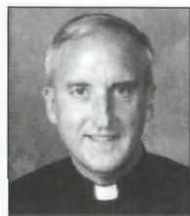


# PREJUDICE AND THE MEDICAL PROFESSION

*Racism, Sometimes Overt, Sometimes Subtle, Continues to Plague U.S. Health Care*

BY PETER A. CLARK, SJ,  
PhD



Fr. Clark is professor of ethics, St. Joseph's University, and bioethicist, Mercy Health System, Philadelphia.

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, which is the envy of the world, is not only flawed by basic injustices but may in fact be the cause of 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 nation's health care system. The report said that people belonging to racial and ethnic minorities often receive a lower quality of health care than do people of European descent, even when their income levels and medical insurance coverage are the same as that of the latter.<sup>1</sup> Another 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 AIDS, they are seriously underrepresented in clinical trials of new treatments for the disease.<sup>2</sup> 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 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 percent more likely to believe that someone like them would be used as a guinea pig without his or her

consent, versus 51.9 percent of the whites surveyed.<sup>3</sup> This study also found that 62.8 percent of African Americans (versus 38.4 percent of whites) believe that physicians often prescribed medication as a way of experimenting on people without consent.

These studies only confirm what many in the minority community have known for years—that racism, whether explicit or subtle, is alive and well 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, it also cited “indirect evidence” that physicians' decisions were influenced by their perceptions of race.<sup>4</sup>

Racism in health care is an issue that should concern everyone in the field. But it should especially concern people in the Catholic health ministry, because it is directly related to the *Ethical and Religious Directives for Catholic Health Care Services*, particularly to Directives 2, 3, and 23.<sup>5</sup> Unless measures are taken to address this racism, unless a new sense of trust is established between the medical establishment and racial and ethnic minorities, these injustices will continue to deepen and expand and more lives will be placed in jeopardy. What is needed is a comprehensive, multilevel, culturally relevant strategy. Developing such a strategy will entail:

- Understanding the causes of racism in the medical profession
- Identifying practical interventions that address this racism in individuals, communities, and the nation as a whole
- Forming partnerships that will work to develop a new sense of trust between the medical establishment and the minority communities

## THE HISTORICAL CONTEXT THE CONSPIRACY MOTIF

The oral folklore tradition is deeply rooted in the African-American heritage. For generations, a variety of negative stories have circulated in that community concerning the medical profession and public health programs. In 1972, when the Tuskegee syphilis study was made public, news about it spread rapidly through the African-American community.<sup>6</sup> The truth about the study was bad enough, but the problem was compounded as this information spread by word of mouth, exaggeration and rumor becoming intertwined with the truth. Today, in the African-American community (and in other minority communities as well), the Tuskegee story is a major part of the folklore passed down by family elders intent on preparing younger members to deal with the harsh realities of life. By contrast, very few white people have even 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."<sup>7</sup> A legend, on the other hand, "is a narrative account set in the recent past and containing traditional motifs that is told as true."<sup>8</sup> Since certain accounts incorporate modern motifs as well as traditional ones, most folklorists and social scientists today 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."<sup>9</sup> Drawing a clear distinction between rumor and contemporary legend is not always possible.<sup>10</sup> I will attempt to make a distinction here, however, in order to demonstrate the ways rumors and contemporary legends have affected, first, the oral folklore tradition of the African-American community and, second, the relationship of that community 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.<sup>11</sup> 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 motif from

the European involvement in the slave trade of black Africans to contemporary "powers that be," including the Federal Bureau of Investigation, the Central Intelligence Agency (CIA), the Food and Drug Administration, the Centers for Disease Control and Prevention (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, Turner says, but it has also appeared in subtle ways during the past century.

