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THE ROLE OF RACE IN END-OF-LIFE CARE

BARBARA A. NOAH*

I. INTRODUCTION

More than a decade into the twenty-first century, racial discrimination, *de facto* segregation, and all of the inequalities that flow from these conditions remain firmly embedded in American society. The impact of racial inequality and racism on the health of African Americans and other racial and ethnic minorities often results in concrete threats to the lives of individual patients and, more generally, is fundamentally inconsistent with the ethics and goals of the health professions.¹ Racial disparities in health care delivery and dysfunctional communication between physician and patient at the end of life can combine to exert a pernicious impact on the process of dying—a process that by its nature poses challenges to individual identity and autonomy.

Even as a portion of society clings to and perpetuates biases against those in the minority,² health professionals, health institutions and regulatory bodies must try harder. At the governmental and institutional levels, policy makers must redouble their efforts to address persistent health disparities. At the individual patient level, physicians and other health care providers owe each patient their best effort—to respect and know each patient as an individual and to provide care for each patient that is consistent with that person’s values, preferences, and beliefs. Some physicians already succeed in communicating well with their patients, but many others struggle with the necessary skills, time pressure, discomfort about confronting death and dying, biases and assumptions about their patients, or simply a lack of awareness of the issues involved in end-of-life care.

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1. See M. Gregg Bloche, *Race and Discretion in American Medicine*, 1 YALE J. HEALTH POL’Y L. & ETHICS 95, 102 (2001) (“[T]he overwhelming majority of physicians see undivided loyalty to individual patients as an ethical lodestar.”).

2. Research into the validity of claims of “colorblindness” strongly suggests that collectively and individually, racial bias continues to exist, even when individuals fail to recognize it within themselves. See Jerry Kang & Kristin Lane, *Seeing Through Colorblindness: Implicit Bias and the Law*, 58 UCLA L. REV. 465, 474, 486–87 (2010) (finding evidence of cognitive racial bias in people who self-report no bias, though acknowledging that implicit bias does not necessarily correlate with biased behavior).

Previous research in the area of health disparities has demonstrated that African Americans and other racial and ethnic minorities suffer disproportionately from certain diseases and are in poorer health overall compared to white Americans.³ African Americans also have shorter life expectancies and higher rates of infant and maternal mortality.⁴ Class independently influences health as well,⁵ and the gap in wealth between whites and racial minorities continues to widen—the median wealth of white households is now 20 times that of African American households.⁶ Other factors such as “health literacy”—the ability to obtain, understand, and utilize health information—also play a profound role.⁷ A

3. See Lisa A. Cooper & Debra L. Roter, *Patient-Provider Communication: The Effect of Race and Ethnicity on Process and Outcomes of Healthcare*, in *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* 552, 570 (Brian D. Smedley et al. eds., 2003) (noting that ethnic minorities have less access to healthcare and poorer health status overall); see also OFFICE OF MINORITY HEALTH, CTRS. FOR DISEASE CONTROL & PREVENTION, *HEALTH DISPARITIES EXPERIENCED BY BLACK OR AFRICAN AMERICANS—UNITED STATES* (2005), reprinted in 293 *JAMA* 922, 922 (2005) (explaining that African Americans have a substantially higher risk of a dying from certain diseases, including stroke, perinatal diseases, certain cancers, and diabetes).

4. See KENNETH D. KOCHANEK ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS, NATIONAL VITAL STATISTICS REPORTS 3 tbl.A (2011) (showing that in 2008 and 2009, the life expectancy for Caucasians was higher than for African Americans, and that the infant mortality rates for African American infants was double the infant mortality rates for Caucasians during the same period).

5. See Stephen L. Isaacs & Steven A. Schroeder, *Class—The Ignored Determinant of the Nation's Health*, 351 *NEW ENG. J. MED.* 1137, 1137 (2004) (“People in upper classes—those who have a good education, hold high-paying jobs, and live in comfortable neighborhoods—live longer and healthier lives than do people in lower classes, many of whom are black or members of ethnic minorities. And the gap is widening.”); see also *id.* at 1138–39 (surveying evidence on relationships between income and types of employment and odds ratio for death from all causes and concluding that socioeconomic status differences contribute substantially to differential death rates between African Americans and whites); Elizabeth Ward et al., *Cancer Disparities by Race/Ethnicity and Socioeconomic Status*, 54 *CA* 78, 82 tbl.2 (2004) (reviewing data from the National Cancer Institute's surveillance and epidemiology program and concluding that cancer death rates are 13 percent higher in men and 3 percent higher in women in counties with 20 percent or more residents living below the poverty line).

6. RAKESH KOCHHAR ET AL., PEW RESEARCH CTR., *WEALTH GAPS RISE TO RECORD HIGHS BETWEEN WHITES, BLACKS AND HISPANICS* 1 (2011), www.pewsocialtrends.org/files/2011/07/SDT-Wealth-Report_7-26-11_FINAL.pdf (noting that “[t]he median wealth of white households is 20 times that of black households and 18 times that of Hispanic households”, the largest gap since the government began publishing this information).

7. See Brietta Clark, *Using Law to Fight a Silent Epidemic: The Role of Health Literacy in Health Care Access, Quality, and Cost*, 20 *ANNALS HEALTH L.* 253, 257–58, 284 (2011) (explaining that “health literacy” includes the ability to obtain, understand, and utilize health information to make sound health decisions and arguing that the ethical principles that underlie health literacy, including autonomy and justice, support legal rights of informed consent and anti-discrimination); see also Ad Hoc Comm. on Health Literacy for the Council on Scientific Affairs, Am. Med. Ass'n, *Health Literacy: Report of the Council on Scientific Affairs*, 281 *JAMA* 552, 553–54 (1999) (concluding that despite the importance of health literacy a variety of health-related materials, including discharge instructions, contraception instructions, and consent forms, are written at levels well above the average patient's reading skills); Mark V. Williams et al., *Inadequate Functional Health Literacy Among Patients at Two Public Hospitals*, 274 *JAMA* 1677, 1679–80 (1995) (finding that approximately 30 percent of English-speaking patients in one study location could not understand simple written health instructions); see, e.g., KAISER FAMILY FOUND., *THE DIGITAL DIVIDE AND ACCESS TO HEALTH INFORMATION ONLINE* (Apr. 2011),

large body of literature addresses the widespread prevalence⁸ and causes of health disparities.⁹ Apart from disparities in health, there is overwhelming evidence that race adversely affects the amount and quality of health care provided to minority patients. In broader terms, there is irrefutable evidence of racial bias in health care delivery.¹⁰ The lasting effects of societal discrimination impact the quality of care that minority patients receive¹¹ and, consequently, their trust in the health care system and its providers.¹² Although attention to these problems in the academic literature has raised awareness of the issues, all agree that there are no simple solutions.

This essay focuses on one important aspect of racial disparities that has received comparatively little attention in the legal literature—the existence and causes of racial differences in end-of-life decision making and in the utilization of

<http://www.kff.org/kaiserpolls/upload/8176.pdf> (noting that, although the gap is somewhat closing, racial and ethnic disparities in computer and Internet access remain substantial and that these disparities foreclose opportunities to access health information online).

8. See, e.g., CARA JAMES ET AL., HENRY J. KAISER FAMILY FOUND., KEY FACTS: RACE, ETHNICITY, & MEDICAL CARE 7–12 (2007), <http://www.kff.org/minorityhealth/upload/6069-02.pdf> (summarizing racial demographics, and documenting the prevalence of health disparities by condition, insurance status, and utilization of primary and preventive care and specialist care).

9. See *id.* at 7 (noting that insurance status and socioeconomic status contribute to poorer overall health status for racial and ethnic minority groups); see also Council on Ethical & Judicial Affairs, Am. Med. Ass'n, *Black-White Disparities in Health Care*, 263 JAMA 2344, 2344 (1990) (noting that while African Americans have a higher probability of needing to access health care, they have less of a chance of obtaining the required services).

