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Empowering and Protecting Patients: Lessons for Physician-Assisted Suicide from the African-American Experience

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While we were watching round her bed,
She turned her eyes and looked away,
She saw what we couldn't see;
She saw Old Death. She saw Old Death.
Coming like a falling star.
But Death didn't frighten Sister Caroline;
He looked to her like a welcome friend.
And she whispered to us: I'm going home,
And she smiled and closed her eyes.[1]

The increasing medicalization of death has led to widespread fear that death is unnecessarily prolonged, painful, expensive, and without dignity. This fear has given momentum to the desire of patients to have more control over their dying and to the movement to legalize physician-assisted suicide (PAS) and active voluntary euthanasia (AVE). Others may have a different fear. They may be concerned that their lives are not highly valued in this society and thus fear that they will not have access to life-prolonging treatment or palliative care that, for them, represents death with dignity. Moreover, many others may not share either of these fears, considering

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1. JAMES WELDON JOHNSON, *Go Down Death—A Funeral Sermon, in* GOD'S TROMBONES 27, 29 (Penguin Books 1990) (1927).

death a "welcome friend" to be greeted with family or, in any event, a process that is beyond their control. Making sure that all of these voices are heard in the PAS debate is a challenge.

While we share many of the concerns and values espoused by proponents of PAS and AVE, we believe that existing prohibitions on PAS and AVE should be maintained for the foreseeable future. Central to our argument is the view that this society does not have a sufficient understanding of how and why competent individuals are rendered vulnerable near the end of life. We are especially concerned that inadequate attention has been given to the sociohistorical and cultural contexts in which competent individuals function. If we do not fully appreciate the multiple ways in which an individual's autonomy and well-being can be compromised, we cannot modify existing institutional arrangements and practices in the health care system in ways that will empower and protect *all* patients. It is important to empower patients so that their decisions will be respected, while at the same time protecting them from abuse and exploitation.

When the Supreme Court held unanimously in *Washington v. Glucksberg*[2] and *Vacco v. Quill*[3] that state laws prohibiting assisted suicides did not violate the Due Process Clause or the Equal Protection Clause, the opinions of the Justices reflected concern that the interests of all patients should be protected. For example, the majority opinion in *Glucksberg* recognized that states have an interest "in protecting vulnerable groups—including the poor, the elderly, and disabled persons—from abuse, neglect, and mistakes."[4] Quoting the work of the New York State Task Force on Life and the Law (New York Task Force), the majority opinion stated that "[t]he risk of harm is greatest for the many individuals in our society whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, advanced age or membership in a stigmatized social group."[5] Significantly, the opinion pointed out that "[t]he State's interest [in protecting the interests of all patients] goes beyond protecting the vulnerable from coercion; it extends to protecting disabled and terminally ill

2. 117 S. Ct. 2258 (1997).

3. 117 S. Ct. 2293 (1997).

4. 117 S. Ct. at 2273.

5. *Id.* at 2273 (quoting THE N.Y. STATE TASK FORCE ON LIFE AND THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT 120 (1994) [hereinafter N.Y. STATE TASK FORCE]).

people from prejudice, negative and inaccurate stereotypes and 'societal indifference.'"[6]

As a result of the rulings in these two cases, the states will have the responsibility for insuring that the interests of patients near the end of life are not imperiled. Whether it is possible for the states to make available at this time a compassionate option of last resort for some competent, terminally ill patients, without, as a practical matter, making it harder for other patients to exercise their preferences for life prolonging treatment or palliative care, is a vexing public policy matter. Since more attention has been paid to elaborating the principles and rules that should govern practices at the end of life than to ascertaining whether the principles or rules can be effectively implemented in the context of actual decisionmaking, the states' task will be complicated. As the New York Task Force has pointed out: "For purposes of public debate, one can describe cases of assisted suicide in which all recommended safeguards would be satisfied. But positing an 'ideal' or 'good' case is not sufficient for public policy, if it bears little relation to prevalent social and medical practices."[7] Moreover, the medical context is inextricably linked with the social and economic inequities existing in the broader society. Again, as the New York Task Force persuasively notes, "no matter how carefully any guidelines are framed, assisted suicide and euthanasia will be practiced through the prism of social inequality and bias that characterizes the delivery of services in all segments of our society, including health care."[8]

This Article examines the African-American experience with medicine for the insights that such scrutiny offers about the vulnerability of competent individuals.[9] We begin by offering reasons why such a perspective is critical to development of policies about PAS and AVE and end-of-life decisionmaking generally. It is important to reflect on the African-American experience because it offers insights into the nature of society's responsibilities for those who are competent but whose autonomy

6. *Id.*

7. N.Y. STATE TASK FORCE, *supra* note 5, at xiii.

8. *Id.* at 125.

9. This article uses the terms black and African-American interchangeably. For a brief discussion of the terms used to describe persons who descend from African slaves, see *The Emergence of the Term 'African American' at Two Prestigious Institutions:* THE NEW YORK TIMES *and the Supreme Court*, 16 J. BLACK HIGHER EDUC. 12 (1997).

and well-being may be compromised by historical, social, and cultural forces at work in society itself. Thus, some individuals are in need of protection because they have been rendered vulnerable by their own society.

We turn next to a historical exploration of the relationship between African-Americans and medicine, because, in order to understand the black patient today, there must be some appreciation of the legacy that is carried forward in memories of those who went before. This examination makes clear that, as a historical matter, black lives have not been as highly valued as white lives. We continue by documenting existing disparities in health status, access to health care, and the scope and quality of health care between blacks and whites. The existence of these disparities perpetuates the view among African-Americans that their lives are devalued. Significantly, these disparities also indicate that blacks are severely disadvantaged in negotiating all aspects of the health care system.

Initial efforts to understand the causes of these disparities suggest that their existence may be due to limited access to health care, cultural differences, differences in patient preferences, and unconscious bias. This preliminary work offers insights about the role of race, culture, and mistrust in the physician-patient relationship and medicine generally. It suggests that African-Americans as a group have little reason to believe that their preferences regarding end-of-life decisions will be either understood or respected.

We conclude by indicating ways in which the African-American experience with medicine might inform the states' consideration of PAS and AVE. We hope that others will be motivated to offer similar analyses of other groups for the implications that their history and culture have for PAS.

THE AFRICAN-AMERICAN EXPERIENCE ILLUMINATES THE PAS DEBATE

In a real sense all patients near the end of life are at risk of having their autonomy and well-being compromised. It is commonly accepted, however, that members of certain groups are at special risk and perhaps in need of protection. The term *vulnerable*, which is applied to a broad spectrum of groups, reflects this concern. What makes group members vulnerable, or how their vulnerability is the same or different across groups, however, is neither well defined nor understood.

There is broad consensus that groups whose members lack capacity altogether or have impaired capacity should be viewed as vulnerable. There is less agreement on whether groups whose members are primarily competent adults, such as prisoners or physically disabled persons, should be considered vulnerable to coercion. Even if we can agree that these groups are deserving of special attention, controversy may remain about what circumstances, conditions, or social practices should trigger closer scrutiny of decisions made by members of the group.[10]

Whether particular group members, in contrast to groups themselves, are at special risk of coercion, presents an even more difficult question to unravel. Individuals may belong to multiple groups and thereby be potentially vulnerable for many different reasons. Alternatively, individual members of a group that is regarded as vulnerable may not be susceptible to coercion or undue influence. Here the danger is that appeal to a shared experience may obscure the heterogeneity of group members.[11]

Our dilemma is this: There is general agreement that with competent adults paternalism or interference with self-determination should be avoided. At the same time there is fear that the institutional and social context will constrain competent patients' choices in such a way as to suggest that their choices are coerced. We seem to have only two options.

One approach is to protect vulnerable persons through increased vigilance or special procedural safeguards. Frequently, however, there is disagreement about how to modulate such restrictions. On the one hand, weaker safeguards that promote self-determination may provide so little protection that exploitation results. On the other hand, stronger safeguards may result in denying desired benefits to individuals who are members of the group we are seeking to protect.

