Barriers to Optimum End-of-life Care for Minority Patients

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Although major efforts are underway to improve end-of-life care, there is growing evidence that improvements are not being experienced by those at particularly high risk for inadequate care: minority patients. Ethnic disparities in access to end-of-life care have been found that reflect disparities in access to many other kinds of care. Additional barriers to optimum end-of-life care for minority patients include insensitivity to cultural differences in attitudes toward death and end-of-life care and understandable mistrust of the healthcare system due to the history of racism in medicine. These barriers can be categorized as institutional, cultural, and individual. Efforts to better understand and remove each type of barrier are needed. Such efforts should include quality assurance programs to better assess inequalities in access to end-of-life care, political action to address inadequate health insurance and access to medical school for minorities, and undergraduate and continuing medical education in cultural sensitivity. J Am Geriatr Soc 50:182–190, 2002.

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The medical literature contains abundant evidence that care for terminally ill patients needs improvement.¹⁻⁴ Numerous barriers to high-quality end-of-life care have been identified.¹⁻³,⁵⁻¹⁹ Although major efforts have been undertaken in the past decade to improve end-of-life care, there is growing evidence that improvements are not reaching those at especially high risk for inadequate end-of-life care: minority patients. This paper explores barriers to optimum end-of-life care that particularly affect minority patients. Current knowledge in several relevant domains is reviewed, including ethnic differences in access to medical services and cultural differences in attitudes toward physicians and end-of-life care. Based on this review, specific types of barriers to optimum end-of-life care for minority patients are identified, and strategies for lowering the barriers are proposed.

BARRIERS TO MEDICAL CARE IN GENERAL FOR MINORITY PATIENTS

Large disparities exist between use of the most varied medical services by minorities and use of the same services by European Americans. At least some of this lower use is due to decreased access.²⁰⁻²² Evidence of disparities is most plentiful for African Americans. Multiple studies document decreased use of cardiac procedures for African Americans with coronary artery disease.²³⁻²⁷ Other studies found similar disparities in use of renal dialysis for African Americans with end-stage renal disease.²⁸,²⁹ Ayanian et al. found that quality of care was lower for black Medicare beneficiaries than for others hospitalized for congestive heart failure or pneumonia.³⁰ Ayanian’s group also found substantially lower access to renal transplantation for black than for white patients.³¹ This finding remained after controlling for patients’ preferences and other factors. It also has been found that older African American women receive mammography less often than socioeconomically and demographically matched European American women,³²,³³ and that non-white (mostly African American) pneumonia patients were less frequently admitted to intensive care units than similarly ill and similarly insured European American patients.³⁴ Likewise, ethnic disparities were found in rates of surgery for early-stage non-small–cell lung cancer and glaucoma.³⁵,³⁶ Another study found that black Medicare patients hospitalized with heart failure or pneumonia received poorer quality of care than other patients.³⁷ In a large study of Medicare beneficiaries, Kahn et al. showed that “patients who are black or from poor neighborhoods have significantly worse processes of care and greater instability at discharge than other patients.”³⁸ A second large study of Medicare beneficiaries by Gornick et al. found that African Americans have fewer visits to physicians for ambulatory care, fewer mammograms, and fewer immunizations against influenza than European Americans. African Americans are also hospitalized more often, have higher rates of lower-limb amputation for peripheral vascular disease and bilateral orchectomy for prostate cancer, and have higher mortality rates. These differences remained after controlling for income.³⁹