10. See Bloche, *supra* note 1, at 97–98 (describing the evidence of racial bias in health care delivery and the difficulty in identifying the sources of this “pervasive, often subtle discrimination”); see also Vernellia R. Randall, *Slavery, Segregation, and Racism: Trusting the Health Care System Ain't Always Easy! An African American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191, 210–12 (1996) (noting many examples of racial barriers to health care access, including discrimination by providers, shrinking access in traditionally African American communities, patient dumping, and segregation); Ruqaiijah Yearby, *Racial Inequities in Mortality and Access to Health Care*, 32 J. LEGAL MED. 77, 90 (2011) (noting that African Americans have higher rates of hospitalization and death because of structural racial bias). See generally Barbara A. Noah, *Racial Disparities in the Delivery of Health Care*, 35 SAN DIEGO L. REV. 135 (1998) (exploring multiple examples of racial disparities in health care delivery and suggesting remedies to address the disparities).

11. See Arnold M. Epstein, *Health Care in America—Still Too Separate, Not Yet Equal*, 351 NEW ENG. J. MED. 603, 603–05 (2004) (commenting on study data that suggests that some of the differences in care received by white versus African American patients “seem[s] to reflect the place in which patients seek care, rather than the specific doctor they choose within that place” and noting that the data suggests that geographical segregation also can restrict health care options for minority patients). See generally Peter B. Bach et al., *Primary Care Physicians Who Treat Blacks and Whites*, 351 NEW ENG. J. MED. 575 (2004) (concluding that black patients are often treated by different doctors than white patients and that those physicians may have less training and clinical resources); Kevin Outterson, *Tragedy and Remedy: Reparations for Disparities in Black Health*, 9 DEPAUL J. HEALTH CARE L. 735, 746–77 (2005) (providing a detailed history and insightful comments about the historic role of societal discrimination on the health of African Americans).

12. See Randall, *supra* note 10, at 191 (noting that many African Americans fear and distrust the health care system as a result of historical abuses, which reflects their views of the system).

palliative and hospice care.¹³ African Americans and other racial minorities in the United States utilize palliative care and hospice less frequently than white Americans.¹⁴ These minority populations also tend to resist advance care planning and instead opt to receive more life-prolonging care at the end of life, even when quality of life and prognosis are poor.¹⁵ After a lifetime of limited access to health care compared with whites and, in some cases limited treatment options (because of lack of insurance coverage or biased clinical judgment by physicians), African Americans and other racial and ethnic minorities utilize strikingly higher levels of aggressive, life-prolonging care at the end of life.¹⁶ Much of the explanation for these disparities in end-of-life care appears to lie in problems with communication and trust between physician and patient,¹⁷ although broader influences of culture and religious belief also play a role.¹⁸ The complexities of communication between minority patients and their physicians run in two directions, creating a destructive synergy that can dampen empathy in the relationship and negatively impact care at

13. See *infra* Part II.

14. See Jane L. Givens et al., *Racial and Ethnic Differences in Hospice Use Among Patients with Heart Failure*, 170 ARCHIVES INTERNAL MED. 427, 429–30 (2010) (finding, in a large sample of Medicare beneficiaries, that African Americans and Hispanics with heart failure used hospice care at significantly lower rates than white patients with heart failure, even when adjusting for individual sociodemographic factors and geographic and market factors); see also K. Allen Greiner et al., *Hospice Usage by Minorities in the Last Year of Life: Results from the National Mortality Followback Survey*, 51 J. AM. GERIATRICS SOC'Y 970, 970 (2003) (discussing data that demonstrates that minority patients utilize hospice care at disproportionately lower rates compared with white patients); Michael J. Lepore et al., *Hospice Use Among Urban Black and White U.S. Nursing Home Decedents in 2006*, 51 GERONTOLOGIST 251, 252 (2011). See generally Polly M. Mazanec et al., *Hospice Utilization and End-of-Life Care Decision Making of African Americans*, 27 AM. J. HOSPICE PALLIATIVE CARE 560, 560–66 (2010) (noting that hospice care is already underutilized by African Americans and that the rate is declining).

15. See Jennifer W. Mack et al., *Racial Disparities in the Outcomes of Communication on Medical Care Received Near Death*, 170 ARCHIVES INTERNAL MED. 1533, 1534–35 (2010) (finding that African American patients with advanced cancer who discussed end-of-life preferences with their physicians were more likely to prefer symptom-directed care, even African American patients with do-not-resuscitate orders were still more likely to receive cardiopulmonary resuscitation, ventilator support, or ICU care in the last week of life).

16. See Amresh Hanchate et al., *Racial and Ethnic Differences in End-of-Life Costs: Why Do Minorities Cost More Than Whites?*, 169 ARCHIVES INTERNAL MED. 493, 497–98 (2009) (finding that minorities are more likely to take advantage of aggressive life-sustaining measures such as mechanical ventilation, resuscitation and inpatient chemotherapy).

17. See Randall, *supra* note 10, at 191; see also H. Russell Searight & Jennifer Gafford, *Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians*, 71 AM. FAM. PHYSICIAN 515, 515 (2005) (describing three common situations in which culture may impact end-of-life communication: informing about “bad news,” decision-making process, and thoughts about using advance directives and end-of-life care).

18. See, e.g., Kimberly Johnson et al., *What Explains Racial Differences in the Use of Advance Directives and Attitudes Towards Hospice Care?*, 56 J. AM. GERIATRICS SOC'Y 1953, 1955–57 (2008) (documenting significant differences between African American and Caucasian patients over the age of 65 in completion of advance directives, desire for life-sustaining therapies, and trust in the health care system and attributing some of these differences to cultural beliefs).

the end of life. Although many cultural factors play a role in the decision making of African American patients regarding end-of-life care, this essay focuses primarily on issues of trust and communication because these impact African Americans most directly.

Several responses to these trends deserve consideration, including improving those aspects of medical education that emphasize quality communication and cultural competence, recruiting more physicians from different races in order to build trust at the institutional and individual level, relaxing rigid notions of when hospice and palliative care are appropriate, and recognizing that more medical care at the end of life does not necessarily produce better outcomes. The United States is a nation that struggles collectively with confronting mortality¹⁹ and has witnessed significant ethical and legal conflicts about appropriate end-of-life care in individual cases.²⁰ In this broader context, minority patients must navigate the dying process with all of the additional complexity that arises from lack of trust in the system, poorer overall health status, limited access to care and, sometimes, the biases of health care providers. Unfortunately, though unsurprisingly, the law addresses these issues only at the margins.²¹

19. See Barbara A. Noah, *Timor Mortis: Some Reflections on Law and Dying* (2012) (unpublished manuscript) (on file with the author); see also George J. Annas & Frances H. Miller, *The Empire of Death: How Culture and Economics Affect Informed Consent in the U.S., the U.K., and Japan*, 20 AM. J.L. & MED. 357, 358 (1994) (noting that Americans openly discuss the inevitability of death yet still spend large amounts of money to postpone it even when it is inevitable); Sarah Hales et al., *The Quality of Dying and Death*, 168 ARCHIVES INTERNAL MED. 912, 917 (2008) (explaining that emphasis in the health literature on a “good death” risks sounding euphemistic or unachievable and suggesting that reconceptualizing the goal as “an acceptable, if not ideal, death may have the advantage of being a less . . . value-laden and more realistic framework for end-of-life care”).