An alternative approach permits competent persons to make choices. This approach ignores the conditions that make for vulnerability and emphasizes the potential and undesirability of paternalism, leaving vulnerable persons to look after themselves and to secure access to benefits they desire. The Ninth

10. For a general consideration of these issues, see ALAN WERTHEIMER, COERCION (1987).

11. *See* ELIZABETH V. SPELMAN, INESSENTIAL WOMAN, at ix (1988) (discussing how generic grouping under a label, such as *woman*, "obscures the heterogeneity of women").

Circuit opinion in *Compassion in Dying v. Washington*[12] is instructive in this regard. The majority opinion reasoned:

> This rationale [prohibiting PAS in order to protect the poor and minorities from exploitation] simply recycles one of the more disingenuous and fallacious arguments raised in opposition to the legalization of abortion. It is equally meretricious here.... [A]s with abortion, there is far more reason to raise the opposite concern: the concern that the poor and the minorities, who have historically received the least adequate health care, will not be afforded a fair opportunity to obtain the medical assistance to which they are entitled—the assistance that would allow them to end their lives with a measure of dignity. The argument that disadvantaged persons will receive *more* medical services than the remainder of the population ... is ludicrous on its face. So, too, is the argument that the poor and the minorities will rush to volunteer for physician-assisted suicide because of their inability to secure adequate medical treatment.[13]

The court ignores the fact that minorities and the poor have historically been abused and had their preferences ignored, if indeed their preferences were solicited at all. While it correctly points out that some minority group members may be denied a benefit that they seek, the court overlooks the fact that minorities might prefer, rather than access to PAS, benefits that promote health and well-being in view of existing inequities in health status, health care coverage, and the delivery of health care services. Even if minority individuals desired access to PAS, they would not necessarily be able to secure this or other benefits because they lack power in the society. Thus, neither approach is optimal because each fails to guarantee access to benefits and avoidance of harm.

It is therefore important to assess carefully the conditions of inclusion or access to benefits. For example, an empowered patient may need fewer protections from society because the ability to protect oneself may have increased. The starting point, then, is to develop thick descriptions of patients in order to learn why, if at all, they are vulnerable. We need to know patients not merely in terms of abnormalities in the structure and function of their body organs and systems, but also as persons situated in broader social, economic, historical and cultural contexts.[14] In actual encounters with health care professionals,

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12. 79 F.3d 790 (1996) (en banc), *rev'd sub nom.* Washington v. Glucksberg, 117 S. Ct. 2258 (1997).

13. *Id.* at 825.

14. *See* Arthur Kleinman et al., *Culture, Illness, and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research*, 88 ANNALS INTERNAL MED. 251 (1978) (stating "physicians treat *diseases*" while "patients suffer *ill-*

the patient's understanding of illness and how the patient communicates about his or her health problems is shaped by these factors. We also need to understand who the physician is, the dynamics of the relationship between professional and patient, and the impact of societal structures on that relationship. It is only by understanding these matters that we will be able to identify and modify the structural inequities in medicine that compromise the interests of competent persons when making end-of-life decisions.

An examination of the African-American patient will expand the array of portraits of patients who face death and worry about dying with dignity. In expanding the images of patients faced with end-of-life decision making, we enhance our understanding of patients' cultural, religious, and family values, and the complexity of decisionmaking with respect to PAS. Some of these patients will prefer life-prolonging treatment or palliative care. Other patients will not seek access to PAS and AVE because they mistrust health care professionals and medical institutions.

Yale Kamisar points out that "[m]any people, understandably, are greatly affected by the heart-wrenching facts of individual cases."[15] There is no doubt that the suffering and anguish of some patients is compelling. Many people identify with these patients and worry that they will find themselves in the same position. We are understandably reluctant to deny interventions that would relieve suffering and bring about desired relief through death. There are also moving stories that demonstrate the dangers of too quickly acceding to requests for PAS and euthanasia. Yet the portraits of potential victims of PAS and euthanasia have attracted less public attention. John Arras, a philosopher and bioethicist writes:

> The victims of the current policy are easy to identify: they are on the news, the talk shows, the documentaries, and often on Dr. Kevorkian's roster of so-called "patients." The victims of legalization, by contrast, will be largely hidden from view: they will include the clinically depressed 80-year-old man who could have lived for another year of good quality if only he had been treated; the 50-year-old woman who asks for death because doctors in her financially

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ness"); Dorothy E. Roberts, *Reconstructing the Patient: Starting with Women of Color, in* FEMINISM & BIOETHICS 116 (Susan M. Wolf ed., 1996) (arguing medical ethics has focused on the treatment of disease rather than on the patient and the patient's values).

15. Yale Kamisar, *The Reasons So Many People Support Physician-Assisted Suicide—And Why These Reasons Are Not Convincing*, 12 ISSUES L. & MED. 113, 113 (1996).

> stretched HMO cannot/will not effectively treat her unrelenting but mysterious pelvic pain; and perhaps eventually, if we slide far enough down the slope, the uncommunicative stroke victim whose distant children deem an earlier death a better death. Unlike Dr. Kevorkian's "patients," these victims will not get their pictures in the paper, but they will have faces and they will all be cheated of good months or perhaps even years.[16]

Most descriptions of potential victims of legalizing PAS, however, fail to include images of members of stigmatized minority groups.[17]

There is evidence that members of those groups regarded as vulnerable have different attitudes about end-of-life treatment than do the majority of Americans who support assisting the terminally ill to die. Disparities are greatest, however, in attitudes, values, and beliefs about end-of-life decisionmaking with racial and ethnic minorities. Studies show that blacks are substantially less likely than whites to support legalization of PAS.[18] Although the support for legalization has increased over time in both groups, the gap in support between blacks and whites persists.[19] There is also evidence that these differences

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16. John Arras, *News from the Circuit Courts: How Not to Think About Physician-Assisted Suicide*, BIOLAW, July-Aug. 1996, Special Section, at S:171, S:184-185.

17. An exception is a composite description of an elderly black woman in Annette Dula, *The Life and Death of Miss Mildred*, 10 CLINICAL ETHICS 419 (1994). Sister Mildred says at one point:

> [L]ook like every time I turn on the TV, somebody's talking about euthanasia, and doctors helping kill off old and sick folks. Well, I ain't seen them ask nary a elderly black on none of them TV shows and news programs what they thought about euthanasia. I believe the Lord will take me away when it's time to go.

Id. at 424-25.

For a literary exploration of black experience of health and illness see TRIALS, TRIBULATIONS, AND CELEBRATIONS: AFRICAN-AMERICAN PERSPECTIVES ON HEALTH, ILLNESS, AGING AND LOSS (Marion Gray Secundy ed., 1992) [hereinafter TRIBULATIONS & CELEBRATIONS].

18. *See* Robert J. Blendon & Ulrike S. Szalay, *The American Public and the Future of the Right-to-Die Debate*, *in* REFORMING THE SYSTEM: CONTAINING HEALTH CARE COSTS IN AN ERA OF UNIVERSAL COVERAGE 223 (Robert J. Blendon & Tracey Stelzer Hyams eds., 1992); P.V. Caralis et al., *The Influence of Ethnicity and Race on Attitudes Toward Advance Directives, Life-Prolonging Treatments, and Euthanasia*, 4 J. CLINICAL ETHICS 155 (1993); Harold G. Koenig et al., *Attitudes of Elderly Patients and Their Families Toward Physician-Assisted Suicide*, 156 ARCHIVES INTERNAL MED. 2240 (1996); Richard L. Lichtenstein et al., *Black/White Differences in Attitudes Toward Physician-Assisted Suicide*, 89 J. NAT'L MED. ASS'N 125 (1997); V.V. Prakasa Rao et al., *Racial Differences in Attitudes Toward Euthanasia*, 2 EUTHANASIA REV. 260 (1988).