It is clear that lack of insurance is a major barrier to receiving health care and that minority Americans are at
least twice as likely to be uninsured as European Americans. Other causes for these ethnic disparities in access and outcomes are less clear and have not been empirically proven. The search for causes is complex. Studies that use different methods, populations, or variables or that define variables differently are not easily comparable. Although many studies of such disparities may control for “race” or socioeconomic status, or even for more specific variables such as income or insurance, the meanings of these terms are not standardized and sometimes remain unclear. Possible causes or associations include unmeasured socioeconomic factors such as differences in insurance type, availability of transportation, and job and familial obligations; cultural differences in attitudes toward or preferences for health care; and actual and perceived racial bias at individual and institutional levels. Further clarification of these possible social, economic, institutional, cultural, and psychological barriers to optimum care for minority patients is particularly important because of poorer overall health among African Americans and Latinos as measured by various parameters. These include higher infant and maternal mortality rates, shorter life expectancy (for African Americans), and higher incidence of many diseases associated with high morbidity and mortality, such as diabetes mellitus, hypertension, end-stage renal disease, cardiovascular disease, stroke, some cancers, tuberculosis, and acquired immunodeficiency syndrome (AIDS).

Decreased access to care for minorities is reflected in decreased access to medical school for the same groups. Minorities continue to be underrepresented in medical schools, in the medical profession, and on medical school faculties at all levels. The recent assault on affirmative action is already making this underrepresentation worse, especially in the states that dropped affirmative action first: California, Texas, Louisiana, and Mississippi. More states plan to follow suit. Minority physicians are known to care disproportionately for underserved, poor, and minority patients. Therefore, barriers to medical education are likely to heighten barriers to care and worsen overall health for these populations.

BARRIERS TO OPTIMUM END-OF-LIFE CARE FOR MINORITY PATIENTS

Disparities in Provision of Analgesia and Other Care

Ethnic disparities also have been found in access to end-of-life care. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) investigators demonstrated that, in five major medical centers, fewer resources were used in caring for seriously ill African Americans than for other patients with similar illness severity and sociodemographics. Several studies reveal lower use of analgesia for minority cancer patients with pain. When Bernabei et al. analyzed data obtained with the Minimum Data Set instrument from 14,000 older cancer patients in over 1,400 nursing homes, they found that African American and minority patients were significantly more likely to receive no pain medication. Cleeland et al. studied 281 minority (mostly black and Hispanic) patients and 627 majority patients with cancer. They found that minority patients were significantly less likely to receive guideline-recommended analgesia. Engle et al. used a qualitative ethnographic approach to evaluate the needs and concerns of black and white nursing home residents with terminal cancer. They concluded that pain relief was inadequate for the black residents.

A study of analgesia use in a large Los Angeles emergency department found that Hispanic trauma patients were twice as likely to receive no pain medication as non-Hispanic white patients with similar injuries despite the fact that physician assessment of pain severity did not differ between the two groups. In a similar study of black and white patients in an Atlanta emergency department, blacks were significantly less likely than whites to receive analgesics. In a survey of pharmacies in New York City, Morrison et al. found that pharmacies in predominantly non-white neighborhoods do not stock sufficient medications to treat patients with severe pain. Although these studies did not focus on analgesia for terminally ill patients, they too indicate that undertreatment of pain disproportionately affects minorities.

Ethnic Differences in Preference for End-of-Life Care

A number of studies reveal differences between ethnic groups in attitudes toward end-of-life care. A difference between African Americans and European Americans in attitudes toward life-sustaining treatment and advance directives is particularly well documented. Multiple studies show that African Americans prefer aggressive life-sustaining treatment more often than European Americans. In their study of African American, Mexican-American, Korean-American, and European American senior citizens in Los Angeles, Blackhall et al. found that African Americans were the most likely to want life-sustaining treatment, whereas European Americans were least likely. Caralis et al. found that African Americans were less likely than Hispanics or non-Hispanic European Americans to want “physician-assisted death” under any circumstances or to want life-prolonging treatments withheld or withdrawn. Non-Hispanic whites were most likely to agree to both. These results remained after controlling for socioeconomic status. Garrett et al. and Gramelspacher et al. found that African American patients were significantly more likely than white patients to desire aggressive life support in the event of terminal illness. A study of nursing home residents in the Philadelphia area revealed that African Americans were significantly more likely than those classified as “white or other ethnicity” to prefer cardiopulmonary resuscitation (CPR) in the event of cardiac arrest and to prefer tube feeding in the event of inability to eat due to brain damage. The SUPPORT investigators found that, among hospitalized patients with terminal diagnoses, black patients were significantly more likely to want CPR than white patients. Although adjustment for self-pay or Medicaid coverage eliminated this difference, African Americans were more likely than European Americans to continue to prefer CPR 2 months after hospitalization and were more likely to change a do-not-resuscitate (DNR) order to preferring CPR. In the same study, African American patients who experienced cardiopulmonary arrest were more likely to receive CPR than “white or other ethnicity” patients. Among SUPPORT patients who experienced economic hardship, African Americans were more likely than European Americans to prefer life-extending care. Reese et al. found a
significantly lower interest in hospice care among African Americans than among European Americans. 78