Turner's second motif of danger is the *contamination* motif, which she sees as dominant in the 20th century and continuing to be so in the early years of the 21st. 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. Turner uses "contamination" to refer to "any item in which the physical well-being of individual black bodies is being manipulated for racist reasons."<sup>12</sup>

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, on the part of African Americans, reasonable. Such suspicion and distrust is the basis of their 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 society at large. As such, it has been influenced by race and racism both directly and in subtle ways.<sup>13</sup> 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 somehow justified their enslavement. These medical theories not only reinforced the societal attitude that black people were inferior—something less than human—but also justified the use of blacks for medical experimentation and dissection.<sup>14</sup> This is not to say that poor whites were not abused in the United States; the point is that blacks were used more often and with greater disregard, because of their race.

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.<sup>15</sup> Medical students need living people to study in order to learn anatomy, recognize and diagnose diseases, treat conditions requiring surgery, and to 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.<sup>16</sup> In the 30 years preceding the Civil War, fierce competition among Southern medical schools in the recruitment of students put additional pressure on each school to have an abundant supply of clinical materials.<sup>17</sup> This need for human speci-

mens, 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.<sup>18</sup>

Such advertisements led both blacks and poor whites to fear mistreatment in Southern hospitals. 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 proves that this

## Stories about “night doctors” are still told in the black community.

fear was not groundless.

After the Civil War, the absence of laws providing for the legal acquisition of human bodies led the medical profession to resort to illegal means of procuring cadavers. Bodies were either illegally exhumed from graveyards or bought or stolen before they could be buried; in some cases, people were murdered so that their corpses could be sold to medical schools.

Of the three methods, grave robbing was the most popular.<sup>19</sup> The term “night doctor” became well-known in these years, especially in the black community. The term (derived from the fact that victims were sought only during the hours of darkness) applied to both medical students and to professional grave robbers who sold stolen bodies to physicians for medical research.<sup>20</sup> The appearance of the “night doctors” coincided with the post-Reconstruction era, when blacks were migrating to industrial centers. This migration lasted from about 1880 to the end of the First World War.<sup>21</sup> The folklorist Gladys-Marie Fry contends that “many blacks are convinced that Southern 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.”<sup>22</sup> Her theory appears to be historically well-founded. However, there is also evidence indicating 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 belief in their existence had on blacks living in the United States at the time. Stories about “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.<sup>23</sup> By the 1920s, legislation had eliminated body snatching in most parts of the United States, but that legislation did not substantially alter the social origins of the supply of cadavers for medical schools.<sup>24</sup>

Not only did “night doctor” stories and the unethical practices of medical schools in obtain-

ing bodies foster a fear of the medical establishment among African Americans; it also reinforced societal attitudes concerning race and racism. From 1619 until at least the early 1900s, 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 white people, including members of the medical profession. As a result, many African Americans today, aware of what occurred in earlier 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; it became more subtle. The conspiracy motif in black thinking was replaced, for the most part, by the motif of contamination.

### THE CONTAMINATION MOTIF

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.<sup>25</sup> Racist assumptions and stereotypes still existed within the medical establishment. Blacks were seen as inferior, a view that continued to be used to justify using black bodies in ways that white bodies would never be used. The predominantly white medical establishment maintained that "intrinsic racial characteristics such as excessive sexual desire, immorality, and over-indulgence 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."<sup>26</sup> These racist assumptions became the basis for launching what became known as the "Tuskegee Study of Untreated Syphilis in the Negro Male."

In 1932 the U.S. Public Health Service initiated a study of African-American men with syphilis in Macon County, AL, the idea being to track 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. These people, recruited from churches and clinics in Macon County, were led to believe they would receive free meals, burial insurance, and "special free treatment" for what they were told was "bad blood." In short, they were enrolled in the study without their 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 from the infected men the standard treatment of mercury and arsenic

compounds. 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. As late as 1969, a committee at the 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.<sup>27</sup> 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 bearing 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 that community who believe today that condom distribution was part of a government plan to reduce the number of black births.<sup>28</sup> This belief became more credible when Norplant came on the market.<sup>29</sup> Following the legalization of Norplant as a contraceptive device, stories began to circulate that African-American women who lived in the inner city and were welfare recipients were being forced to use it. Such stories intensified when various editorial writers and public policy makers began to suggest that "welfare mothers" be required to have the device implanted as a condition for further benefits.<sup>30</sup>

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. Tending to reinforce the notion is the recent finding that a direct correlation exists between the race of a patient and the availability of certain medical 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 than on other people. On the other hand, blacks are *more* likely to undergo such other pro-

\*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).

cedures as hysterectomies, bilateral orchidectomies, and the amputation of lower limbs.<sup>31</sup> Does this represent a subtle form of sterilization policy? These findings, coming as they do from reputable medical journals, have only increased African-American cynicism concerning the medical establishment.