19. *See* Lichtenstein et al., *supra* note 18, at 126.

arise in attitudes towards other end-of-life issues, such as use of life-prolonging treatment, advance directives, and living wills.[20]

Why these substantial gaps in attitudes about end-of-life decisionmaking exists is not clear and warrants additional study. The available evidence indicates that these differences persist even when controlling for education, age, and socioeconomic status.[21] Possible reasons for this difference in attitude include religious preferences,[22] blacks' distrust of physicians, medical institutions, and the health care system generally,[23] and cultural characteristics like trusting families more than physicians.[24]

Specifically, these differences in attitude towards PAS may reflect differences in black expression of health and illness as well as concerns about death. Not only have African-Americans experienced disrespect for their autonomy, they have suffered injustice in medicine as well as in the broader society. As a group, blacks have been abused, neglected, and exploited. They have reason to believe that their lives are not valued in the same way as whites, and in their encounters with the health care system they frequently perceive that they are treated differently solely because of their race.[25] African-Americans have reason to be suspicious of physicians and rightly worry about giving them too much authority. In the

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20. *See id.* at 129; Joshua M. Hauser et al., *Minority Populations and Advance Directives: Insights from a Focus Group Methodology*, 6 CAMBRIDGE Q. HEALTHCARE ETHICS 58 (1997); Sheila T. Murphy et al., *Ethnicity and Advance Care Directives*, 24 J.L. MED. & ETHICS 108 (1996).

21. *See* Lichtenstein et al., *supra* note 18, at 126; Murphy et al., *supra* note 20, at 115.

22. *See* Lichtenstein et al., *supra* note 18, at 123; Murphy et al., *supra* note 20, at 116. In one study, religion seemed both to assist a patient's recovery and to constrain the physician's authority. *See* Hauser et al., *supra* note 20, at 65.

23. *See* Caralis, *supra* note 18, at 161; Lichtenstein et al., *supra* note 18, at 133; Murphy et al., *supra* note 20, at 116.

24. *See* Lichtenstein et al., *supra* note 18, at 133. The Hauser focus group on advance directives generated this report: "For a number of the African American participants, family was perceived as protectors against physicians: 'I don't know about the physicians because I don't trust all physicians. No offense. Life is life. Let's face facts .... So I would try to let my family know. People that I think, you know, that care for me.'" Hauser et al., *supra* note 20, at 62.

25. *See* Annette Dula, *African American Suspicion of the Healthcare System Is Justified: What Do We Do About It?*, 3 CAMBRIDGE Q. HEALTHCARE ETHICS 347 (1994).

medical context, physician paternalism builds on and reenforces race differentials in power and authority that occur in the broader society. In short, historical and current experiences with American medicine have made African-Americans acutely aware of the difficulty of looking after their own interests.

Ordinary practices, norms, and habits of well-intentioned institutions and professions can result in unjust practices vis-à-vis some groups.[26] Those with power in the society are able to impose their norms, values, and beliefs on those who lack power. The dominant group's ideas, beliefs, and judgments serve to stigmatize and mark other groups as different and deficient. Behaviors and practices of the stigmatized group are often considered unworthy of study or respect.

The myth of white superiority persists and has profoundly affected both whites and blacks. As Professor Charles Lawrence notes, "We do not recognize the ways in which our [shared] cultural experience has influenced our beliefs about race or the occasions on which those beliefs affect our actions."[27] Stereotypes that capture and reflect negative attitudes towards African-Americans flourish and become embedded in the culture to the point where they may not be consciously noticed. Thus, injury frequently is inflicted on blacks without the actor being consciously aware of racial motivation.[28]

It is not only the dominant group, however, that is affected. The negative messages are also absorbed by blacks. Feelings of inferiority and unworthiness are among the psychic injuries inflicted on blacks. As a result, in addition to all the disadvantages that blacks suffer, they carry the additional burden of not always appreciating their own worth as human beings. As Herbert Nickens points out, "such stigma is never far from consciousness for minorities and is one of the lenses through which life is perceived."[29]

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26. For a more complete account of this aspect of justice, see IRIS MARION YOUNG, JUSTICE AND THE POLITICS OF DIFFERENCE 39 (1990).

27. Charles R. Lawrence III, *The Epidemiology of Color-Blindness: Learning to Think and Talk About Race, Again*, 15 B.C. THIRD WORLD L.J. 1, 4 (1995).

28. *See* Charles R. Lawrence III, *The Id, the Ego and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317 (1987).

29. Herbert Nickens, *The Genome Project and Health Services for Minority Populations, in* THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE 58, 65 (Thomas H. Murray et al. eds., 1996). A particularly chilling example of internalization of negative stereotypes by African-American children is recounted in Marc Elrich, *The Stereotype Within: Why Students Don't Buy Black History Month*, WASH. POST, Feb. 13, 1994, at C1.

Although other racial and ethnic groups have separate and distinct experiences with American medicine, an additional reason for examining the African-American experience is that in some real sense African-Americans are the paradigmatic minority group in this country. They constitute approximately twelve percent of the population. Although they were not willing immigrants and endured slavery and its aftermath of rigid segregation, as people of color they have not been easily assimilated and do not share the western European heritage and culture of some immigrants. Features of black health experience such as persistent poverty, limited access to health care, different health status, and low numbers of health care professionals are common to other minorities as well.

AN INHERENT DISTRUST OF MEDICINE

The relationship between blacks and medicine has, in the main, not been beneficial for blacks. Medicine played a critical role in the development of racial differences that stamped blacks as an inherently inferior people.[30] It provided much of the theory and data that supported beliefs about biological differences observed in differences in skin color, hair, appearance,

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30. *See, e.g.*, TODD L. SAVITT, MEDICINE AND SLAVERY: THE DISEASES AND HEALTH CARE OF BLACKS IN ANTEBELLUM VIRGINIA 7 (1978); Atwood Gaines, *Race and Racism, in* 4 ENCYCLOPEDIA OF BIOETHICS 2189 (Warren T. Reich ed., rev'd ed. 1995).

Race is an imprecise concept used to explain differences between humans. The major theoretical issue is whether race is a matter of nature or of culture. Gamble and Blustein explain the two approaches as follows:

> Biological constructionists hold that races are genetic entities that are fixed, immutable, and genetically determined.... The social construction model holds that race is a social, historical, and political entity without any essential biological coherence. It is not a natural, fixed category; rather it has been created by society to recognize difference and establish social relationships.... [I]t cannot be understood outside of its historical and social context.

Vanessa Northington Gamble & Bonnie Ellen Blustein, *Racial Differentials in Medical Care: Implications for Research on Women, in* 2 WOMEN AND HEALTH RESEARCH: ETHICAL AND LEGAL ISSUES OF INCLUDING WOMEN IN CLINICAL STUDIES 174, 175 (Anna C. Mastroianni et al. eds., 1994) [hereinafter WOMEN AND HEALTH RESEARCH].

In addition, the relationship between the terms 'race' and 'ethnicity' is not well understood. In general, ethnicity pertains to characteristics of a group of people who share a culture, religion, language or the like. In health care and health research classifying patients and subjects in terms of ethnic group identity may provide valuable information about lifestyle, diet, or values that relate to health outcomes. *See* 1 WOMEN AND HEALTH RESEARCH, *supra*, at 115-19.

and behavior between blacks and whites and confirmed the superiority of whites.[31]

The assumption that blacks were biologically inferior to whites paved the way for abuse and exploitation of blacks in medical research, education, and experimentation. Racial ideology posed obstacles to the development of adequate health care for blacks. Biological explanations were sometimes invoked to explain black-white differences in health. Indeed, race is still used without appropriate explanation as a key variable in medical and epidemiological research because the assumption is that race conveys important health information. Medicine's interest in black health status historically was motivated by self-interest of whites rather than the needs of African-Americans. Suspicion of medical professionals and institutions explains why African-Americans are likely to approach PAS with caution.

A MEANS TO ACHIEVE THE ENDS OF OTHERS

The rise of medical institutions in the nineteenth century affected blacks in at least two ways: (1) Blacks were used as specimens for clinical instruction and public display,[32] and (2) blacks were disproportionately involved in research and experimentation.[33] Further, although there was widespread public sentiment opposed to dissection and autopsy, black bodies were used because blacks were in no position to protect their dead.[34] Professor Todd Savitt notes that "[s]outhern medical schools could and did boast that their cities' large black populations provided ample supplies of clinical and anatomical material. White physicians trained at these institutions carried with them into their own careers this idea of the medical usefulness of blacks."[35]

Use of black bodies for dissection and autopsy is just one example in a long history of blacks being used as a means to

31. *See* John S. Haller, Jr., *The Physician Versus the Negro: Medical and Anthropological Concepts of Race in the Late Nineteenth Century*, 44 BULL. HIST. MED. 154, 157 (1970).