Multiple studies also show that African Americans are less likely than European Americans to have completed an advance directive or be interested in doing so. Caralis et al. found that African Americans were significantly more likely to feel that they would be treated differently or cared for less if they had a living will. The authors interpreted their results as suggesting a lack of trust by many minority patients of living wills in particular and the healthcare system in general. 79 Murphy et al. found that European Americans were more likely to have an advance care directive than Mexican Americans, African Americans, or Korean Americans even after controlling for prior knowledge of advance directives. 79 In a random sample of U.S. deaths in 1986, Hanson et al. found that use of living wills was lower by blacks than whites even after controlling for socioeconomic factors. 80 A study of AIDS patients in Boston showed that non-European Americans were significantly less likely to have discussed resuscitation with their physician than European Americans. 81 In two large studies of hospitalized patients in the Cleveland area, the use of DNR orders was substantially lower in African Americans than in whites. 82,83

Cultural Difference

The process of dying entails great stress and vulnerability for most patients and families. Patients may feel very removed from the quotidian concerns that preoccupy most people. 84 This feeling of aloneness and extreme stress suffice to make communication with clinicians difficult. Cultural differences between patients and clinicians make the gap still more difficult to bridge.

Culture—defined as a constellation of shared meanings, values, rituals, and modes of interacting with others that determines how people view and make sense of the world—strongly influences how patients experience health, illness, and medical care. 85–87 It is especially important in shaping attitudes about death and dying and preferences for end-of-life care. 70,88–92 Religious and cultural beliefs, practices, and rituals help people cope with the fear, stress, and grief associated with dying by providing a context of meaning and a structure of support. Thus, even patients and families who do not usually follow traditional practices may resort to them in this situation. 78,93 Clinicians too hold strong culturally determined beliefs about death and dying and resort to particular practices in caring for the dying. Vincent and others have shown that physicians’ attitudes toward end-of-life care vary significantly along religious and cultural lines. 94–96 In addition, modern medicine itself is a culture, and medical education an acculturation process, that helps determine physicians’ attitudes. 97–99 Thus, the process of dying, perhaps more than any other moment in the course of medical care, can accentuate cultural differences between patients, families, and providers.

Several recent studies in the medical literature document cultural differences in attitudes toward medicine and dying. Carrese et al. report that exposing Navajo patients to advanced care planning as required by the Patient Self-determination Act and the principle of autonomy can inadvertently harm them. 100 Paradoxically, the antipaternalistic belief in the patient’s right to know, strongly promoted in the medical ethics literature of the last 30 years, may lead in some instances to a cultural paternalism that can psychologically injure patients from certain cultures. 101,102

The study by Blackhall et al. suggests that many Korean Americans and Mexican Americans in southern California may be at risk for such injury. 88 Blackhall found that Korean Americans and Mexican Americans were more likely than African Americans or European Americans to believe that only the family, and not the patient, should be told the truth about a diagnosis of metastatic cancer or a terminal prognosis and that the family rather than the patient should make decisions about life support. These attitudinal barriers were associated strongly with culture and acculturation, and these associations remained after controlling for socioeconomic status. The investigators also found that Korean Americans had the most positive general attitude about life-sustaining treatment but had a low personal desire to receive it. One subject’s explanation for this seeming paradox was that, in spite of her low interest in life support, the decision belonged to her son who was obligated by filial piety to request life support. 70 The investigators concluded that a family-centered style of medical decision-making is common in some cultures and that physicians ought not, therefore, adhere blindly to the patient autonomy model. Rather, they must take care to learn the beliefs and preferences of each individual patient regarding medical decision-making and to respect those beliefs and preferences.