Genetic screening and public immunization programs have also raised suspicions among blacks. The sickle cell anemia screening programs of the 1970s created misinformation, confusion, and fear. Inadequate planning and preparation on the part of the medical profession and public health officials—and a failure to educate the U.S. public on the difference between being a carrier of the disease and having it—resulted in unnecessary stigma and discrimination. As a result of this confusion and misinformation, a great suspicion arose in the African-American community that sickle cell policy was another instrument of genocide.<sup>32</sup>

The same has been true of public immunization campaigns. Especially widespread is the fear that certain drugs may be experimental and thus potentially toxic. Inoculations have been suspected of being vehicles for the introduction 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.”<sup>33</sup> As a result, diagnostic tuberculosis skin testing has often been refused, because it involves injecting tuberculin material directly under the skin. Some believe that the test is tended to *give* TB rather than detect it.<sup>34</sup> Such misinformation has greatly contributed to the “legacy of mistrust” of the medical establishment in African-American and other minority communities.

In the later 20th century, the contamination theory also became associated with the AIDS epidemic. Indeed, many believe that AIDS was conceived

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as a deliberate plot to exterminate African Americans and other minorities.<sup>35</sup> In a 1990 survey conducted by the Southern Christian Leadership Conference, 35 percent of the 1,056 black church members who responded said they believed that AIDS was a form of genocide.<sup>36</sup> A rumor found consistently among African Americans is that the AIDS virus was created in the laboratories of the CIA. Ac-

ording 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.<sup>37</sup> No matter which form the rumor takes, it has been devastating in the way it undermines anti-AIDS efforts in the African-American community.

A recent study has shown that even though African Americans and other minorities make up a growing percentage of Americans infected with HIV/AIDS, these groups are underrepresented in clinical trials for new treatments.<sup>38</sup> Examining a nationally representative sample, the authors found that some 14 percent of adults receiving care for HIV infection had participated in a medical trial or study; of those, 24 percent had received experimental medications and 8 percent had tried and failed to obtain experimental treatment. According to multivariate models, non-Hispanic blacks and Hispanics were less likely to participate in such trials than non-Hispanic whites.<sup>39</sup> These findings confirm, the authors write,

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.<sup>40</sup>

Although the authors did not pinpoint a single reason for the racial disparities seen, they believe that minority communities possess less awareness of and more negative attitudes about clinical research and experimental medications than do other communities. "Black persons may interpret informed consent procedures as 'liability waivers' for researchers to do little to protect patients," they write.<sup>41</sup>

It is clear that minority communities exhibit a general attitude of mistrust toward the medical profession. But there is also mistrust of minority communities on the part of 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."<sup>42</sup> Is not this avoidance itself a form of racism? Studies have shown that many of these supposed compliance problems are probably surmountable and, more important, have not in many cases predicted poor compliance.<sup>43</sup> 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. Only through the building of trust will patient involvement in care, adherence to recommended treatment, and willingness to participate in clinical research increase.<sup>44</sup>

Distrust of the medical establishment by minority groups was further confirmed in another study. In this case, 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 percent to 23.4 percent) to expect their physicians to give less than a full explanation of research participation; they were also more likely (45.5 percent to 38.8 percent) to believe their physicians would expose them to unnecessary risks. African American respondents were in general more distrustful than white respondents.<sup>45</sup>

Finally, as mentioned, the March 2002 IOM report showed that racial and ethnic minorities received a lower quality of health care than whites, even when their insurance and income were the same as whites. "Even among the better-controlled studies," the authors wrote, "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 prob-

lems."<sup>46</sup> The study found that patients' attitudes, such as their preferences concerning treatment, do not vary greatly according to race and so cannot explain racial and ethnic disparities in health care. In addition, the report's authors write, "There is considerable empirical evidence that well-intentioned whites who are not overtly biased and who do not believe that they are prejudiced [nevertheless] 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."<sup>47</sup>

Research suggests that health care providers' diagnostic and treatment decisions, as well as their feelings about patients, are influenced by patients' race or ethnicity.<sup>48</sup> Whether explicit or unconscious, racism among medical professionals is a form of bigotry and must be addressed from both a medical and an ethical perspective.