20. See, e.g., Marcia Angell, *After Quinlan: The Dilemma of the Persistent Vegetative State*, 330 NEW ENG. J. MED. 1524, 1525 (1994) (discussing how the case of Karen Ann Quinlan was not just a medical matter, but rather an ethical, social, and legal matter); George J. Annas, *Asking the Courts to Set the Standard of Emergency Care—The Case of Baby K*, 330 NEW ENG. J. MED. 1542, 1542 (1994) (explaining that the mother of Baby K believed that “all human life has value, including her anencephalic daughter’s life”); Norman L. Cantor, *The Permanently Unconscious Patient, Non-Feeding and Euthanasia*, 15 AM. J.L. & MED. 381, 385, 433 (1989) (discussing how the removal of a respirator leads to an ethical debate regarding life-prolonging treatments); Kathy L. Cerminara, *Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo*, 29 W. NEW ENG. L. REV. 279, 303–04 (2007) (stating that in *Schiavo*, politics determined the outcome of the case more than ethics); Barbara A. Noah, *The Role of Religion in the Schiavo Controversy*, 6 HOUS. J. HEALTH L. & POL’Y 319, 319–20, 330 (2006) (discussing the ethical and legal principles involved in end-of-life decision making, including religious issues, such as the Catholic Church’s impact on end-of-life decision making); Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo Controversy*, 59 U. MIAMI L. REV. 107, 109 (2004) (discussing how there have been many end-of-life disputes that turn family members against one another and cause doctors to deal with both ethical and legal issues).

21. See Bloche, *supra* note 1, at 108–13 (discussing the lack of legal response to racial disparities within the health care system); Noah, *supra* note 10, at 156–57 (discussing possible legal responses and limitations when it comes to disparities in health care and how the law cannot fully address the racial disparities in healthcare).

II. RACE AND TRENDS IN END-OF-LIFE CARE

In order to understand the ways in which the trends discussed here are troubling, it is necessary to first address two common misconceptions about end-of-life care. In the context of terminal illness, people frequently believe that more therapeutic care (such as tests, procedures, and drug therapies) leads to longer life and improved physical well-being.²² In fact, a growing body of evidence demonstrates that an emphasis on palliative care rather than aggressive therapy can improve patients' quality of life and even prolong survival.²³ Continuing aggressive care also poses risks of iatrogenic harm and additional pain or discomfort, often with no discernable off-setting benefit.²⁴ As medical commentators have recognized, sometimes less is more and there is a real risk of harm "in an environment that values treatment over care."²⁵ In one recent study of patients with advanced cancer, those who discussed end-of-life decisions with their physicians had significantly lower health care costs compared with patients who did not, including a lower frequency of cardiopulmonary resuscitation and ventilator use and a lower likelihood of being admitted to intensive care.²⁶ Survival times between the two studied groups were equal, but higher health care spending at the end of life was associated with poorer quality of life in the last weeks before death.²⁷ Continuing therapy when it offers only speculative benefit to the patient also needlessly increases costs in a health care system that is already straining to meet its obligations.²⁸

22. See Corita Grudzen & Deborah Grady, *Improving Care at the End of Life*, 171 ARCHIVES INTERNAL MED. 1202, 1202 (2011) (arguing against the widely held belief that more care at the end of life is better and suggesting that doctors should determine whether comfort or aggressive care is appropriate on an individual basis).

23. *Id.* "Palliative care" refers to medical care intended to alleviate symptoms associated with illness, whatever the patient's prognosis. See Lise M. Stevens, *Palliative Care*, 296 JAMA 1428, 1428 (2006). Such care may treat symptoms such as pain, shortness of breath, insomnia, depression, nausea and lack of appetite, among others. *Id.*

24. See Grudzen & Grady, *supra* note 22, at 1202-03.

25. See, e.g., *id.* at 1202. All treatment includes care, but not all care necessarily involves therapeutic treatment; cf. Sean Palfrey, *Daring to Practice Low-Cost Medicine in a High-Tech Era*, NEW ENG. J. MED. (2011), available at <http://www.nejm.org/doi/pdf/10.1056/NEJMp1101392?source=hrc> (last visited Mar. 3, 2011) (commenting on the mistaken belief that "'doing everything' is the best practice and the way to prevent harm").

26. See Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 480-82 (2009).

27. See *id.* 482-84 (finding that the average expenditure in the final week for patients who discussed end-of-life options with their physicians was 1,876 dollars compared with 2,917 dollars for those who did not and noting that those patients did not experience any shortening of life as a result of their decisions not to use intensive interventions such as ventilator support).

28. See *id.* at 480, 484-85. It is well-documented that one-third of medical expenses for the last year of life are spent in the final month. *Id.* at 480. Specifically, aggressive therapies and technologies in that final month account for nearly 80 percent of these costs. *Id.* Moreover, thirty percent of Medicare dollars are used to care for the five percent of Medicare beneficiaries who die each year. Amber E.

Another common misconception is that palliative care is only necessary or appropriate during the final stages of terminal illness.²⁹ In fact, although patients with terminal illnesses have the option to discontinue therapeutic care and to receive hospice care instead,³⁰ palliative care in addition to therapy is often appropriate early in the disease process to manage disease symptoms and treatment side-effects in order to minimize suffering.³¹ At this point, formal palliative care programs are not widely available and may not be available via home hospice programs, though medical organizations urge physicians to become “proficient in aggressive symptom management and discussions of advance care planning.”³² Overall, the evidence strongly supports the conclusion that early availability of palliative care improves quality of life for seriously ill and dying patients.³³

There are two main trends that, independent of each other, affect African Americans’ and Latinos’ quality of life at the end of life—the over-utilization of futile therapeutic treatment³⁴ and the under-utilization of palliative and hospice

Barnato et al., *Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life*, 39 HEALTH SERVS. RES. 363, 364 (2004).

29. See Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 734 (2010) (finding that palliative care “has traditionally been delivered late in the course of disease”).

30. See Alexi A. Wright & Ingrid T. Katz, *Letting Go of the Rope—Aggressive Treatment, Hospice Care, and Open Access*, 357 NEW ENG. J. MED. 324, 324 (2007) (noting that more Americans are choosing hospice care instead of continuing therapeutic care).

31. See Temel et al., *supra* note 29, at 734, 737 (noting that palliative care services should be provided to patients earlier to manage patients’ symptoms and lead to improved health outcomes). Recent research has demonstrated the positive impact of early palliative care. See *id.* at 736–38 (finding that patients recently diagnosed with lung cancer who began receiving palliative care immediately lived an average of three months longer than patients who received standard therapeutic treatment only); see also Teresa A. Rummans et al., *Impacting Quality of Life for Patients with Advanced Cancer with a Structured Multidisciplinary Intervention: A Randomized Controlled Trial*, 24 J. CLINICAL ONCOLOGY 635, 635, 640 (2006) (describing a study that demonstrates how a comprehensive and coordinated care approach to treating patients with advanced cancer can improve patients’ quality of life).

32. See *Last Days of Life*, NAT’L. CANCER INST., <http://www.cancer.gov/cancertopics/pdq/supportivecare/lasthours/healthprofessional> (last visited May 20, 2012) (discussing the importance of palliative care for cancer patients, but recognizing these formal programs are not available in many hospitals and even fewer homes); see also Bridget M. Kuehn, *Guideline for End-of-Life Care Released*, 299 JAMA 888, 888 (2008) (discussing a guideline issued by the American College of Physicians that emphasizes management of symptoms to improve quality of life for dying patients, and urges physicians to encourage their patients to consider advance care planning to minimize unnecessary and ineffective treatments).

33. See Karl A. Lorenz et al., *Evidence for Improving Palliative Care at the End of Life: A Systematic Review*, 148 ANNALS INTERNAL MED. 147, 155–56 (2008) (reviewing the literature and finding moderate to strong evidence in support of palliative measures to improve quality of life and reduce suffering at the end of life); see also Amir Qaseem et al., *Evidence-Based Interventions to Improve the Palliative Care of Pain, Dyspnea, and Depression at the End of Life: A Clinical Practice Guideline from the American College of Physicians*, 148 ANNALS INTERNAL MED. 141, 144 (2008) (recommending that physicians strive to manage pain, dyspnea, and depression in their dying patients).