Lack of sensitivity to, and respect for, cultural difference may compromise end-of-life care for minority patients. As the country becomes culturally more diverse, the risk to minorities of poor end-of-life care due to cultural misunderstanding is likely to grow. Thus, many have called for training in cultural sensitivity for medical students and residents and in continuing medical education (CME) courses. 103–106

A small study by Cykert et al. suggests a cultural difference between older African Americans and European Americans in attitudes toward debility and death. When asked about preferences for remaining in a severely debilitated state rather than undergoing a potentially lethal attempt at cure, Cykert et al. found that African Americans had much higher health utility scores: a greater preference to remain alive in spite of severe disability. 107 Another study showed that differences between African American and European American women in cultural beliefs about cancer partially explain differences in breast cancer stage at diagnosis. 108 The question arises as to whether the reported “ethnic” (or “racial”) differences in preferences for end-of-life care summarized in the preceding section are better described as cultural differences. Although the definitions of “ethnicity” and “culture” overlap, “ethnicity” denotes, at least in part, a shared genetic or geographical origin. It may be useful for medical purposes to distinguish between diseases particularly prevalent in certain ethnic groups—diseases whose manifestations are primarily genetically rather than culturally determined, such as Tay-Sachs disease or sickle cell anemia—and diseases or conditions related primarily to cultural beliefs or practices. “Race” has always denoted a linkage between physical features such as skin color on the one hand and intellect or behavior on the other. 109 It is widely accepted that this specious con-
cept is not scientifically applicable to anything in reality and has little value in medical research or practice. The documented greater preference among African Americans than among European Americans for aggressive life-sustaining treatment and against use of advance directives is due neither to population-specific genetic differences nor to “racial” differences in intellect or behavior. It is due rather to differences in shared meanings and values formed by shared historical and social experience. It is due to differences in culture.

The question now arises as to what might determine this cultural preference in African Americans. Might it be due, as Caralis and others have suggested, to a lack of trust in physicians or the healthcare system on the part of African American and minority patients? Do minority patients sometimes suspect that they may be experimented upon surreptitiously or that physicians may wish to save money or effort by withholding treatment from them? If this were the case, mistrust might constitute a major barrier to optimum care for minority patients. It may compromise patient-physician communication or dissuade patients from seeking needed medical attention and following physicians’ recommendations. Care of terminally ill patients would be compromised for the same reasons. In addition, mistrust may make patients hesitant to complete advance directives and motivate them to insist on aggressive and often painful life-sustaining treatment rather than comfort care. Thus, mistrust may be an especially important barrier to optimum care of terminally ill minority patients.

Mistrust

There now are some data documenting cultural differentials in trust. When Kao et al. surveyed over 2,000 patients to try to discern any relationship between method of physician payment and patients’ trust of their physicians, they found that whites trusted their physicians more than non-whites regardless of the method of physician payment. Among patients with end-stage renal disease on dialysis in four geographic regions, Ayanian et al. found that blacks were less likely than whites to report trust in their primary nephrologist’s judgment. Davidson et al. studied mistrust as a possible barrier to organ donation by African Americans and concluded that “distrust of the medical community is a powerful deterrent to organ donation.” In addition, three recent studies using focus-group methodologies revealed mistrust of physicians and the healthcare system by African American patients.