## **ETHICAL ANALYSIS**

### **APPLICATION OF THREE PRINCIPLES**

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, MD, the former U.S. surgeon general, argues that this evidence correlates with persistent health disparities in statistics concerning illness and death.

Compared with their white counterparts [Satcher writes], 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.<sup>49</sup>

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.<sup>50</sup> This is certainly a medical problem, but it is also an ethical problem for all Americans. To allow race and ethnicity to play any role in providing health care to our fellows 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 in the medical profession, whether explicit or unconscious.

### RESPECT FOR PERSONS

This principle incorporates two ethical convictions: First, that persons should be treated as autonomous agents; and 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.<sup>51</sup> The physician-patient relationship is a covenant based on mutual trust. It is a fiduciary relationship based on honesty. Edmund Pellegrino, MD, and David Thomasma, PhD, 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," they write.<sup>52</sup> Patients, that is, should be able to expect their physicians to have the technical skills to assess and manage their medical conditions.

Unfortunately, racial and ethnic minorities believe their medical conditions are *not* being assessed and managed by physicians in the same way that the medical conditions of white patients are being assessed and managed. The IOM report made it clear that disparities between whites and minorities exist in a number of disease areas.<sup>53</sup> Giselle Corbie-Smith, MD, 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."<sup>54</sup> Medical abuses have come to light through the oral tradition of minority groups and published reports. Minorities believe that their physicians cannot be trusted, that physicians sometimes use them as guinea pigs in experiments, and that minorities 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 the options available to manage their illnesses. Violations of informed consent by medical professionals have been documented and, in some cases, 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 treatment that is the "standard of care," 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 on the part of medical professionals, minority patients are suffering 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 risk to others and to promote and enhance their good. 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 take preference over 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 treatment trials and about half as likely to receive experimental medicines.<sup>55</sup> This lack of participation is caused by, first, minorities' distrust of the medical establishment, and, second, the tendency of physician-researchers to avoid

# Minorities suffer disproportionately from cardiovascular disease.

recruiting minorities because they believe poor compliance is common in these groups.<sup>56</sup> As a result, blacks have, in absolute numbers, outnumbered whites in new AIDS diagnoses and deaths since 1996; since 1998, they've outnumbered whites in the number of people living with AIDS.<sup>57</sup> 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. The stereotyping by researchers and physicians of racial and ethnic minorities (assuming, for example, that they are more likely to abuse drugs, comply poorly 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.

Physicians have, as moral agents, an ethical responsibility to treat their patients in a way that will maximize benefits and minimize harm. Failure to adequately assess and manage medical conditions, for whatever reason, is not in the best interest of the patient. Statistics show that, for men and women combined, blacks have a cancer death rate about 35 percent higher than that for whites and that the death rate for cancer among black men is about 50 percent higher than it is for white men.<sup>58</sup> Minorities suffer disproportionately from cardiovascular disease. The rate of diabetes for blacks is approximately 70 percent higher than for whites, and the rate in Hispanics is double that of whites. The prevalence of diabetes among American Indians and Alaska Natives is nearly three times that for the total population. Finally, compared to white babies, American Indian and black babies are 1.5 and 2 times, respectively, more likely to die in their first year of life.

It is clear, after reviewing these statistics and identifying the biases and stereotyping that exist

in the medical profession, 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 either overcome that

impediment or transfer the patient to another physician, one who will do what is demanded by the basic precepts of medicine—seek the patient's good. Failure to recognize prejudice and bias is a failure not only of the test of beneficence; it 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 justice principle can be applied to the problem under discussion in two ways.