34. See Hanchate et al., *supra* note 16, at 498 (stating that some studies have found minorities to be less likely to have do-not resuscitate orders and more likely to prefer life-sustaining treatments at the end of life).

care.³⁵ Despite the fact that most patients prefer to die at home, nearly one-third of all patients still die in the hospital.³⁶ Moreover, many patients receive therapeutic care, cardiopulmonary resuscitation, ventilator support, or ICU care even when death is imminent.³⁷ Physicians also tend to over-estimate the remaining life spans of seriously ill patients, and are thus more likely to accede to patients' requests for additional interventions.³⁸ In this far from ideal context, African Americans and other racial and ethnic minorities discontinue aggressive therapy and utilize hospice care³⁹ at disproportionately lower rates compared with white patients.⁴⁰ A number of studies document that African Americans utilize hospice services at lower rates than white patients, even when controlling for variables such as insurance

35. See *id.* at 497 (2009) (finding that only 20 percent of blacks, 23 percent of Hispanics, and 26 percent of whites use hospice care in contrast to the larger number of people who seek out aggressive treatments).

36. See Yafu Zhao & William Encinosa, *Statistical Brief #81: The Costs of End-of-Life Hospitalizations, 2007*, in HEALTHCARE COST AND UTILIZATION PROJECT (HCUP) STATISTICAL BRIEFS 1 (2011) (describing data from 2007 that indicates a large portion of patients, 32 percent in 2007, die in the hospital despite the prohibitive costs of hospital care that may dissuade people from wanting to go to the hospital).

37. See Hanchate et al., *supra* note 16, at 497–98 (surveying the use of expensive end-of-life interventions among a large sample of Medicare beneficiaries and finding patterns of substantial expenditure on life-sustaining treatment in the final six months of life).

38. See Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients: Prospective Cohort Study*, 320 BRIT. MED. J. 469, 471 (2000) (stating that most doctors' predictions on survival times for terminally ill patients were overestimates, as most passed away before the end of the timeframe). Interestingly, the conundrum is more complex than it appears superficially. Physicians who communicate well with their patients and feel closer to them were more likely to over-estimate life expectancy for those patients, suggesting that a close doctor-patient relationship makes it more difficult for physicians to be frank with patients about their prognoses. See *id.* at 470–71; cf. Paul Glare, *Predicting and Communicating Prognosis in Palliative Care*, 343 BRIT. MED. J. d5171, d5171 (2011) (“Temporal predictions based on clinical judgment are notoriously inaccurate and usually overoptimistic. Although probabilistic predictions are more accurate . . . actuarial judgment of survival is now recommended. Several statistical models that predict survival have been developed . . . but none has entered routine clinical practice.”).

39. See Mazanec et al., *supra* note 14, at 561. The term “hospice” refers to an approach to care at the end of life that prioritizes the management of symptoms (such as pain, depression, or difficulty breathing) over the treatment of the disease itself. Brian Pace, *Hospice Care*, 295 JAMA 712, 712 (2006). Hospice may include in-home care by trained nurses and physicians or inpatient care at a specialized facility or skilled nursing facility, as well as support for the patient's family through respite services, counseling, and grief counseling. See *id.* Hospice by definition includes palliative care but palliative care does not necessarily require that a patient enter a hospice program. *Id.*

40. See Givens et al., *supra* note 14, at 429–30 (finding, in a large sample of Medicare beneficiaries, that African Americans and Hispanics with heart failure used hospice care at significantly lower rates than white patients with heart failure, even when adjusting for individual socio-demographic factors and geographic and market factors); Greiner et al., *supra* note 14, at 971 (discussing a study that showed black Medicare recipients utilized hospice care less than nonblack recipients); Lepore et al., *supra* note 14, at 254, 257; see also Mazanec et al., *supra* note 14, at 561–62 (describing the decline of African American hospice care utilization since 2007).

coverage.⁴¹ In 2009, the last year for which data are available, 94.7 percent of hospice patients were of non-Hispanic or non-Latino origin, while 5.3 percent were of Hispanic or Latino origin.⁴² In that same year, the statistics for hospice utilization also showed disproportionately low utilization by African Americans—only 8.7 percent of hospice patients were African American.⁴³ Overall, only one in five hospice patients were non-Caucasian.⁴⁴

There are a number of structural influences on the utilization of palliative and hospice care. Lack of insurance or under-insurance only partially explains these differential hospice utilization rates.⁴⁵ Although Medicare covers all eligible individuals over age 65 for the same benefits, patients who are not yet eligible for Medicare and who are terminally ill must rely on private insurance or Medicaid (if they are eligible) for hospice coverage.⁴⁶ The recently enacted federal health care reforms attempt to expand health insurance coverage across many uninsured populations with an eventual goal of universal coverage, but the implementation of these reforms, if they work, will take years.⁴⁷ Meanwhile, many African Americans and other racial minorities remain uninsured in disproportionate numbers compared to white Americans.⁴⁸ Moreover, most insurance providers, including Medicare,

41. See, e.g., Hanchate et al., *supra* note 16, at 497 (finding that 26 percent of whites in the studied group utilized a hospice, compared with 20 percent of African Americans and 23 percent of Hispanics); Johnson et al., *supra* note 18, at 1955–57 (documenting significant differences between African American and white patients over the age of 65 in advance directive completion, desire for life-sustaining therapies, and trust in the health care system); Robert L. Ludke & Douglas R. Smucker, *Racial Differences in the Willingness to Use Hospice Services*, 10 J. PALLIATIVE MED. 1329, 1330–33 (2007) (finding that African Americans were significantly less willing to consider hospice services than whites, even when their physicians strongly recommended hospice, noting that a commonly cited reason for refusal was lack of trust in physicians).

42. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES: HOSPICE CARE IN AMERICA 7 tbl.4 (2010).

43. *Id.*

44. *Id.*

45. See Greiner et al., *supra* note 14, at 971 (discussing various reasons why minority patients might use hospice care at disproportionately lower rates than white patients).

46. See Karl A. Lorenz et al., *Charity for the Dying; Who Receives Unreimbursed Hospice Care?*, 6 J. PALLIATIVE MED. 585, 585 (2003) (finding that hospice care is limited for terminally ill patients and not all states offered hospice care as a benefit for low-income individuals under Medicaid).

47. See generally Patient Protection and Affordable Care Act, Pub. L. No. 111–148, 124 Stat. 119 (2010) (codified as amended in scattered sections of 21, 25, 26, 29 and 42 U.S.C.). Legal challenges to the Obama administration's health care reform legislation continue and states are hesitant to implement changes demanded by the legislation. See Amy Goldstein & N.C. Aizenman, *States Slow to Adopt Health Care Transition*, WASH. POST, June 5, 2011, at A03 (explaining that fewer than one-quarter of the states have taken steps to create statutorily-mandated health care marketplaces that will allow individual purchasers of health insurance better bargaining power and noting that 43 states have cut their Medicaid budgets for the coming fiscal year).