Clear data linking culturally based mistrust to specific preferences for end-of-life care are scant. The best evidence linking mistrust of physicians to a preference by African Americans for aggressive life-sustaining treatment comes from Blackhall et al., who followed up their quantitative study with ethnographic interviews. There emerged in interviews with African Americans the prominent theme that “doctors could not be entirely trusted to know when, and if, to stop life support because their motives might be tainted by economic considerations.” Morrison et al. found that older Hispanics reported less trust in physicians and in the healthcare system than did African Americans or whites. They also found significant differences between Hispanics, African Americans, and whites in completion rates of healthcare proxies. However, these latter differences resolved with multivariable analysis that controlled not for trust but for reversible barriers to completing a proxy such as knowledge of proxies and availability of a healthcare agent. In a small study using a focus group methodology, Hauser et al. did find that mistrust and suspicion about the healthcare system influenced attitudes of African Americans toward advance directives. Similarly, when Reese et al. conducted qualitative interviews with six African American pastors to explore reasons for low use of hospice by African Americans, lack of trust in the healthcare system emerged as a major theme. These findings have yet to be confirmed in larger or quantitative studies.

Using quantitative methods, McKinley et al. specifically sought to test the hypothesis that African Americans prefer more live-sustaining treatment and use fewer advance directives than whites because African Americans mistrust the healthcare system. Although they confirmed these differences in preference for end-of-life care and in use of advance directives, they found no difference between cultural groups in trust. They speculated that this inability to document mistrust may have been due to an inadequate study design that was not conducive to maximizing patients’ forthrightness about a very sensitive issue: trust in their physicians.

Given the evidence that many African American and other minority patients mistrust the healthcare system and the possibility that this mistrust may compromise care, it is important to try to understand mistrust more fully. What has produced mistrust? Is there a historical and social context to which mistrust is an adaptive and reasonable response and within which it makes sense?

Medical Racism

We have seen that widespread disparities exist today in access to many medical services for minority patients. Although precise reasons for these disparities remain unclear, it would not be unreasonable to suspect that racism of various kinds may play a role—individual or institutional, conscious or unconscious. Thus, these widespread disparities are reason enough for minority patients to mistrust the healthcare system. The history of American medicine provides further reasons.

Regrettably, American physicians were among those who supported and profited professionally from slavery. Williams notes that in 19th century United States, “medical research was used to justify racial domination and support the prevailing ideology of racial inferiority.” Gamble writes, “Antebellum physicians contended that black people possessed peculiar physiological and anatomical features” that made them “not only inferior but inherently suited for slavery.” Such features included thicker skin, better tolerance of heat and sun, less sensitivity to pain, and less susceptibility to diseases such as yellow fever and malaria, than white people. This belief in a racial difference in pain sensation served as a justification for physicians to perform agonizing experiments on slaves and to use them brutally as teaching material. Given recent evidence of decreased use of analgesia for African American and other minority cancer patients, the question arises as
to whether a racial belief in differential pain sensation continues to unconsciously—or even consciously—aﬄict contemporary physicians.

In the late 19th and early 20th centuries, many medical and public health journal articles discussed the intrinsic “racial” characteristics of African Americans that supposedly produced high rates of syphilis.113 These racist attitudes served as a background for the most infamous American medical research project of the 20th century: the Tuskegee Syphilis Study.129 It is estimated that between 28 and 100 of the 399 poor African American sharecroppers who were deceived into serving as subjects died of untreated syphilis. James Jones, author of the deﬁnitive book on the Tuskegee Study, notes that for many African Americans the Study is a symbol of mistreatment and deceit by the medical establishment.130 Several small studies performed in different locations have documented the pervasiveness and power of this symbol in the black community.122,123,131