**Inequality in Health Care** Inequality concerning adequate health care for Americans is a well-documented fact. For years this inequality was attributed to socioeconomic causes resulting in a lack of access to care. With the publication of the IOM report, however, it is apparent that subtle racial and ethnic prejudice and differences in the quality of health plans are also among the reasons why even insured members of minorities sometimes 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.

**Inequitable Allocation of Resources** 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 dialysis, kidney transplants, or the best diagnostic tests and treatments for cancer. They are also less apt to receive the



most sophisticated treatments for HIV.

We Americans espouse the belief that all men and women are equal. If we truly believe it, we should insist that all men and women must, whatever their race or ethnicity, receive equal medical treatment and resources. Denying certain minorities such treatment—when whites receive them as a standard of 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 destructive not just to minority patients but to society as a whole.

#### TOWARD SIGNIFICANT REFORM

Racial and ethnic disparities in health care are now documented. 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 will address the issues of racial and ethnic disparities directly and concretely are needed. To accomplish this task, we must (or, in some cases, follow through on) the following initiatives.

**Research** Society should undertake research that allows it to understand both 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 high-quality health services, environmental hazards in homes and neighborhoods, and lack of effective prevention programs tailored to the needs of specific communities.<sup>59</sup> However, we need research that focuses on the unconscious biases that seem to pervade the medical establishment.

One such initiative began in 1999 when Congress required the Agency for Health Care Research and Quality to produce a new annual report to be called *A National Health Care Disparities Report*. The committee established to write this report held two open meetings that year, during which it was presented with a great deal of valuable information, including papers it had com-

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missioned and testimony from experts. The committee issued its first report in 2002; a volume called *Guidance for the National Health Care Disparities Report* was published this year.\* These reports should call attention to the inequality in U.S. health care services, thereby providing the impetus for new initiatives to correct these disparities. Further studies like this would be of great benefit.

**Education** Also needed is education for both medical professionals and patients. Medical professionals need to become more aware of the subtle forms of prejudice that affect their medical decisions. Patients need education that makes them more active and better informed in *their* decisions concerning medical treatment.

The education of health care professionals should begin in medical school and continue throughout their careers. It should focus on the fact that racial and ethnic disparities do exist and on the ways they can be identified and confronted. The IOM has recommended cross-cultural education programs that, first, enhance 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.<sup>60</sup> These approaches focus, respectively, "on *attitudes* (cultural sensitivity/awareness approach); *knowledge* (multicultural/categorical approach), and *skills* (cross-cultural approach), and [have] 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 health care 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 recommen-

\**Guidance for the National Healthcare Disparities Report* is available from the National Academies Press ([www.nap.edu/catalog/10512.html](http://www.nap.edu/catalog/10512.html)).

dation of the American Medical Association: "Physicians should examine their own practices to ensure that racial prejudice does not affect clinical judgment in medical care."<sup>61</sup> 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 the medical establishment and communities. Partnerships involving schools, churches, faith-based organizations, and local civic 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.<sup>62</sup> Medical professionals must engage target communities through such mechanisms as advisory boards, free medical screening for various illnesses, health fairs, and public education lectures. 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 various diseases, research protocols, new medications, and other matters.

Dialogue 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 health care decision making. Hopefully, this honest communication will also help dispel myths circulating in the minority communities concerning diseases, medications, experiments, and similar issues. Health care professionals must 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.<sup>63</sup>

**Adequate Care for All** One way to foster trust in the minority communities is to offer every citizen adequate health care coverage. Marcia Angell, the

# U niversal coverage would help foster trust among African Americans.

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 in health care. 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.<sup>64</sup> "It's by far the most efficient part of our health-care system, with overhead costs of less than 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 trust between health care professionals and the minority communities, who would benefit the most from this initiative. In addition, offering access to high-quality health services for all Americans would help to eliminate the disparities that exist today.