48. See JAMES ET AL., *supra* note 8, at 13–19 (documenting disparities in health insurance coverage by race).

require patients to cease curative care in order to become eligible for hospice,⁴⁹ a decision that some patients may resist because it represents relinquishing hope for a cure.⁵⁰

Even when African American patients have adequate insurance coverage for hospice care and have similar rates of end-of-life discussions with their physicians as white patients, research shows that African Americans receive more life-prolonging care in the last week of life.⁵¹ Other studies also demonstrate that African Americans and Hispanics are more likely to request expensive interventions such as cardiopulmonary resuscitation, mechanical ventilation, intensive care, and artificial feeding, regardless of prognosis.⁵² Among a very large and nationally representative group of Medicare beneficiaries whose care in the final six months of life was studied, 32.5 percent of African Americans were admitted to the intensive care unit and 39.6 percent of Hispanics, compared with only 27 percent of whites.⁵³ Among the same studied group, 18 percent of African Americans and 21 percent of Hispanics received mechanical ventilation, compared with 11.6 percent of whites.⁵⁴ Despite the demonstrated patterns of under-treatment for African Americans and other racial minorities for various diseases and conditions,⁵⁵ in the final six months of life, health care spending was 32 percent higher for African American patients and 57 percent higher for Hispanic patients compared with white patients.⁵⁶

Other evidence corroborates this overall under- and over-utilization trend. In one survey of patients over the age of 65, African Americans were significantly less likely to have completed an advance directive or durable power of attorney for health care compared with white patients.⁵⁷ African Americans also request or anticipate that they will request more life-sustaining treatments when terminally ill

49. See Kathy L. Cerminara, *Pandora's Dismay: Eliminating Coverage-Related Barriers to Hospice Care*, 11 FLA. COASTAL L. REV. 107, 108–09 (2010).

50. See *id.* at 125–26.

51. See Mack et al., *supra* note 15, at 1534–35 (finding that African Americans preferred symptom directed-care). Although African American patients with advanced cancer that have discussed end-of-life preferences with their physicians were more likely to prefer symptom-directed care, those patients with do-not-resuscitate orders in place were still more likely to receive cardiopulmonary resuscitation, ventilator support, or ICU care in the last week of life. *Id.* at 1535.

52. See Hanchate et al., *supra* note 16, at 497–98 (finding a significantly higher pattern of expensive care utilization among African American and Hispanic populations compared with white patients).

53. See *id.* at 497 (adding similar figures for higher use of feeding tubes and resuscitation).

54. See *id.* (adding that rates of inpatient chemotherapy were about the same for all three groups).

55. See *supra* notes 3–12 and accompanying text.

56. See Hanchate et al., *supra* note 16, at 495–98.

57. See Johnson et al., *supra* note 18, at 1955 (finding only 35.5 percent of African Americans have a living will and 67.4 percent of whites have a living will). Another study of elderly Americans found that while 41 percent of white patients had an advance directive, only 16 percent of African American patients had completed one. See Faith P. Hopp & Sonia A. Duffy, *Racial Variations in End-of-Life Care*, 48 J. AM. GERIATRIC SOC'Y 658, 659–61 (2000).

compared with white patients.⁵⁸ Even when African Americans choose hospice care, these patients are nevertheless 70 percent more likely than white patients to leave hospice in order to resume curative care.⁵⁹ When asked about trust in the health care system, African Americans express significantly more distrust in the system.⁶⁰

Not surprisingly given the rates of hospice utilization and the rules requiring cessation of curative care, African Americans and other racial and ethnic minorities utilize more health care services at the end of life than white Americans.⁶¹ The key question is whether these trends reflect individual patient preferences for more care, cultural influences that favor more care, or whether they arise out of deficiencies in patient-physician communication and lack of trust in the medical system.

III. PERSPECTIVES OF HEALTH CARE PROVIDERS AND PATIENTS

Explanations for minority patients' under-utilization of hospice care and the over-utilization of therapeutic care at the end of life are complex. In addition to coverage barriers described in the previous section, other less tangible factors also influence racial differences in hospice utilization rates, including religious beliefs, cultural differences from the Western norm, and distrust in the medical system and its providers.⁶² In the context of end-of-life care decisions, the interplay of multiple cultural factors appears to have a pronounced effect on attitudes toward advance care planning and end-of-life treatment preferences.⁶³

58. See Johnson et al., *supra* note 18, at 1955–56.

59. Kimberly Johnson et al., *Racial Differences in Hospice Revocation to Pursue Aggressive Care*, 168 ARCHIVES. INTERNAL MED. 218, 219–20 (2008).

60. See Johnson et al., *supra* note 18, at 1955–56.

61. See Hanchate et al., *supra* note 16, at 497–98.

62. See Alina M. Perez & Kathy L. Cerminara, *La Caja de Pandora: Improving Access to Hospice Care Among Hispanic and African-American Patients*, 10 HOUS. J. HEALTH L. & POL'Y 255, 261 (2010) (providing a detailed discussion of the many influences of culture on end-of-life decision making and explaining that culture can influence “how people perceive the symptoms of illness, how they explain the causes of their diseases, and patients’ attitudes toward treatment and the use of medications and technology”); see also Marjorie Kagawa-Singer & Leslie J. Blackhall, *Negotiating Cross-Cultural Issues at the End of Life: “You Got to Go Where He Lives”*, 286 JAMA 2993, 2993–94 (2001) (explaining how culture “fundamentally shapes how individuals make meaning out of illness, suffering, and dying” and therefore also influences how they make use of medical services at the end of life); Searight & Gafford, *supra* note 17, at 516 (describing three common situations in which culture may impact end-of-life communication: “communication of ‘bad news,’ locus of decision making, and attitudes toward advance directives and end-of-life care”).

63. See LaVera Crawley et al., *Palliative and End-of-Life Care in the African American Community*, 284 JAMA 2518, 2518–20 (2000) (providing a detailed discussion of the impact of religion, bioethics issues, health policy factors, trust, and education on African Americans’ willingness to use palliative and hospice care); see also Johnson et al., *supra* note 18, at 1956–57 (explaining that the impact of multiple factors, including lack of comfort discussing death, distrust in the medical system, and religious beliefs, reduce the willingness of African Americans to plan for end-of-life care or to consider hospice care).

One cultural factor that clearly plays a role in the reluctance of some minority patients to discontinue therapeutic care is the higher rate of religious belief among these minority populations.⁶⁴ Research suggests that African Americans are more likely to consider themselves religious than whites and that religious belief is associated with higher utilization of care at the end of life.⁶⁵ A recent study concludes that terminally ill patients who profess some sort of religious faith or practice are more likely than agnostic or atheist patients to seek aggressive care at the end of life.⁶⁶ Patients who are religious or spiritual may feel that it is inappropriate to leave decisions about life or death with the doctor or to make these decisions themselves, and may also feel compelled to undergo potentially painful or futile treatments in order to demonstrate moral strength in preparation for life after death.⁶⁷ Different cultures may also hold beliefs about illness and health care decision making that conflict with Western orthodox values such as autonomy, preferring to withhold the truth of the diagnosis from the ill family member, or to allow a designated family member other than the patient to make health care decisions.⁶⁸

The well-documented, widespread and deeply rooted lack of trust of African Americans and other racial minorities in the medical system presents perhaps the most significant challenge to meaningful communication with and by physicians at the end of life.⁶⁹ For African American patients, end-of-life decisions present a

64. See Johnson et al., *supra* note 18, at 1953, 1956.

65. See *id.* at 1956 (finding that African Americans were more likely to agree that belief in God makes it unnecessary to plan for end-of-life care).

66. See Andrea C. Phelps et al., *Religious Coping and Use of Intensive Life-Prolonging Care Near Death in Patients with Advanced Cancer*, 301 JAMA 1140, 1144 (2009) (concluding that high levels of religious coping were strongly associated with a preference for intensive life-prolonging care in the last week of life, including mechanical ventilation and resuscitation). The authors of the study were unable to explain the association between religiousness and the preference for aggressive care at the end of life. *Id.* at 1141. The authors speculate that perhaps these preferences arise from a sense that the sanctity of life requires all available efforts to prolong it and that suffering at death furthers a religious purpose. *Id.* at 1145.

67. See Kagawa-Singer & Blackhall, *supra* note 62, at 2997 (describing studies in which African American participants explained that only God has power over life and death and that, therefore, God can help patients more than physicians can and noting that religious beliefs may also encourage an “ethic of struggle” in which the patient must subject himself to pain or suffering including life support as a test of strength before the afterlife).