Even after the Tuskegee Study was shut down, potentially harmful medical experimentation without informed consent continued on prisoners in the Philadelphia prison system who were disproportionately African American and minority. When news of the experiments became public in 1980 and 1981, it was reported particularly thoroughly in minority newspapers.132 Major public health projects in recent decades also have proven injurious to minorities. “Voluntary” sterilization initiatives in poor communities in the 1960s disproportionately subjected minority women to coerced sterilization.114,115 Federal and state efforts to address sickle cell disease in the 1970s included conﬂation of sickle cell disease and trait in education materials and senseless mass screening programs. The result was job and insurance discrimination against African Americans.133,134

The history of American medicine includes torturous exploitation, deception, withholding of needed treatment, experimentation without consent, coerced treatment, and stigmatization, perpetrated by healthcare institutions and physicians upon African American and other minority patients. Given this history of medical racism, and given widespread inequalities in access to health care today, mistrust is not surprising.115

Whose problem is mistrust? The literature often construes mistrust as a characteristic of minority patients and populations. This implies that mistrust is a problem of minorities that minorities must overcome. It blames the victims of discrimination and racism for a normal response to being victimized. The basic problem is that physicians and healthcare institutions have not always been trustworthy.135 The onus should be on physicians and on the healthcare system to consistently demonstrate trustworthiness, not simply on mistrustful minority patients to try to overcome their misgivings.

CONCLUSION: TOWARD CULTURALLY SENSITIVE END-OF-LIFE CARE AND RESEARCH

Many barriers exist to optimum end-of-life care for minority patients. First, there are large-scale structural or institutional barriers. These include the economic barrier of inadequate health insurance that disproportionately aﬀects minorities,136 social barriers to equal access unrelated to insurance, underrepresentation of minorities in medicine, and the dismantling of aﬄective action programs designed to remedy this underrepresentation. These institutional barriers are forms of institutional racism.41,50 Second, there are cultural barriers arising from cultural diﬀerences between patients or families and healthcare providers and the insensitivity of providers to these diﬀerences. Part of this problem is the confusion of cultural diﬀerence with genetic or ethnic diﬀerence. Third, there are individual barriers. These include racially discriminatory practices by individual physicians41 and the psychological barrier of mistrust generated by individual and institutional discrimination and by cultural insensitivity. Fourth, the highly stressful process of dying, perhaps more than any other moment in the course of medical care, can heighten each of these barriers. It can make manifest latent cultural diﬀerences, latent racism—individual or institutional, conscious or unconscious—and latent mistrust due to a legacy of racism. Thus, provision of compassionate and individualized end-of-life care for minority patients can be complicated and challenging and requires special knowledge, communication skills, and sensitivity.

How can these barriers be lowered? Institutional barriers must be addressed at institutional or societal levels. A national, single-payer health insurance program could end the national disgrace of 40 million Americans—disproportionately minority—being without health insurance. The likelihood that this alone would reduce barriers to optimum care and improve outcomes for minorities is suggested by research done in Veterans Affairs Medical Centers where insurance is not an issue.137–139 Yet even in this setting disparities in access and outcome remain.25,140,141 We believe that a national health insurance program is necessary but not suﬃcient to eliminate these disparities, because lack of insurance is not the only barrier.

Institutional barriers to equal access also can be addressed in other ways. Legally mandated quality assurance protocols for hospitals and managed care organizations (MCOs) have been proposed to assess diﬀerences between social groups in use of services and health outcomes.41,142,143 Hospices could make similar assessments. This would require scrupulous collection of data on the ethnicity and socioeconomic status of patients by all such organizations. If ethnic diﬀerences are found, further research should explore the cause. Studies of ethnic disparities in access must take care to avoid exaggeration that might needlessly exacerbate mistrust.144 Reimbursement policies should provide incentives rather than disincentives to hospitals, MCOs, and hospices to serve minorities, the poor, and the chronically and terminally ill.142 In addition, debt repayment programs and a revitalized National Health Service Corps could provide incentives to young physicians to practice in underserved areas. Affirmative action programs should be protected and strengthened to improve access to medical school for minority students and make the medical profession ethically more representative of society.