**Minority Physicians** Efforts should also be made to increase the number of minority doctors. Recent statistics show that "Minorities, including African Americans, Asian Americans, Hispanics and American Indians, account for just 9% of the nation's doctors."<sup>65</sup> Increasing the number of minority doctors would both increase the trust factor between minorities and the medical establishment and foster open discussion of communication and cultural issues between patients and physicians.

**Evidence-Based Guidelines** The IOM study also suggests that physicians should rely on "evidence-based guidelines" to determine the care given to patients. If physicians were to adhere to such guidelines, and if their adherence were made known to patients, that would help dispel patients' fears that they may be given inferior care because of their race or ethnic background.

**Equity in Organ Donation** On November 14, 2002, the board of directors of the Organ Procurement and Transplantation Network/United Network for Organ Sharing revised the allocation priority for tissue matching. The change means that about 250 kidney transplants that would previously have gone to white patients will now be given to minority patients. The organizations involved hope that, by ensuring equity among organ transplant recipients, they will boost the

public's confidence in the transplant system.<sup>60</sup> Changes like this should encourage trust within the minority communities and may even increase organ donation from minorities.

**Myth and Rumor** Meanwhile, leaders in the minority communities have an ethical responsibility to address the many rumors and myths surrounding HIV/AIDS, vaccinations, and similar matters that spread in their communities. This is not to say that what has happened in the past should be ignored or forgotten. Minority communities cannot close their eyes to what events like the Tuskegee syphilis study exposed. But civic and church leaders 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 to improve the health and safety of their constituents.

Racial and ethnic disparities in health care constitute a complex issue that pertains to individuals, institutions, and society as a whole. Unless we Americans 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 a price in the future. □

NOTES

1. Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, National Academies Press, Washington, DC, 2002.
2. A. L. Gifford, et al., "Participation in Research and Access to Experimental Treatments by HIV-Infected Patients," *New England Journal of Medicine*, vol. 346, no. 18, 2002, pp. 1,373-1,382.
3. G. Corbie-Smith, S. Thomas, and D. St. George, "Distrust, Race, and Research," *Archives of Internal Medicine*, vol. 162, no. 21, 2002, pp. 2,458-2,463.
4. Committee on Understanding, p. 4.
5. U.S. Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, Washington, DC, 2001, pp. 9, 18.
6. The Tuskegee study is discussed below. See also James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment: A Tragedy of Race and Medicine*, Free Press, New York City, 1981.
7. Gordon W. Allport and Leo Postman, *The Psychology of Rumor*, Henry Holt, New York City, 1947, p. ix.
8. Patricia A. Turner, *I Heard It through the Grapevine: Rumor in African-American Culture*, University of California Press, Berkeley, CA, 1993, p. 4.
9. Turner, p. 5.
10. Allport and Postman make a case that legends are often little more than solidified rumors (p. 167).