68. For more about the wide-ranging impact of culture and language on end-of-life decision making among multiple racial and ethnic groups, see Perez & Cerminara, *supra* note 62, at 273–74 (explaining that Hispanic families, for example, “are less likely to place the burden of decision making on the patient with a terminal illness” and emphasizing that language barriers add to substantive communication complexities); see also Searight & Gafford, *supra* note 17, at 516–19 (explaining that principlism, including values of autonomy and beneficence, serves as the framework for medical decision making in the United States but that other cultures place the value beneficence above autonomy and thus prefer to protect patients from worry by avoiding direct discussion of death and dying).

69. See Searight & Gafford, *supra* note 17, at 515, 519, 521 (noting the lack of trust and suggesting potential guidelines for cross-cultural communication, including “demonstrating an interest in [a patient’s] cultural heritage”).

greater than usual challenge because many mistrust the medical system and its health care providers.⁷⁰ Health care scholars have demonstrated that the minority patient populations' lack of trust in the predominately white medical system discourages these patients from seeking early medical attention, even when care is available and affordable.⁷¹ The research suggests that African American and Hispanic patients are less likely to trust their physicians because of perceived discrimination, the legacy of racial discrimination in medicine and medical research, and social distance between physicians and their minority patients.⁷²

The evidence suggests that, in the case of some physicians, this distrust is well-justified. The discretionary nature of medical decision making opens the door to conscious and unconscious racially biased assumptions on the part of health care providers.⁷³ As Professor Gregg Bloche has explained, most medical decisions lack empirical, scientific support, and because physicians usually have a variety of diagnostic and therapeutic choices, studies have documented significant racial

70. See Frederick M. Chen et al., *Patients' Beliefs About Racism, Preferences for Physician Race, and Satisfaction with Care*, 3 ANNALS FAM. MED. 138, 140–43 (2005) (finding that African American and Latino patients who perceived racism in the health care system were more likely to prefer a physician of their own race and more likely to express satisfaction about care received from a racially-concordant physician); see also Chanita Hughes Halbert et al., *Racial Differences in Trust in Health Care Providers*, 166 ARCHIVES INTERNAL MED. 896, 898 (2006) (concluding that African Americans were significantly more likely to express distrust in their physicians compared to white patients); Searight & Gafford, *supra* note 17, at 519 (“Among blacks, nonacceptance of advance directives appears to be part of a much broader pattern of values regarding quality of life, as well as a historical legacy of segregation. DNR orders may be viewed as a way of limited expensive health care or as cutting costs by ceasing care prematurely.”).

71. See Carol M. Ashton et al., *Racial and Ethnic Disparities in the Use of Health Services: Bias, Preferences, or Poor Communication?*, 18 J. GEN. INTERNAL MED. 146, 148 (2003) (concluding that poor communication between physicians and minority patients contributes substantially to health disparities and recommending ways to improve communication); see also Mark P. Doescher et al., *Racial and Ethnic Disparities in Perceptions of Physician Style and Trust*, 9 ARCHIVES FAM. MED. 1156, 1157 (2000) (explaining that trust is a crucial element of the relationship between the doctor and patient and noting a study that found whites had more trust in their physicians than nonwhites); Randall, *supra* note 10, at 191–92 (noting that the history of experimentation and abuse has led African Americans to fear the health care system and kept them from seeking treatment). Distrust even appears to exert a negative impact on patients' physical well-being. See Nalini Ranjit et al., *Psychosocial Factors and Inflammation in the Multi-Ethnic Study of Atherosclerosis*, 167 ARCHIVES INTERNAL MED. 174, 177 (2007) (concluding that patients who expressed high levels of “cynical distrust” in their health care providers or in the medical system had concurrently high levels of inflammatory markers which are associated with cardiovascular disease).

72. See Irena Stepanikova et al., *Patients' Race, Ethnicity, Language, and Trust in a Physician*, 47 J. HEALTH & SOC. BEHAV. 390, 391 (2006) (providing an overview of reasons for mistrust based on a review of the relevant literature).

73. See Noah, *supra* note 10, at 154–56 (suggesting that the evidence of racial disparities in how health care is delivered supports the conclusion that physician's treatment decisions, at least sometimes, reflect unstated prejudices about their patients). Professor Randall concludes that the disparate care received by African American patients constitutes a more explicit and avoidable kind of racism: “Eurocentric bioethical principles such as autonomy, beneficence, and informed consent . . . leave considerable room for individual judgment by health care practitioners. . . . In a racist society (such as ours), the judgment is often exercised in a racist manner.” Randall, *supra* note 10, at 231.

variations in the utilization of many medical procedures, even within the same geographic area.⁷⁴ For example, several studies have demonstrated that African Americans are less likely to receive surgical treatment of early-stage lung cancer than whites, and, consequently, have a lower overall survival rate for the disease.⁷⁵ In another highly publicized study, researchers found that physicians referred lower percentages of African American patients than white patients for cardiac catheterization, even when all other factors, i.e., age, sex, and severity of disease, were equal.⁷⁶ There is a wealth of this type of research, with equally disheartening conclusions.⁷⁷ These sorts of research results are, of course, based on the

74. See Bloche, *supra* note 1, at 100.

75. See Peter B. Bach et al., *Racial Differences in the Treatment of Early-Stage Lung Cancer*, 341 NEW ENG. J. MED. 1198, 1198, 1202 (1999) (introducing studies that found a correlation between race and the probability of receiving surgical treatment for resectable non-small-cell lung cancer); see also Howard P. Greenwald et al., *Social Factors, Treatment, and Survival in Early-Stage Non-Small Cell Lung Cancer*, 88 AM. J. PUB. HEALTH 1681, 1682–83 (1998) (finding that white patients were 20 percent more likely to undergo surgery than African American patients and 31 percent more likely to survive five years, and stating that “[p]oor general health and adverse health behavior (such as smoking), which often coincide with low income and membership in minority groups, may lead to lower rates of surgery as providers judge disadvantaged patients to be relatively poor surgical risks”). One study followed nearly 11,000 lung cancer patients over the course of eight years and controlled for variables including disease stage, insurance coverage, socioeconomic status, access to care, and coexisting illness. See Bach et al., *supra* note 75, at 1202 tbl. 2. The investigators found that African Americans underwent surgical resection of the cancer only 64 percent of the time, compared with a rate of nearly 77 percent for white patients in the studied group. *Id.* The five-year survival rate for the African American group was correspondingly lower—approximately 26 percent versus 34 percent of white patients—whereas the five-year survival rate among patients who *had* undergone surgery was the same in both racial groups. *Id.* at 1202. Most strikingly, however, surgical resection incontrovertibly represents the optimal treatment for early-stage lung cancer, leaving little room for the argument that some other, less common, but equally effective, treatment was indicated for any particular patient. *Id.* Two physicians, commenting on this study, lament that the results “suggest that there is a difference in how physicians manage cancer that is based on the patient’s race, regardless of other attributes, and that the consequence of these lapses in care is reduced survival among blacks.” Talmadge E. King, Jr. & Paul Brunetta, *Racial Disparity in Rates of Surgery for Lung Cancer*, 341 NEW ENG. J. MED. 1231, 1231 (1999). “Evidence that bias on the part of physicians (either overt prejudice or subconscious perceptions) influences access to optimal cancer care is disheartening. . . .” *Id.* at 1231–32.