32. *See* Todd L. Savitt, *The Use of Blacks for Medical Experimentation and Demonstration in the Old South*, 48 J. S. HIST. 331, 333 (1982).

33. *See* SAVITT, *supra* note 30, at 282.

34. *See* David C. Humphrey, *Dissection and Discrimination: The Social Origins of Cadavers in America, 1760-1915*, 49 BULL. N.Y. ACAD. MED. 819, 820 (1973).

35. Savitt, *supra* note 32, at 341.

achieve the ends of others in medical research and experimentation.[36] During slavery, blacks were subject to experimental procedures that were painful and exploitive.[37] After slavery, the extent to which blacks were experimental subjects without their consent has not been documented. Professor Vanessa Northington Gamble's examination of folklore in the late nineteenth and early twentieth centuries makes clear that blacks believed that these practices persisted.[38] It is clear that concerns about abuse and exploitation of blacks in medical experimentation were used to press for the creation of black-controlled hospitals in the early twentieth century.[39]

The best known twentieth century example of the use of blacks as unconsenting experimental subjects is the Tuskegee Syphilis Study. It illustrates the nature of the relationship between medicine and blacks that evolved during slavery, continued during the post-emancipation period, and, in some aspects, is still prevalent today.

The United States Public Health Service (PHS) sponsored the Tuskegee Study which began in 1932 and lasted 40 years. It involved 399 black men who lived in Macon County, Alabama.[40] The study was intended to observe the effects of untreated syphilis on blacks and thus held out no promise of benefit to the subjects. The subjects never consented. They were never given important information about the study.

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36. For an exploration of the involvement of African-Americans in medical research, see Patricia A. King, *Race, Justice, and Research, in* BEYOND CONSENT (Jeffrey P. Kahn et al. eds., forthcoming 1998).

37. For example, Dr. Marion Sims, considered by medical historians to be the father of American gynecology and a former president of the American Medical Association, used slave women in developing surgical procedures to repair vesico-vaginal fistulas, or tears in the vaginal wall, that resulted in chronic leakage from the bladder. Dr. Sims operated repeatedly on three slave women, without the benefit of anesthesia, and only sought white volunteers for the procedure after its success was demonstrated in the slave women. *See* Diana E. Axelsen, *Women as Victims of Medical Experimentation: J. Marion Sims' Surgery on Slave Women, 1845-1850*, SAGE, Fall 1995, at 10, 10-12; David A. Richardson, *Ethics in Gynecologic Surgical Innovation*, 170 AM. J. OBSTETRICS & GYNECOLOGY 1 (1994) (detailing Dr. Sims's wrongful operations).

38. *See* Vanessa Northington Gamble, *Under the Shadow of Tuskegee: African Americans and Health Care*, 87 AM. J. PUB. HEALTH 1773, 1774 (1997).

39. *See* VANESSA NORTHINGTON GAMBLE, MAKING A PLACE FOR OURSELVES: THE BLACK HOSPITAL MOVEMENT 1920-1945, at 13 (1995).

40. The seminal account of the Tuskegee syphilis experiment is found in JAMES H. JONES, BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT (expanded ed. 1993).

When effective treatment for syphilis became available, the subjects were not provided with penicillin. Indeed measures were taken to prevent their treatment.

Assumptions about biologically based differences in disease between blacks and whites and negative stereotypes about blacks played an important role in the creation and implementation of the Tuskegee Study. For example, the investigators accepted the medical view prevailing in the United States that syphilis affected blacks differently than whites. The PHS doctors believed that blacks had different sexual natures than whites and that blacks were more promiscuous. They also wrongly believed that blacks would not seek medical care.[41]

The PHS investigators took advantage of the bleak social and economic situation of the subjects. These men were poor and lived in a rural and segregated county in the Deep South. They were accustomed to responding to the authority of whites. Offers of free health care and payment of burial expenses were powerful incentives for participation in the Tuskegee Study. In sum, although these men were capable of making rational decisions for themselves in terms of their own interests and preferences, they were vulnerable to exploitation because of conditions in their environment that they were powerless to change.

The lesson of the Tuskegee Study is not only that vulnerable people can be easily exploited, but also that health care professionals do not always act in the best interests of their patients. It shows how scientific objectivity can be infected with bias. It suggests that abstract concepts like autonomy, self-determination, and informed consent have little meaning in circumstances where an individual's ability to protect himself or herself is blunted by persons and forces that are authoritative and powerful.

Black experience as objects in medical research and experimentation has left a legacy of distrust that continues to affect the behavior and beliefs of blacks.[42] There is concern that

41. *See* Allan M. Brandt, *Racism and Research: The Case of the Tuskegee Syphilis Study*, HASTINGS CENTER REP., Dec. 1978, at 21, 23. Brandt provides a detailed account of the many negative stereotypes about blacks that influenced those who formulated the study.

42. *See* Dula, *supra* note 25, at 347; Vanessa Northington Gamble, *A Legacy of Distrust: African-Americans and Medical Research*, 9 AM. J. PREVENTIVE MED., Nov.-Dec. 1993, at 35-38; James H. Jones, *The Tuskegee Legacy: AIDS and the Black Community*, HASTINGS CENTER REP., Nov.-Dec. 1992, at 38.

despite reforms in the conduct of human experimentation blacks are devalued in the modern research context.[43] Distrust is also evident in organ donations. Historically, blacks have been less likely than whites to agree to organ donation.[44] Blacks have consistently identified the concern that they might not receive adequate care in the hospital as a reason for not becoming an organ donor.[45] Louis Farrakhan's statement in a 1994 speech that whites do not stop black-on-black violence because it provides a source of organs for whites,[46] while controversial, echoes the fear expressed by many blacks that somehow their lives as organ donors would be valued less than the lives of white recipients.

This distrust of the medical profession and the feeling that black lives are devalued in our society is also reflected in the allegations of genocidal intent that frequently arise within the African-American community. The Tuskegee Study left its mark in this respect with the widespread and often repeated (mis)understanding that the men of Tuskegee were deliberately infected with syphilis.[47] The genocide allegation also arose in connection with efforts to establish sickle-cell anemia

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43. In a recent government-sponsored measles vaccine study in which a large proportion of the subjects were African-Americans and other minorities, parents were not informed that the vaccine was experimental and not licensed for use in the United States or that it was associated with an increase in death rates in other countries. *See* Charles Marwick, *Questions Raised About Measles Vaccine Trial*, 276 JAMA 1288 (1996). The FDA's recent adoption of regulations allowing waiver of informed consent of research subjects in emergency room research has also raised concern that minorities are likely to be disproportionately the subjects of the research. *See* Gamble, *supra* note 38, at 1776-77 (noting that racism pervades health care).

44. *See* Clive O. Callender et al., *Attitudes Among Blacks Toward Donating Kidneys for Transplantation: A Pilot Project*, 74 J. NAT'L MED. ASS'N 807 (1982).

45. *See, e.g.*, Callender et al., *supra* note 44, at 809; *Why More Blacks Do Not Donate Organs*, JET, Dec. 11, 1995, at 15 ("Many Blacks don't want to sign as organ donors because they feel if I'm in an accident and they know I'm an organ donor, they might want to use my organ. I go into the hospital to have a toenail removed and come out with no kidney or something like that."'); *see also* Robert F. Creecy & Roosevelt Wright, *Correlates of Willingness to Consider Organ Donation Among Blacks*, 31 SOC. SCI. & MED. 1229, 1230 (1990) (associating blacks willingness to consider donation with confidence in the medical doctors and perceived need for organs among blacks).

46. *See Farrakhan Links Race to Transplants*, N.Y. TIMES, May 2, 1994, at A18.

47. *See* Gamble, *supra* note 38, at 1775 (noting, among other things, that this misunderstanding was reported in April 1997 on a major network newscast).

screening programs and birth control programs.[48] More recently, the allegation has arisen in connection with the AIDS epidemic. Professor Gamble cites to surveys indicating that up to one-third of African-Americans believe either that the AIDS virus was created to infect African-Americans or that it could have been created for that purpose.[49]

In short, African-Americans have reason believe that they are not always viewed as persons of unconditioned worth who are deserving of respect. These beliefs are reenforced because so little progress has been made in improving the health status of African-Americans.

