to develop effective treatments for those diseases that disproportionately affect minority populations; educational strategies to end health disparities; strategies to develop and promote increased minority representation in medicine and health professions; and the causes of health and health care disparities and their best solutions.

Fourth, one way to foster a sense of trust with the minority communities is to offer every citizen adequate health care coverage. Marcia Angell, former editor of the New England Journal of Medicine, believes that the United States needs a national “single-payer” system that would eliminate unnecessary administrative costs, duplication, and profits. She has proposed extending Medicare to the entire population. “Medicare is, after all, a government-financed single-payer system embedded within our private, market-based system” she writes. “It’s by far the most efficient part of our health-care system, with overhead costs of less that 3 percent, and it covers virtually everyone over the age of 65.” Offering all Americans, adequate health care coverage would be a significant step in building a sense of trust with the minority communities, who would benefit the most from this initiative. In addition, offering access to the same quality of health services for all Americans would help to eliminate the disparities that exist today.

Fifth, efforts should be made to increase the number of minority doctors. Recent statistics show that “[m]inorities, including African Americans, Asian Americans, Hispanics and American Indians, account for just 9% of the nation’s doctors.” More specifically, “some 12% of the American population is Black, but only 4% of physicians are Black.” Increasing the number of minority doctors would both increase the trust factor between minorities and the medical establishment, and it would also assist in the communication and cultural issues between patients and physicians.

Sixth, the IOM study also suggests that physicians should rely on “evidence-based guidelines” to determine what care should be given to patients. Adherence to such guidelines, if made known to patients, could help dispel any fears that minority patients have regarding inferior care due to their race or ethnicity.

Seventh, to improve health care among the minority populations, there is a need to follow Martin Luther King’s example of grass-roots efforts and organize accordingly. This means organizing church by church and health fair by health fair to persuade African Americans and other minorities to participate in clinical trials, become organ donors, etc. Currently only 8% of people on the national list to donate bone marrow are black, but about 12% of the population is black. In bone marrow, even more so than for solid organs such as kidneys and livers, it is important to find a donor of the same ethnic group. Barriers to adequate health care include lack of education, lack of empowerment, economic issues such as transportation, child care, time off from work, etc. To address these issues, some medical centers are using grant money from the National Cancer Institute to hire women from the community to do outreach, such as spreading the word about mammograms and helping distrustful or over-
whelmed patients to navigate the health care system.

This grass-roots effort is one effective way to gain the trust needed in the minority communities.

Eighth, leaders in the minority communities have an ethical responsibility to address the many rumors and myths surrounding HIV/AIDS, vaccinations, etc., that are spreading within their communities. This is not to say that what has happened in the past should be ignored or forgotten. The minority communities cannot close their eyes to events like the Tuskegee Syphilis Study. Instead, civic and church leaders within these communities should begin an honest dialogue with the community about HIV/AIDS, clinical trials, and other health-related issues. It is time for leaders in the minority communities to work with the medical establishment for the health and safety of their constituents.

Ninth, underrepresentation in clinical trials can lead to results that do not account for a variety of factors — genetic, cultural, racial, religious, linguistic, as well as variables related to age and gender — that could have a significant impact on how well new drugs perform in the real world. To address these shortcomings, the following policy solutions have been proposed: government regulatory changes; increased collaboration between government and private industry on clinical trial design; increased community involvement in patient participation; scientific journal oversight of patient breakdowns; new, specialized training for review boards; reallocation of research funding to avoid duplication and address disparities; increased public education; increased focus on the patient participation process; and guaranteed insurance coverage for all related costs. Instituting these policy solutions would not only minority representation in clinical trials but would go a long way toward gaining the trust of the minority populations in the United States.

Racial and ethnic disparities in health care constitute a complex issue that pertains to individuals, institutions, and society as a whole. Unless we address these disparities and begin to eradicate them, we will never attain the goal of providing high-quality health care in the United States. If we do not make this a priority now, everyone will pay the price in the future.

References
4. The term “medical profession” is a social construct and in this paper is being used in a broad sense. The medical profession is comprised of millions of individuals in which, many may be racist and insensitive, but there are many of whom are not racist. For lack of a better term, the term “medical profession” will be used to designate medical professionals in the United States knowing full well not all are being deemed racist.
5. See Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, supra note 1, at 4.
10. Id., at 5.
11. Allport and Postman make a case that legends are often little more than solidified rumors. See Allport and Postman, supra note 8, at 167.
12. Id., at xv and 108.
13. See Turner, supra note 9, at 138.
16. Id., at 35-36.
19. Id., at 333.
23. Id. (Fry), at 171.
25. See Fry, supra note 20, at 171.
26. Id., at 172.
28. Id. (Humphrey), at 824.
29. Id., at 824-825.
30. See Gamble, supra note 14, at 36.
35. Norplant is the trade name for a birth control product consisting of six thin capsules that, upon being implanted in the woman’s arm, releases an ovulation-inhibiting hormone. See Turner, supra note 9, at 221.
38. Id., at E-1.
41. Id.
42. Id. (Wilkenson), at 30.
45. A national survey, conducted by the Roper Starch Worldwide polling company, found that out of 500 blacks, 18% said they believed AIDS was a man-made virus; 9% in the general population agreed. When asked more specifically whether HIV and AIDS were part of a plot to kill blacks, 9% of the all-black group said it was definitely true; compared to 1% in the general group. See L. Richardson, “An Old Experiment’s Legacy: Distrust of AIDS Treatment,” New York Times, April 21, 1997, at A-9.
49. It should be noted that “age, sex, diet, underlying disease, and the concomitant use of other medications, race and genetic factors may play pivotal parts in the variability of subjects’ responses to a medication.” See T. King, “Racial Disparities in Clinical Trials,” New England Journal of Medicine 346, no. 18 (May 2, 2002): 1400-1402.
50. See Gifford et al., supra note 2, at 1372-1382.
51. Id., at 1376-1379. The NIH and the FDA both established guidelines encouraging inclusion of more women and minority groups in clinical trials. See, National Institutes of Health, “Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Trials,” Federal Register 59 (1994): 14508-14513; and Food and Drug Administration, Modernization Act of 1997 (FDAMA or the Act), Public Law No. 105-115 (November 21, 1997). It should be noted that experts at the NIH challenged the findings of Gifford et al., saying that because the study was based on patient interviews in 1996-1998, it was therefore out of date.
52. See Gifford et al., supra note 2, at 1379.
53. See Corbie-Smith et al., supra note 3, at 2458-2463.
54. See King, supra note 49, at 1402.
56. See King, supra note 49, at 1401.
See Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, supra note 1, at 2.


See United States Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ), supra note 6, at Chapter 4, "Priority Populations," at 1-10.


Id., at 2.


See Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, supra note 1, at 5-6.


See Corbie-Smith et al., supra note 3, at 2462.

Id., at 2462.

See U.S. Department of Health and Human Services, supra note 74, at 10.


See Gardner, supra note 80, at 3.


See Barrett, supra note 81, at 2-3.