11. Turner, pp. xv and 108.
12. Turner, p. 138.
13. See Vanessa Gamble, "A Legacy of Distrust: African Americans and Medical Research," *American Journal of Preventative Medicine*, vol. 9, no. 6, p. 35.
14. Gamble. See also T. D. Weld, *American Slavery as It Is: Testimony of a Thousand Witnesses*, American Anti-Slavery Society, New York City, 1839; F. N. Boone, *Dr. Thomas Hamilton: Two Views of a Gentleman of the Old South*, Phylon, New York City, 1967; and J. M. Sims, *The Story of My Life*, Da Capo, New York City, 1868.
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16. Todd Savitt, "The Use of Blacks for Medical Experimentation and Demonstration in the Old South," *Journal of Southern History*, vol. 48, no. 3, 1972, pp. 332-333.
17. Savitt, p. 333.
18. Gladys-Marie Fry, *Night Riders in Black Folk History*, University of Georgia Press, Athens, GA, 1991, pp. 174-176.
19. Fry, p. 176. See also Alan Gutmacher, "Bootlegging Bodies," *Society of Medical History of Chicago*, January 1935, pp. 353-402.
20. Fry, p. 171.
21. For an analysis of this historical episode, see "The Negro Migration of 1916-1918," *Journal of Negro History*, January 1921, pp. 383-498.
22. Fry, p. 171.
23. David C. Humphrey, "Dissection and Discrimination: The Social Origins of Cadavers in America," *Bulletin of the New York Academy of Medicine*, vol. 49, 1973, p. 822.
24. Humphrey, p. 824.
25. Gamble, p. 36.
26. Gamble; see also T. W. Murrell, "Syphilis and the American Negro," *JAMA*, vol. 54, no. 11, 1910, p. 847; and H. H. Hazen, "Syphilis in the American Negro," *JAMA*, vol. 63, no. 13, 1914, p. 463.
27. In August 1972, HEW appointed an investigatory panel, which then issued a report a year later. The panel found the study to have been "ethically unjustified," arguing that penicillin should have been provided to the men involved in it. See Allen Brandt, "Racism and Research: The Case of the Tuskegee Syphilis Study," *Hastings Center Report*, December 1978, p. 21; and Ad Hoc Advisory Panel, Department of Health, Education, and Welfare, "Final Report of the Tuskegee Syphilis Study," Washington, DC, 1973. For a more detailed analysis of the study, see the following articles from the *Hastings Center Report* (vol. 22, no. 6, 1992): Arthur Caplan, "When Evil Intrudes" (pp. 29-32), Harold Edgar, "Outside the Community" (pp. 32-35), Patricia A. King, "The Dangers of Difference" (pp. 35-38), and James H. Jones, "The Tuskegee Legacy: AIDS and the Black Community" (pp. 38-40).
28. For a discussion of the impact of birth control on the black community, see R. G. Weisbord, "Birth Control and the Black American: A Matter of Genocide?"