THE ABSENCE OF EQUAL OPPORTUNITY IN HEALTH CARE ACCESS AND DISTRIBUTION

From the time blacks were first brought to America, one fact has been overwhelming: Blacks by any measure have been sicker and die younger than whites. Initially, medical theories affirmed race-based explanations, as opposed to social and economic ones, for the difference in health status between blacks and whites.[50] For example, during the post-emancipation period, census reports, insurance statistics, and military data all indicated high mortality and morbidity rates among blacks. It was believed that the peculiar susceptibility of blacks to disease, vice, and crime were responsible for these differences.[51]

At times, belief in the inherent differences between blacks and whites posed obstacles to sorting through the complexities of disease such as tuberculosis and syphilis.[52] It was reassuring for whites to believe that a disease affected whites and blacks differently (and blacks more harshly) or that close observation confirmed the presence of two diseases rather than one. Negative stereotypes about blacks were frequently employed to justify perceived disparities in disease or health status disparities between blacks and whites. Often these stereotypes involved sexual promiscuity, intellectual performance, or susceptibility of blacks to disease and vice.

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48. *See id.*

49. *See id.*

50. *See, e.g.*, Haller, *supra* note 31, at 155-67; Marion M. Torchia, *The Tuberculosis Movement and the Race Question, 1890-1950*, 49 BULL. HIST. MED. 152 (1975).

51. Haller, *supra* note 31, at 155-67.

52. For a good example of this phenomenon, see Gamble & Blustein, *supra* note 30, at 180-82.

Explicit discrimination against African-Americans in all areas of medicine was the norm until the mid-1960s. As P. Preston Reynolds notes, "African-American students were denied admission to most medical and nursing schools, [African-American] physicians were rejected from membership to state and national medical societies, and African-Americans were refused care at most hospitals in this country."[53] Moreover, the Hospital Survey and Construction Act (Hill-Burton Act), passed in 1946, contained a provision that required that hospital facilities of equal quality be built for minorities, thus introducing the concept "separate but equal" into health care. As Justice Harlan points out in his dissent in *Plessey v. Ferguson*, the "real meaning" of segregation is "that colored citizens are so inferior and degraded that they cannot be allowed to sit in public coaches [or to share hospital wards and doctors' waiting rooms] occupied by white citizens."[54]

This explicit segregation in health care did not begin to change until the passage of the Civil Rights Act of 1964, which prohibited provision of federal funds to programs and institutions that discriminated on the basis of race. The creation of the Medicare program in 1965 virtually assured that every hospital in the nation would be subject to the Act.[55]

Although hospitals, unlike public schools, were required by the federal government to comply immediately with federal guidelines promulgated to achieve integration, resistance was strong. Nevertheless, substantial progress towards integration of facilities providing health care services was eventually achieved. Yet there is little reason to believe, in the health domain any more than in public education, that desegregation brought about equal access or equal quality of health care for blacks.[56] There is evidence to suggest that contemporary changes in the U.S. health care system is causing a further decline in an admittedly small pool of African-American physicians. In 1890 there were fourteen black medical schools. Today there are only four predominantly black schools training

53. P. Preston Reynolds, *The Federal Government's Use of Title VI and Medicare to Racially Integrate Hospitals in the United States, 1963 Through 1967*, 87 AM. J. PUB. HEALTH 1850, 1850 (1997).

54. 163 U.S. 537, 560 (1896) (Harlan, J., dissenting).

55. *See* Reynolds, *supra* note 53, at 1850.

56. For a thoughtful series of essays on the difficulty of eliminating separate but equal in public education, see SHADES OF *BROWN*: NEW PERSPECTIVES ON SCHOOL DESEGREGATION (Derrick Bell ed., 1980).

African-American physicians. Moreover, the persistent disparities in health care status between blacks and whites indicate that we have a long way to go before equal opportunity in health care will be achieved.

African-Americans perceive that they are treated differently within the health care system. They are more likely than whites to report difficulties in obtaining access to the health care system and, once they obtain care, to express dissatisfaction with the care they receive, including their communications with health care providers.[57] The perceptions of racial disparities in the health care system are supported by a host of studies demonstrating racial differences in health status, access to health care, and quality of health across a variety of conditions and settings. While the majority of African-Americans may not be familiar with the details of these studies, reports about them in the media reinforce the perception that African-American lives are devalued in our society.[58] The results of a recent study of Medicare beneficiaries—combined with other studies of racial disparities in health that persist after controlling for other factors thought to influence health, such as age, sex, insurance status, income, disease severity, other health conditions, and underlying incidence and prevalence rates—led one commentator to conclude that "although both race and income have effects, race was the overriding determinant of disparities in care" and that "[h]igher incomes for blacks had a modifying—but never an equalizing—effect on black/white ratios for" certain types of care.[59]

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57. *See, e.g.*, Council on Ethical and Judicial Affairs, *Black-White Disparities in Health Care*, 263 JAMA 2344, 2345 (1990) (discussing evidence of disparities in medical treatment); Sally Trude & David C. Colby, *Monitoring the Impact of the Medicare Fee Schedule on Access to Care for Vulnerable Populations*, 22 J. HEALTH POL. POL'Y & LAW 49, 55 (1997) (citing R.J. Blendon et al., *Access to Medical Care for Black and White Americans: A Matter of Continuing Concern*, 261 JAMA 278 (1989) and L.J. Cornelius, *Barriers to Medical Care for White, Black, and Hispanic American Children*, 85 J. NAT'L MED. ASS'N 281 (1993)).

58. For example, the preliminary results of a study looking at differences in life expectancies within different communities in the United States was reported on the front page of the Dec. 4, 1997, *Washington Post* under the headline "Death Knocks Sooner for D.C.'s Black Men."

59. H. Jack Geiger, *Race and Health Care—An American Dilemma?*, 335 NEW ENG. J. MED. 815, 816 (1996) (citing Marian E. Gornick et al., *Effects of Race and Income on Mortality and Use of Services Among Medicare Beneficiaries*, 335 NEW ENG. J. MED. 791, 794 (1996)).

Evidence of the racial disparities in health and health care comes in a number of different forms. For example, the U.S. mortality statistics have provided dramatic evidence of the racial difference in health status year in and year out. These statistics reveal that African-Americans have an overall mortality rate approximately seventy percent higher than that of whites.[60] In addition, black infants continued to die at almost two-and-a-half times the rate of white infants.[61] The mortality differences exist across disease categories, such that the 1995 age-adjusted death rates for blacks were higher than the rates for whites for most of the leading causes of death.[62] Indeed, a recent study reported that declines in breast cancer mortality were found only among white, not black, women.[63]

African-Americans also experience higher morbidity with respect to various disease categories, including diabetes, high blood pressure, and AIDS.[64] Similarly, numerous studies have demonstrated that African-Americans, when they receive care, receive *different* care than whites for the same conditions. For example, a number of studies have shown that blacks are less likely to receive angiography or to undergo coronary artery bypass surgery or angioplasty than whites.[65] Some of these dif-

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60. The racial difference in overall mortality rates (a ratio of 1.7) has persisted since 1987 and represents an increase from the 1960-1986 period, when the death ratio was approximately 1.5. *See* Robert N. Anderson et al., *Report of Final Mortality Statistics, 1995*, 45 MONTHLY VITAL STAT. REP. 2 (1997).

61. *See id.* at 2-3, 11.

62. *See id.* at 2, 8.

63. *See* Frances Chevarley & Emily White, *Recent Trends in Breast Cancer Mortality Among White and Black US Women*, 87 AM. J. PUB. HEALTH 775, 777 (1997).

64. *See* U.S. DEP'T HEALTH & HUMAN SERVICES, PUB. NO. (PHS) 91-50212, HEALTHY PEOPLE 2000: NATIONAL HEALTH PROMOTION AND DISEASE PREVENTION OBJECTIVES 33 (1991) (noting that diabetes is a third more common in blacks than whites, severe high blood pressure is four times more common in black men than white men, AIDS is three times more common in blacks than in whites, and between 10 and 15 times more common in black women than white women).