76. See Kevin A. Schulman et al., *The Effect of Race and Sex on Physicians’ Recommendations for Cardiac Catheterization*, 340 NEW ENG. J. MED. 618, 623 (1999). The study received an enormous amount of public attention, including criticism about its design and methodology, some of which was valid. See Lisa M. Schwartz et al., *Misunderstandings About the Effects of Race and Sex on Physicians’ Referrals for Cardiac Catheterization*, 341 NEW ENG. J. MED. 279, 279 (1999). The New England Journal later published corrections and a partial retraction of the research. *Id.*

77. See, e.g., Ashish K. Jha et al., *Racial Trends in the Use of Major Procedures Among the Elderly*, 353 NEW ENG. J. MED. 683, 688, 690 (2005) (finding differences in rates of utilization of surgical procedures among elderly patients enrolled in Medicare, and concluding that efforts to eliminate racial disparities in the use of high-cost surgical procedures were ineffective); see also Amal N. Trivedi et al., *Trends in the Quality of Care and Racial Disparities in Medicare Managed Care*, 353 NEW ENG. J. MED. 692, 698 (2005) (finding that racial disparities existed but appeared to be declining among the populations studied); Viola Vaccarino et al., *Sex and Racial Differences in the Management of Acute Myocardial Infarction, 1994 Through 2002*, 353 NEW ENG. J. MED. 671, 678 (2005) (concluding that

unfortunately common experiences of actual patients—they are not statistical estimates but real world numbers.⁷⁸ It is no wonder that distrust in the medical system and in physicians continues to influence minority patients' willingness to seek medical treatment and to rely on the advice of their physicians.

As suggested by the research discussed above, in the context of end-of-life care, the evidence documents that the same patterns of distrust play a significant role. When faced with life-threatening illness, research suggests that African Americans reject hospice or turn to hospice later in the course of terminal illness, at least in part out of fear that ceasing therapeutic care would be premature, despite the advice of their physicians.⁷⁹ One commentator has summarized the conundrum quite elegantly:

Are health care resources for nonwhites misallocated over a lifetime, with racial and ethnic minorities receiving fewer life-extending and life-enhancing interventions than whites throughout their lives but more at the end, when there is less opportunity to improve the quantity and quality of life? Perhaps the use of aggressive, hospital-based interventions at the end of life is a well-considered preference. However, even if such interventions are a choice, the decision to use them may stem less from settled views than from distrust of the medical care system⁸⁰

There is no single answer to this question. Each patient's choices are informed by a unique combination of culture, religious belief, concern about bias, personal experience with the health care system and its providers, and more. Nevertheless, the evidence suggests a pervasive pattern of distrust or at least caution among African Americans and other racial and ethnic minorities when making choices about discontinuing therapy or life-supportive measures. Notwithstanding various contributing factors (such as coverage barriers and religious beliefs) which are individually race-neutral, the amalgam of these factors creates suspicion and distrust as a logical consequence of race-based misallocation of medical services in individual patient cases and, thus, in the medical system in its entirety.

rates of several treatments for heart attack varied significantly by race and that the differences in rates of utilization have not improved in the later years).

78. See Johnson et al., *supra* note 18, at 1957 (“Not surprisingly, issues of trust may be especially important in determining attitudes toward hospice, because the hospice philosophy of care focuses on palliative rather than more-traditional cure-directed therapies.”); see also Mack et al., *supra* note 15, at 1533 (describing research that supports findings that impaired trust between African American patients and physicians can lead these patients to request life-sustaining treatment when they are concerned that they might otherwise be denied such measures).

79. See Perez & Cerminara, *supra* note 62, at 278–79 (citing potential reasons why African Americans comprise such a small percentage of hospice patients, including a lower level of comfort talking about death).

80. See Hanchate, *supra* note 16, at 498.

From the provider perspective, a combination of poor communication skills, misconceptions about different cultures, and conscious or unconscious racial bias contribute to false assumptions about African American patients' preferences with respect to health care.⁸¹ Doctors, like the rest of us, have various characteristics, personalities, prejudices, and failings.⁸² Some physicians surely are open, unbiased, and excel at communication, but the evidence suggests that others struggle with unconscious biases and racism.⁸³ In one recent study attempting to document the effects of racial bias on how physicians make clinical decisions, the investigators uncovered a clear association between negative stereotypes about African Americans and decreased tendency to provide appropriate medical treatment.⁸⁴ Good communication requires empathy (and empathy requires caring) and these misconceptions and biases can also result in weak or only superficial communication between physicians and minority patients about individual patient preferences.⁸⁵ Even in the absence of bias, the prevalence of racial disparities in health care delivery suggests that physicians pay little attention to differential patterns of care based on race and therefore may fail to recognize and respond to such patterns.⁸⁶

81. See Searight & Gafford, *supra* note 17, at 521 (suggesting guidelines for cross-cultural communication).

82. See Allan S. Detsky & Mark O. Baerlocher, *Do Nice Patients Receive Better Care?*, 306 JAMA 94, 94 (2011) ("Patients vary in their background, age, sex, intelligence, socioeconomic status, and demeanor. Similarly clinicians vary in those same attributes, except perhaps socioeconomic status.").

83. See Kang & Lane, *supra* note 2, at 486–87 (reviewing evidence of cognitive racial bias in people who self-report no bias, though acknowledging that implicit bias does not necessarily correlate with biases behavior). Research into the validity of claims of "colorblindness" strongly suggests that, collectively and individually, racial bias continues to exist, even when individuals fail to recognize it within themselves. *Id.*

84. See Alexander R. Green et al., *Implicit Bias Among Physicians and Its Prediction of Thrombolysis Decisions for Black and White Patients*, 22 J. GEN. INTERNAL MED. 1231, 1237 (2007). In the study, researchers tested physicians for unconscious racial bias using a well-regarded series of psychological tests called Implicit Association Tests (IATs). *Id.* at 1234. After measuring the degree of bias in participating physicians, researchers presented each participant with a medical vignette of a patient presenting with symptoms of heart attack and asked whether they would recommend treatment with thrombolytic therapy. *Id.* at 1235. Participants with higher levels of unconscious bias as measured by the IATs were substantially less likely to recommend thrombolytic therapy for African American patients than for white patients with otherwise identical medical conditions. See *id.* at 1235, 1237. But see Adil H. Haider et al., *Association of Unconscious Race and Social Class Bias with Vignette-Based Clinical Assessments by Medical Students*, 306 JAMA 942, 942, 949 (2011) (evaluating the IATs of over 200 first-year medical students and finding that the majority of students demonstrated a preference for white persons and members of the upper class, but concluding that these implicit preferences did not translate into different clinical assessments by race in a variety of patient vignettes).

85. See Bloche *supra* note 1, at 104–05 ("[T]he attenuation of empathy across racial lines in clinical relationships can engender unconscious devaluation of minority patients' hopes, fears, and life prospects, with invidious consequences for clinical judgment. . . . Cultural and language barriers between patients and providers can both amplify this effect and impede communication . . .").

86. See Ashton et al., *supra* note 71, at 146 (noting that stereotypes often cause bias that people are unaware is bias).

The overall racial bias trend in health care takes on an even more ominous significance when combined with the general struggle of health care providers to broach the issue of dying.⁸⁷ Even those providers in specialties that regularly care for terminally ill patients may feel reluctant to have difficult conversations about prognosis, stopping treatment, and withdrawal or withholding of life-supportive measures.⁸⁸ Physicians may worry that discussing these matters with patients will generate anxiety or may give the patient the idea that the physician is abandoning care of the patient.⁸⁹ In spite of these concerns, the value of meaningful communication with patients about prognosis and end-of-life planning is well-established.⁹⁰ Discussions about treatment choices between physicians and seriously ill patients offer a valuable opportunity for both parties and for the patient's family.⁹¹ Unfortunately, the design of our health care system does not foster long-term relationships between physicians and patients.⁹² Those patients who are fortunate enough to have insurance are still likely to change general practitioners fairly frequently.⁹³ And when patients become seriously ill, specialists often take charge of the necessary medical care, necessitating new doctor-patient relationships and thus new efforts at communication and building trust.⁹⁴ Lack of

87. See Searight & Gafford, *supra* note 17, at 515 (explaining the challenge of handling "cultural factors" in end-of-life discussions).

88. See Stephen Barclay & Jane Maher, *Having the Difficult Conversations About the End of Life*, 341 *BMJ* 653, 653 (2010).