- Demography*, vol. 10, no. 4, 1973, pp. 571-590.
29. Norplant is the trade name for a birth control product consisting of six thin capsules that, when implanted in a woman's arm, releases an ovulation-inhibiting hormone. Turner, p. 221.
  30. Turner, p. 222. See also "One Well-Read Editorial," *Newsweek*, December 31, 1990, pp. 65-66; and "Poverty and Norplant," *Philadelphia Inquirer*, December 12, 1990, p. A-18.
  31. See, for example, the following articles from the *New England Journal of Medicine* (vol. 335, no. 11, 1996): H. Jack Geiger, "Race and Health Care—an American Dilemma" (pp. 815-816); and M. E. Gornick, et al., "Effects of Race and Income on Mortality and Use of Service Among Medicare Beneficiaries" (pp. 791-799).
  32. D. Y. Wilkenson, "For Whose Benefit? Politics and Sickle Cell Anemia," *Black Scholar*, vol. 5, no. 8, pp. 26-31. See also King, p. 37.
  33. Curtis Cost, *Vaccines Are Dangerous: A Warning to the Black Community*, A&B Books, Brooklyn, NY, 1991, p. 5.
  34. Bonnie O'Connor, "Foundations of African-American Mistrust of the Medical Establishment" (Hahnemann University Medical School, Philadelphia, n.d.), pp. 10-11.
  35. A national survey of 500 black people conducted by Roper Starch Worldwide Inc. found that 18 percent believed AIDS was a virus concocted by humans; only 9 percent in the general population agreed. Among the blacks surveyed, 9 percent said they believed that HIV and AIDS were part of a plot to kill blacks; only 1 percent in the general population agreed. See Lynda Richardson, "An Old Experiment's Legacy: Distrust of AIDS Treatment," *New York Times*, April 21, 1997, p. A-9.
  36. Gamble, p. 37. See also S. B. Thomas and S. C. Quinn, "The Tuskegee Syphilis Study, 1932-1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community," *New York Times*, April 21, 1997, p. A-9.
  37. Turner, p. 158. See also E. A. Klonoff and H. Landrine, "Do Blacks Believe that HIV/AIDS Is a Government Conspiracy against Them," *Preventative Medicine*, vol. 28, no. 5, 1998, pp. 451-457; G. Corbie-Smith, et al., "Attitudes and Beliefs of African Americans toward Participation in Medical Research," *Journal of General Internal Medicine*, vol. 14, no. 9, 1999, pp. 537-546.
  38. Gifford and colleagues note 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 also Talmadge King, "Racial Disparities in Clinical Trials," *New England Journal of Medicine*, vol. 346, no. 18, pp. 1,400-1,401.
  39. Gifford, et al.
  40. Gifford, et al., pp. 1,376-1,379. The National Institutes of Health (NIH) and the Food and Drug Administration have encouraged the 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*, vol. 59, March 28, 1994, pp. 14,508-14,513; and Food and Drug Administration, "Modernization Act of 1997," PL 105-115 (November 21, 1997). It should be noted that NIH experts challenged the findings of Gifford and his colleagues, arguing that because the study was based on patient interviews conducted in 1996-1998, its conclusions were out of date.
  41. Gifford, et al., p. 1,379.
  42. Talmadge King, p. 1,402.
  43. Talmadge King. See also L. Fogarty, et al., "Patient Adherence to HIV Medication Regimens: A Review of Published and Abstract Results," *Patient Education and Counseling*, vol. 46, no. 2, 2002, pp. 93-108.
  44. Talmadge King, p. 1,401.
  45. Corbie-Smith, et al., "Distrust, Race, and Research."
  46. Committee on Understanding, p. 2.
  47. Committee on Understanding, pp. 3-4.
  48. Committee on Understanding, pp. 4-5. See also K. A. Schulman, et al., "The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization," *New England Journal of Medicine*, vol. 340, no. 8, 2002, pp. 618-626; J. M. Abreu, "Conscious and Nonconscious African American Stereotypes: Impact on First Impression and Diagnostic Ratings by Therapists," *Journal of Consulting and Clinical Psychology*, vol. 67, no. 3, 1999, pp. 387-393; and M. Van Ryn and J. Burke, "The Effect of Patient Race and Socio-Economic Status on Physicians' Perceptions of Patients," *Social Science and Medicine*, vol. 50, no. 6, 2000, pp. 813-828.
  49. David Satcher, "Our Commitment to Eliminate Racial and Ethnic Health Disparities," *Yale Journal of Health Policy, Law, and Ethics*, vol. 1, no. 1, 2001, pp. 1-14.
  50. Satcher, p. 1.
  51. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, U.S. Government Printing Office, Washington, DC, 1979, p. B-1.
  52. E. D. Pellegrino and D. C. Thomasma, *A Philosophical Basis of Medical Practice*, Oxford University Press, New York City, 1981, p. 213.
  53. Committee on Understanding, p. 2.
  54. Corbie-Smith, et al., p. 2,460.
  55. Gifford, et al., p. 1,373.
  56. Talmadge King, p. 1,402. See also C. K. Svensson, "Representation of American Blacks in Clinical Trials of New Drugs," *JAMA*, vol. 269, no. 2, 1989, pp. 263-265.
  57. Centers for Disease Control and Prevention, "United States HIV/AIDS Statistics," *HIV/AIDS Surveillance Report*, June 2001, pp. 1-4.
  58. Satcher, pp. 1-14.
  59. Satcher, p. 2.
  60. Committee on Understanding, pp. 5-6.
  61. Council on Ethical and Judicial Affairs, *Code of Medical Ethics: Current Opinions with Annotations*, American Medical Association, Chicago, 1998, pp. 9, 121.
  62. Corbie-Smith, et al., 2,462.
  63. Corbie-Smith.
  64. Marcia Angell, "The Forgotten Domestic Crisis," *New York Times*, October 13, 2002, Week section, p. 13.
  65. Sheryl Gay Stolberg, "Race Gap Seen in Health Care of Equally Insured Patients," *New York Times*, March 21, 2002, pp. A-1-A-4.
  66. The change involves modifying human leukocyte antigen (HLA) matching that measures the immune system compatibility of an organ donor and a recipient. Patients who have better HLA matches with potential donors have historically received a higher priority for transplantation. But medical science has enhanced graft survival, easing the need to seek perfect matches. See Mike Mitka, "Change in Kidney Transplantation Priority Will Help Organ Recipients in the Minority," *JAMA*, vol. 288, no. 23, 2002, p. 2,953.

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