65. *See, e.g.*, Marie A. Bernard, *The Health Status of African-American Elderly*, 85 J. NAT'L MED. ASS'N 521, 522 (1993); Council on Ethical and Judicial Affairs, *supra* note 57, at 2344-45; Geiger, *supra* note 59, at 815. Treatment differences have also been demonstrated for pneumonia, cesarean sections, and kidney disease, *see* Council on Ethical and Judicial Affairs, *supra* note 57 at 2344-45 (and studies cited therein), as well as breast cancer, *see* John Z. Ayanian & Edward Guadagnoli, *Variations in Breast Cancer Treatment by Patient and Provider Characteristics*, 40 BREAST CANCER RES. & TREATMENT 65, 72 (1996) (noting that black women are less likely than white

ferences in health status, but not all, may be explained by the fact that blacks are less likely than whites to have access to health care. For example, blacks are less likely than whites to have insurance[66] and they make fewer visits to office based physicians than whites.[67] In addition, regardless of income level, blacks are at least twice as likely as whites to obtain their care regularly in a clinic or an emergency room setting.[68]

Recent studies suggest, however, that these disparities in access to treatment remain even when blacks gain access to the health care system.[69] For example, a number of studies have shown that blacks still have fewer physician visits and receive different treatments than whites,[70] even within Medicare or Veteran's Affairs populations where disparities in access have been minimized or eliminated.[71] Not only have studies shown

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women to receive breast cancer treatment consistent with national guidelines).

66. *See* Bureau of the Census, *Health Insurance Coverage Status, by Selected Characteristics: 1987-1994*, *in* U.S. DEP'T OF COMMERCE, STATISTICAL ABSTRACT OF THE UNITED STATES: 1996, 120 (116th ed. 1996).

67. *See* Bureau of the Census, *Visits to Office Based Physicians*, *in* U.S. DEP'T OF COMMERCE, STATISTICAL ABSTRACT OF THE UNITED STATES: 1996, 125 (116th ed. 1996).

68. *See* Barbara Bloom et al., *Access to Health Care Part 2: Working-Age Adults*, 197 VITAL & HEALTH STAT., Series 10, 4 (1997).

69. *See* Council on Ethical and Judicial Affairs, *supra* note 57, at 2344.

70. *See, e.g.*, Marian E. Gornick et al., *Effects of Race and Income on Mortality and Use of Services Among Medicare Beneficiaries*, 335 NEW ENG. J. MED. 791, 793 (1996) (reporting that black Medicare patients made 7.2 office visits compared to 8.1 visits for white Medicare patients); Philip J. Held et al., *Access to Kidney Transplantation: Has the United States Eliminated Income and Racial Differences?*, 148 ARCHIVES INTERNAL MED. 2594 (1988) (stating that black Medicare beneficiaries are less likely than whites to receive a kidney transplant); Katherine L. Kahn et al., *Health Care for Black and Poor Hospitalized Medicare Patients*, 271 JAMA 1169 (1994) (observing that black Medicare patients were less likely than whites to receive mammograms); Eric D. Peterson et al., *Racial Variation in Cardiac Procedure Use and Survival Following Acute Myocardial Infarction in the Department of Veterans Affairs*, 271 JAMA 1175, 1178 (1994) (finding that blacks in Veterans Affairs system are less likely than whites to undergo coronary artery bypass grafting, angioplasty and coronary revascularization); Trude & Colby, *supra* note 57, at 56-57 (noting that black Medicare beneficiaries were more likely than whites and other beneficiaries to report access problems, delay in medical care, and lack of a usual source of care).

71. Medicare minimizes the inequalities in access to health care by providing premium-free hospital benefits to people over age 65 with qualifying work history, permitting those resident citizens without qualifying work history to purchase this insurance, and providing *all* resident citizens the opportunity to purchase supplemental medical insurance (for example, for outpatient services). *See* DAVID CALKINS ET AL., HEALTH CARE POLICY 105-06, 112 (1995). Although some gaps in coverage remain, Medicare has improved ac-

that blacks are less likely than whites to receive certain, more common treatments, but that blacks are more likely than whites to receive certain, less common treatments. For example, blacks are more than three-and-a-half times more likely than whites to undergo amputation of all or part of the lower limb, even though diabetes mellitus (the most common reason for the amputation) is only 1.7 times as prevalent in elderly blacks as in whites.[72] In addition, there is evidence that, among patients seen in similar hospitals, blacks receive poorer quality of treatment than whites.[73]

While the racial disparities in treatment decisions cannot be denied, the reasons for the disparities are harder to identify.[74] Because race is often used as a proxy for socioeconomic status,[75] some have suggested that the racial disparities seen in health and health care reflects socioeconomic or class differences, rather than racial differences.[76] However, racial differences in health and health care persist in studies that control or adjust for indicators of socioeconomic status, such as income, educational level, and insurance status. For example, a recent study that compared mortality rates among blacks and among whites living in comparable areas demonstrated that, although both poor blacks and poor whites experienced mortality rates higher than nationwide rates, poor blacks had lower survival rates than poor whites in all but one location.[77] This and other

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cess to care among previously underserved populations. *See* José J. Escarce et al., *Racial Differences in the Elderly's Use of Medical Procedures and Diagnostic Tests*, 83 AM. J. PUB. HEALTH 948, 948 (1993).

The Veterans Health Administration system provides medical care to all veterans who are disabled or financially disadvantaged without regard to patient's ability to pay. Patients within the Veterans Affairs system are more likely than patients in the private sector to share the same socioeconomic status (middle- to low-income). *See* Peterson et al., *supra* note 70, at 1178.

72. *See* Gornick et al., *supra* note 70, at 791.

73. *See* Kahn et al., *supra* note 70, at 1169 (finding differences in care in similar hospitals for black Medicare patients hospitalized with congestive heart failure, acute myocardial infarction, pneumonia, and cerebrovascular accident compared to other beneficiaries).

74. *See* Council on Ethical and Judicial Affairs, *supra* note 57, at 2345 (observing the difficulty of drawing firm conclusions from studies regarding the role of race in medical treatment).

75. *See, e.g.*, David R. Williams, *Socioeconomic Differentials in Health: A Review and Redirection*, 53 SOC. PSYCHOL. Q. 81, 83 (1990) (observing that minority group status is sometimes included as an indicator of socioeconomic status).

76. *See, e.g.*, Council on Ethical and Judicial Affairs, *supra* note 57, at 2345-46.

77. Arline T. Geronimus et al., *Excess Mortality Among Blacks and*

studies indicate that socioeconomic status alone cannot account for all of the documented racial differences in health and health care.

If racial disparities in health and health care access persist among populations in which access issues have been equalized or minimized and among populations which face similar economic difficulties and barriers, we must look beyond access to explain the continuing disparities. Are there differences among the races in their interactions with the health system that might explain the disparities in health status between blacks and whites?

In addressing this question, some commentators have suggested that blacks and whites may differ in terms of their treatment preferences.[78] There is some support for this hypothesis. For example, the Coronary Artery Surgery Study found that whites were more likely than blacks to elect to have bypass surgery, even when some other, less invasive therapy was recommended; it also found that blacks were ten percent more likely than whites to decline an invasive treatment.[79] Differences by race have also been documented with respect to preferences for using life-sustaining treatments.[80] However, blacks still are treated differently, even when their preferences are the same.[81]

Cultural differences in the clinical encounter may account for some of these disparities. Clinical decisionmaking takes place within the context of a clinical relationship. Accordingly, clinical decisions are necessarily influenced by the social struc-

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Whites in the United States, 335 NEW ENG. J. MED. 1552, 1555 (1996).

78. *See* Council on Ethical and Judicial Affairs, *supra* note 57, at 2346 (noting that income differences are probably the most important exploration for medical treatment disparities between blacks and whites).

79. Charles Maynard et al., *Blacks in the Coronary Artery Surgery Study (CASS): Race and Clinical Decision Making*, 76 AM. J. PUB. HEALTH 1446, 1446 (1986). However, the small percentage of black enrollees in the study may limit the generalizability of this observation.