How can physicians learn to provide culturally sensitive end-of-life care? There are no easy answers. No medical algorithm or decision tree will be adequate to this task. Physicians first must recognize that the basic values, principles, and assumptions of western medicine and bioethics are themselves historically situated and culturally determined.26,141 They are the values and assumptions of a dominant, but no less particular, culture: the culture consti-
tuted by European and American philosophical and legal traditions. When we physicians recognize our own culture as a culture, as but one of a limitless variety of possible cultures, we begin to open ourselves to others. Second, funding agencies and journal editors should require greater discipline and specificity in identifying study populations in medical research. In particular, the concepts of culture and ethnicity should be carefully defined and distinguished, and racial categories should not be used unless needed to study or combat racism or unless chosen as self-identifiers by study subjects.

Third, studies of different cultures aimed at discovering characteristic attitudes toward death, dying, and health care can be helpful if they are performed and interpreted carefully and respectfully. Investigators and journal editors must recognize that intracultural differences are as great as or greater than intercultural differences. When reporting or teaching information gleaned from such studies, it is crucial to emphasize that all patients must be approached as unique individuals. Similarly, in patient care, physicians must focus primarily on individual patients and families. Only in dialogue with a patient and family can a physician assess the relevance of knowledge about a particular culture to which the patient and family appear to belong. As Koenig et al. put it, “efforts to use racial or ethnic background as simplistic, straightforward predictors of beliefs or behaviors will lead to harmful stereotyping of patients and culturally insensitive care of the dying... Culture is only meaningful when interpreted in the context of a patient’s unique history, family constellation, and socioeconomic status.”

Attending to the singularity of the other can be accomplished using ethnographic approaches as described, for example, by Kleinman, Carrese, and Carrillo et al. Kleinman has described a method for eliciting a brief ethnography. This provides insight into the patient’s understanding of her illness, causes of her suffering, and her values and goals. It serves as a basis for determining her preferences for end-of-life care and for negotiating a strategy to attain her goals that is agreeable to both patient and physician and that does not impose on minority patients the values and goals of the dominant culture. This method can be adapted for research purposes to provide a deeper understanding of cultural difference than that obtainable with quantitative, epidemiological studies alone. Several groups have used this approach in developing cultural sensitivity training curricula for medical education at various levels, and tools for assessing the effectiveness of such training have been proposed. There is early evidence that training of this type can be effective in promoting cultural sensitivity. We believe that culturally sensitive care should routinely be taught and assessed in introduction to clinical medicine courses in medical school; in courses on death, dying, and end-of-life care; and in continuing medical education and risk-management courses.

Similarly, the problem of individual racial bias and discriminatory practices can and should be attacked with education. Instruction on racism as a public health problem should be required in all medical schools receiving public funding. This instruction should include the history of racism in American medicine and the ongoing problem of ethnic inequalities in access to care.

When mistrust is discovered or suspected in interactions with minority patients or families, physicians should gently explore concerns that patients or families might have about experimentation without informed consent, advance directives, or racially discriminatory withholding of medical resources. Physicians must be prepared to resist any incentives created by MCOs or insurance companies to limit care. They will then be able to reassure patients and families that all options are available to them, that neither information nor resources will be withheld from them, and that treatment plans will be worked out in dialogue with them. This reassurance may be particularly important in end-of-life care. Particular care must be taken to “promise only what can be delivered and to deliver everything promised.” On occasion, it may be helpful to acknowledge that American medicine has not been immune to racism. At the same time, physicians should be prepared to affirm that they do not tolerate discrimination in their practices and that they treat all patients fairly and equally.

Finally, further research is needed on mistrust that takes into account the complexity of this phenomenon. It would be useful, for example, to determine exactly what aspects of physicians, medical care, or the healthcare system evoke the most mistrust and any association between mistrust and cultural differences in preferences for end-of-life care. The answers could guide educational interventions and institutional and policy changes to promote trust.

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