80. In one study, black patients were almost three times as likely as white patients to indicate they wanted more treatment, while whites were almost two-and-a-half times more likely then blacks to indicate they wanted less treatment. *See* Joanne Mills Garrett et al., *Life-Sustaining Treatments During Terminal Illness: Who Wants What?*, 8 J. GEN. INTERNAL MED. 361, 364 (1993).

81. For example, physicians treating AIDS patients were less likely to have conversations about resuscitation with patients of color even though their interest in having such a discussion was similar to that of whites. *See* Jennifer S. Haas et al., *Discussion of Preferences for Life-Sustaining Care by Persons with AIDS*, 153 ARCHIVES INTERNAL MED. 1241, 1246 (1993).

ture and context in which they are made. The "sociologic influences" on the clinical decision include the "social characteristics of patients and physicians, patterns of social interaction and authority in clinical settings, and the structure of health care organizations."[82] For example, cultural differences can result in medical advice that does not "fit" the patient's values and conceptions. They can also result in a physician ignoring the patient's values and conceptions. In neither case will optimum health be achieved. To the extent that medicine's approach to a problem does not coincide with a patient's beliefs, patient noncompliance and dissatisfaction with health care are likely results.[83]

Cultural differences also give rise to communication problems between patient and health care provider. For example, studies have documented that white and black patients express themselves differently within the medical encounter.[84] To the extent that black patients downplay or fail to discuss their symptoms, their health care is likely to suffer.[85] More importantly, to the extent that African-American patients use different language or frame their decisions differently from that of their physicians, they are at greater risk of having their decisions ignored or overridden. One study of physician-patient encounters found that

> the person who hears a vernacular [e.g., Black English] dialect spoken tends to devalue the speaker of that dialect. Consciously or unconsciously, dialect speakers tend to get worse treatment, wait longer for service, are considered ignorant, and are told what to do rather than asked what they would like to do. Therefore, the effect of the

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82. Jack A. Clark et al., *Bringing Social Structure Back into Clinical Decision Making*, 32 SOC. SCI. & MED. 853, 854 (1991).

83. *See* Kleinman et al., *supra* note 14, at 252.

84. *See, e.g.*, Sybil L. Crawford et al., *Do Blacks and Whites Differ in Their Use of Health Care for Symptoms of Coronary Heart Disease?*, 84 AM. J. PUB. HEALTH 957 (1994) (discussing the fact that blacks with repeated chest pain were more likely than whites never to have discussed their pain with their doctor); James M. Raczynski et al., *Diagnoses, Symptoms, and Attribution of Symptoms Among Black and White Inpatients Admitted for Coronary Artery Disease*, 84 AM. J. PUB. HEALTH 951, 955 (1994) (finding blacks reported fewer painful symptoms and were more likely to attribute their symptoms to noncardiac origins); Rayna Rapp, *Constructing Amniocentesis: Maternal and Medical Discourses*, *in* UNCERTAIN TERMS: NEGOTIATING GENDER IN AMERICAN CULTURE 28, 31-32 (Faye Ginsburg & Anna Lowenhaupt Tsing eds., 1990) (reporting that black women were less likely than white women to use medical language in responding to an offer of amniocentesis).

85. *See, e.g.*, Raczynski et al., *supra* note 84, at 955 (offering the difference in reporting symptoms as an explanation for the differences in coronary care treatment).

> patient's vernacular dialect in the medical interview is a potential source of interference to the effective exchange of information.[86]

Cultural differences may create difficulties not only in communication; they may also make health providers less comfortable in their dealings with their patients. This discomfort may hinder effective communication or preclude some communication altogether.[87] For example, at least two studies have suggested that blacks are less likely to be approached for organ donation by predominately white medical teams.[88] Similarly, studies have demonstrated that physicians caring for people with HIV were less likely to discuss end-of-life decisions with their patients of color.[89]

Finally, physicians' unconscious stereotypes and biases, generally influenced by cultural differences, although sometimes influenced by views of biological differences,[90] may affect

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86. Roger W. Shuy, *Three Types of Interference to an Effective Exchange of Information in the Medical Interview, in* THE SOCIAL ORGANIZATION OF DOCTOR-PATIENT COMMUNICATION 189, 192 (Sue Fisher & Alexandra Dundas Todd eds., 1983); *see also* ALEXANDRA DUNDAS TODD, INTIMATE ADVERSARIES: CULTURAL CONFLICT BETWEEN DOCTORS AND WOMEN PATIENTS 77 (1989) (observing a trend in a qualitative study of physician-patient encounters on reproductive issues that "the darker a woman's skin and/or the lower her place on the economic scale, the poorer the care and efforts at explanation she received").

87. Based on her review of the literature and her own experience and research, Jennifer Daley concluded that "[p]atients of a different cultural, ethnic and socioeconomic background from their physicians are . . . less likely to receive information from their doctors." Jennifer Daley, *Overcoming the Barrier of Words, in* THROUGH THE PATIENTS' EYES 72, 83 (Margaret Gerteis et al. eds., 1993).

88. *See* Mary S. Hartwig et al., *Effect of Organ Donor Race on Health Team Procurement Efforts*, 128 ARCHIVE SURGERY 1331, 1332-1333 (1993) (finding that race had a strong influence on identifying organ donors and on actually requesting donation); Alice A. Mitchell & William E. Sedlacek, *Ethnically Sensitive Messengers: An Exploration of Racial Attitudes of Health-Care Workers and Organ Procurement Officers*, 88 J. NAT'L MED. ASS'N 349, 351-52 (1996) (concluding that organ procurement employees may experience cognitive dissonance when dealing with donors of color).

89. *See, e.g.*, Haas et al., *supra* note 81, at 1246. The Haas study confirmed another study's conclusion that "persons with HIV infection were more likely to have been counseled about advance directives if they were male, white, homosexual or bisexual men or well educated." *See* J. Teno et al., *The Use of Formal Prior Advance Directives Among HIV-Related Diseases*, 5 J. GEN. INTERNAL MED. 490 (1990).

90. In a study of racial differences in cardiac treatment in the Veterans Affairs system, researchers pointed out that it had been believed that blacks had worse outcomes than whites following coronary artery bypass surgery, although that belief has not been borne out in the literature. *See* Peterson et al., *supra* note 70, at 1179.

health care decisionmaking.[91] For example, some have suggested that the medical criteria used in clinical decisionmaking may reflect or incorporate unconscious biases.[92] Others have suggested that perceptions of the patient's support system, which may reflect the physician's racial and cultural biases, may influence the decisionmaking process.[93] Physicians' racial and cultural biases have been documented through the anecdotes of African-American patients. In her recent article, Vanessa Northington Gamble relates two powerful examples of racial stereotyping experienced in the emergency room. In one, an African-American professor of nursing describes how her symptoms of severe abdominal pain were met immediately with questions regarding the number of sexual partners she had, recalling persistent stereotypes of black women as sexually promiscuous. The other (reported in the *Los Angeles Times*) describes the experience of an African-American medical school administrator with a broken arm who was assumed to be a welfare mother and told to hold her arm as if she were holding a can of beer.[94] In a similar vein, Herbert Nickens refers to his own experience in comparing the ways in which white health care workers treat those with cystic fibrosis (affects primarily whites) and sickle-cell anemia (affects primarily blacks). He opines that health care workers often question whether those with sickle cell disease are having real pain or are exhibiting analgesic drug-seeking behavior.[95] Finally,

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91. *See, e.g.*, Council on Ethical and Judicial Affairs, *supra* note 57, at 2346 ("Disparities in treatment decisions may reflect the existence of subconscious bias."); Escarce et al., *supra* note 71, at 953 (1993) (suggesting that "[t]he effect of patient race on physician and institutional decision making" may be the cause of persistent racial differences in treatment).

92. *See, e.g.*, Michael Lowe et al., *"These Sorts of People Don't Do Very Well": Race and Allocation of Health Care Resources*, 21 J. MED. ETHICS 356, 358 (1995) (suggesting that seemingly objective outcome criteria such as likely graft survival, patient survival, quality-of-style measures, and presence of significant co-morbidity or disability used to identify recipients who are most likely to benefit from kidney transplantation may incorporate subtle racial discrimination, for example, when prevalence of certain co-morbidities is higher in a minority population).

93. *See, e.g.*, Peterson et al., *supra* note 70, at 1179.

94. *See* Gamble, *supra* note 38, at 1776.

95. *See* Nickens, *supra* note 29, at 67. Nickens's opinion was dramatized in a recent episode of the NBC medical show, *ER*. In that episode, an African-American man presented to the *ER*, complaining of pain from a sickle-cell episode and requesting a specific dosage of a specific pain killer. The emergency room doctor who initially treated him discounted his story about his condition and refused to provide the requested medicine. When the patient later re-

physicians' racial and cultural biases can be inferred from their behavior. For example, the Coronary Artery Surgery Study demonstrated that providers are more likely to recommend whites for bypass surgery than blacks, "despite similar clinical and angiographic characteristics."[96] In a similar vein, researchers found that physicians in one Florida county were almost ten times as likely to report a black woman for substance abuse during pregnancy than a white women, even though rates of drug usage were similar.[97] In addition, a 1987 review of cases of court-ordered cesarean section demonstrated that eighty-one percent of the women were women of color (specifically, African-American, Asian, or Latina), twenty-four percent of the women did not speak English as their primary language, and all of the women were being treated at a teaching hospital clinic or were receiving public assistance.[98]

The enduring disparities in health status between blacks and whites perpetuate black mistrust of medicine. African-Americans rightly wonder what sort of society would allow such disparities to continue unchecked. They are understandably suspicious of those who express concern that blacks are being denied a fair opportunity to assistance in ending their lives if PAS is prohibited. These persistent disparities also indicate that blacks may be severely disadvantaged in efforts to obtain respect for their health care preferences.

CONCLUSION

What lessons do the African-American experience with medicine and the health care system provide for efforts to ensure that the interests and preferences of all patients will be

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ceives the requested dosage from another emergency room doctor, the original doctor berates the second doctor for "giving in" to the drug-seeking behavior. *ER* (NBC television broadcast, Dec. 11, 1997).

96. Maynard et al., *supra* note 79, at 1446.

97. Ira J. Chasnoff et al., *The Prevalence of Illicit-Drug or Alcohol Use During Pregnancy and Discrepancies in Mandatory Reporting in Pinellas County, Florida*, 322 NEW ENGL. J. MED. 1202, 1203-04 (1990).

98. Veronika E.B. Kolder et al., *Court-Ordered Obstetrical Interventions*, 316 NEW ENGL. J. MED. 1192 (1987). Commentators reviewing the court proceedings in these cases have indicated that the women's positions were discounted and viewed as inadequate and the women themselves were characterized negatively. *See, e.g.*, Lisa C. Ikemoto, *Furthering the Inquiry: Race, Class and Culture in the Forced Medical Treatment of Pregnant Women*, 59 TENN. L. REV. 487, 502-04 (1992); Susan Irwin & Brigitte Jordan, *Knowledge, Practice, and Power: Court-Ordered Cesarean Sections*, 1 MED. ANTHROPOLOGY Q. 319, 329 (1987).

respected should PAS be legalized? What does it mean to be rendered vulnerable because of poverty, prejudice, negative stereotypes, societal indifference, or membership in a stigmatized group?

Given the general distrust of medical institutions and the medical profession and the belief that their lives are undervalued, African-Americans are likely to view the legalization of PAS with suspicion. Rather than seeing it as an opportunity to exercise their autonomy at the end of life, African-Americans may sense that this is yet another way that less valued African-American lives can be eliminated. This distrust makes it less likely that African-Americans will be easily manipulated in making their end-of-life decisions. African-Americans may question more vigorously the judgments of their health care providers and resist compliance with the medical regimes recommended to them. While mistrust protects blacks in their contacts with the health care system, it also presents obstacles for them. It is important that patients trust their health care providers, especially in end-of-life decisionmaking. If patients are to participate in managing their illnesses, patients and their families must have confidence in the information they have received about diagnosis, prognosis, and options for care. If the patient's mistrust motivates him or her to ignore these recommendations, the patient may lose an important opportunity to manage her dying. Conflicts between patients and families on the one hand and health care providers on the other can severely compromise patients' ability to die with dignity.[99] Although the historical record is not subject to change, it might be possible to reduce levels of distrust by paying greater attention to eliminating disparities in health status.

Difficulties that exist in the clinical encounter have significant implications for the practice of PAS. Cultural differences between African-American patients and their health care providers may give rise to communication difficulties, either because of differences in values or because of differences in communication styles. However, those cultural differences may create a barrier that prevents even the attempt to communicate about important personal issues like end-of-life care. In a worst case scenario, the cultural differences may cause a phy-

99. *See, e.g., Case Study: Mistrust, Racism and End-of-Life Treatment*, HASTINGS CENTER REP., May-June 1997, at 23.

sician to discount his African-American patient's wishes to such an extent that they are not honored. Improving medical interactions between African-Americans and health care providers may require changes in the education and training of health care providers.

The African-American experience with medicine also cautions against placing too much confidence in the ability of physicians and other health care providers to insure that patient preferences are honored and respected. In the context of the patient-physician relationship, physicians have power. This power derives from several sources. The physician has superior knowledge and skill. The physician has broad discretion and is not easily held accountable for actions by patients or society. Dying patients and their families are disadvantaged in terms of questioning physicians by virtue of the crisis that they find themselves in. They may also be disadvantaged by a sense of helplessness that results from low socioeconomic status or low self-esteem. In the face of the power inequities in this relationship and the historical instances of misuse of power, African-Americans appreciate that making PAS available as an option for terminally ill patients does not necessarily empower those who have been disadvantaged. An important implication of the power inequities in physician-patient relationships is that greater equality for the seriously disadvantaged may be a precondition for the meaningful exercise of autonomy.

Moreover, physicians do not exist in isolation from the social milieu in which they find themselves any more than patients do. Both physicians and patients absorb the prevailing norms, values, and beliefs of the society. Physicians may have assimilated the negative messages about some groups. For example, physicians may be too quick to interpret ambivalent statements made by patients as being pleas to die, because at an unconscious level they perceive the patient as not deserving of money, resources, or other efforts that might be needed for care. Alternately, patients may have absorbed the negative messages that society has heaped upon them and perceive themselves to be unworthy of the efforts that might be needed to prolong their treatment or provide them with palliative treatment. These patients might be easily coerced into believing that it would be easier for them and for others if their lives ended sooner. As a consequence, patients will not be able to effectively manage end-of-life care decisions. They may not be

willing to discuss their medical problems with health care professionals. Still others may be unwilling to risk the lack of respect that they have encountered with health professionals in the past. In neither scenario will the patient receive optimum care. Thus, requirements for concurring physician diagnoses or that patients make repeated requests for PAS may not provide meaningful protection.[100] The essential point is that physicians have broad discretion and power. Unless there is confidence in physician objectivity and lack of unconscious bias, such cynicism is valid.

One commentator perceptively notes, "How in the world ... is a white, middle class, twenty-five year old male doctor, who wants to perform his role in the most intelligent and beneficent way, to approach a poor, aging, folk-educated, black, female patient?"[101] At a minimum, before health care providers can maximize the participation of African-American patients' in end-of-life decisions they must know and appreciate the realities of their patients lives. Essentially, however, the appeal to develop thick descriptions of patients as persons situated in broader social, historical, and cultural contexts is really an invitation to have a conversation before PAS becomes an option in our health care system. This conversation should be about the changes and modifications that are required in the training of health care providers and the delivery of health care services before we can be confident that all patients will have the opportunity to die with dignity.

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100. One commentator makes the point that features of the Oregon Death with Dignity Act (the only state law that permits PAS) are likely to enhance the coercive features of the physician-patient relationship. He writes:

> The doctor informs the patient of her diagnosis and prognosis, determines whether the patient is capable or in need of counseling, and ensures and records that all the required procedural steps had been taken. . . . Although the requirement that a second doctor confirm the diagnosis may in theory help to alleviate this problem, in practice a doctor called to confirm a colleague's diagnosis or prognosis is unlikely to disagree with her assessment.

See Patrick Curran, *Regulating the Unregulatable: Oregon's Death with Dignity Act and the Legalization of Physician-Assisted Suicide*, 86 GEO. L.J. 725 (1998).

101. TRIBULATIONS & CELEBRATIONS, *supra* note 17, at xvii.