89. See Steven Z. Pantilat, *Communicating with Seriously Ill Patients: Better Words to Say*, 301 *JAMA* 1279, 1279 (2009) (explaining that recent research on physician-patient communication emphasizes the value of a model that involves multiple conversations over time and that offers the prospect of continued care).

90. See *id.* at 1279, 1281 (explaining that good communication is integral aspect of end-of-life care, so much so that California now requires it by law).

91. *Id.* at 1279.

92. See Katrina E. Donahue et al., *Length of Patient-Physician Relationship and Patients' Satisfaction and Preventive Service Use in the Rural South: A Cross-Sectional Telephone Study*, *BMC FAM PRAC.*, Oct. 2005, at 2, 7 (noting the shared value, between physicians and patients, of "continuity in health care"); Mack et al., *supra* note 15, at 1537 ("White patients may have greater continuity of health care provider and sites of care, with confirmation of DNR orders and documentation of preferences, for example, at every encounter."); cf. Timothy E. Quill, *Initiating End-of-Life Discussions with Seriously Ill Patients: Addressing the "Elephant in the Room,"* 284 *JAMA* 2502, 2504 (2000) (quoting a clinician who felt that she had "lost [her patient] in the system" after he was transferred to a long-term care facility where he would likely die, rather than dying at home with hospice, where she could be part of the ending).

93. See Linda J. Weiss & Jan Blustein, *Faithful Patients: The Effect of Long-Term Physician-Patient Relationships on the Costs and Use of Health Care by Older Americans*, 86 *AM. J. PUB. HEALTH* 1742, 1742-43 (1996) (explaining that the prevalence of managed care is often the cause of Americans switching health care providers because not every physician participates in every insurance program).

94. See *id.* at 1746 (noting that patients tend to switch physicians when they become seriously ill); see also Joanne Lynn, *Serving Patients Who May Die Soon and Their Families: The Role of Hospice and Other Services*, 285 *JAMA* 925, 927 (2001) (using a palliative care case study to demonstrate how difficult it can be for seriously ill patients to develop trusting relationships with specialists because of the system of fragmented, impersonal care).

familiarity between patient and physician and demands on physicians' time make conversations about treatment preferences, prognosis and end-of-life care more challenging.⁹⁵

IV. RECOMMENDATIONS

Improving Education of Health Care Providers. End-of-life communication poses serious challenges to physicians.⁹⁶ Physicians have long struggled with feelings of powerlessness, grief, or failure when patients die.⁹⁷ Improved education, both in medical school and as part of continuing education, about effective patient communication can foster participatory decision making and meaningful conversation.⁹⁸ The medical literature indicates that the goal of quality communication receives more attention these days, though time constraints and individual predispositions probably limit it.⁹⁹ Discussions about the imminence of death and the patient's preferences regarding care are too frequently delayed.¹⁰⁰ Talking with patients about end-of-life preferences while patients are still receiving therapeutic interventions can help patients to confront or at least consider that they may not survive their illness,¹⁰¹ and this sort of conversation is not stressful *per se*.¹⁰² Such conversations can provide a pathway to earlier utilization of palliative

95. See Stephen A. Hilty, *Reimbursement for Patient and Family Meetings and the Costs of Care at the End of Life*, 300 JAMA 2119, 2119–20 (2008) (noting that issues with reimbursement discourages doctors from planning family meetings to discuss end-of-life decisions with patients and suggesting that the potential savings from avoiding expensive therapy and ICU admission justifies prompt and reasonable reimbursement); see also Gregory P. Gramelspacher et al., *Preferences of Physicians and Their Patients for End-of-Life Care*, 12 J. GEN. INTERNAL MED. 346, 350 (1997) (finding that patients who are more familiar with their physicians are more likely to trust those physicians regarding end-of-life treatment recommendations and decisions).

96. See Diane E. Meier et al., *The Inner Life of Physicians and Care of the Seriously Ill*, 286 JAMA 3007, 3007 (2001) (discussing the emotional response of physicians who treat patients with serious illnesses); see also Richard S. Kane, *The Defeat of Aging Versus the Importance of Death*, 44 J. AM. GERIATRICS SOC'Y 321, 322 (1996) (explaining that many physicians face challenges during end-of-life care because discussions of death are considered to be taboo).

97. See Meier et al., *supra* note 96, at 3007.

98. See Dale G. Larson & Daniel R. Tobin, *End-of-Life Conversations: Evolving Practice and Theory*, 284 JAMA 1573, 1577 (2000).

99. See Ronald M. Epstein et al., *Communicating Evidence for Participatory Decision Making*, 291 JAMA 2359, 2359, 2363 (2004) (noting that varying patient preferences do not allow for one single communication technique that will work for every patient and commenting that physicians rarely spend more than one minute out of a twenty minute appointment discussing treatment plans).

100. See Quill, *supra* note 92, at 2503–04 (stating that many physicians feel that end-of-life treatment options should be discussed early to be meaningful and providing a list of clinical indications for discussing end-of-life care).

101. See Ezekiel J. Emanuel et al., *Talking with Terminally Ill Patients and Their Caregivers About Death, Dying, and Bereavement*, 164 ARCHIVES INTERNAL MED. 1999, 2003 (2004) (commenting that having the opportunity to discuss an illness can be emotionally helpful to both patients and caregivers).

102. See *id.* at 2001 (describing a study in which terminally ill patients were interviewed in person about end-of-life issues and asked to rate the level of stress caused by the discussion and concluding that such conversations can be helpful while imposing minimal stress).

medicine and hospice, while avoiding unwanted or aggressive care.¹⁰³ Physicians, however, understandably find such discussions difficult and appear to resist such conversations until therapeutic options are exhausted or the patient indicates a desire to abandon treatment.¹⁰⁴ At the same time, health care providers express frustration and anguish that they do not have the time to spend with patients to address their patients' feelings of shock, depression, or helplessness.¹⁰⁵

Focusing on Care Versus Therapy. Part of the reluctance to discuss treatment choices stems from the arguable over-emphasis in medical education on therapy as opposed to care.¹⁰⁶ Medical "care," a broader term that includes therapy, is not exclusively about preserving life but rather about caring for the patient in optimal ways and alleviating suffering, even when illness is severe or death imminent.¹⁰⁷ The common training of physicians focuses on fighting disease, remaining detached, and continuing to search for a solution to a problem, but perhaps also loses sight of the patient and his goals as an individual.¹⁰⁸ We have endorsed as a society the idea that it is acceptable, even desirable, to take valiant measures to delay death.¹⁰⁹ The instinctive desire of physicians, patients, and families to "do everything possible" comports with and perpetuates the belief that maximal

103. See Larson & Tobin, *supra* note 98, at 1575 ("[D]iscussing palliative care issues while disease-remitting treatments are continued without creating a perception of abandonment requires the utmost empathy and skill.").

104. See Nancy L. Keating et al., *Physician Factors Associated with Discussions About End-of-Life Care*, 116 *CANCER* 998, 1001 (2010) (concluding that most physicians surveyed indicated that they would not discuss end-of-life decisions and choices with terminally ill patients until they exhibited symptoms or there were no remaining treatments available); see also Corita Grudzen, *At the End of Life, Sometimes Less is More*, 171 *ARCHIVES INTERNAL MED.* 1201, 1201 (2011) (acknowledging recent treatment of a patient in which the author and physician was "managing her from one crisis to the next, without real pause to discuss her wishes or her prognosis").

105. See Charles J. Sabatino, *Reflections on the Meaning of Care*, 6 *NURSING ETHICS* 374, 375–76 (1999) (explaining that the dramatic growth of technologies in medical care creates a danger "that care will lose its primary focus on the well-being of the whole person").

106. See J. Andrew Billings & Susan Block, *Palliative Care in Undergraduate Medical Education: Status Report and Future Directions*, 278 *JAMA* 733, 734 (1997) (describing the rarity of education in end-of-life care in both medical schools and residency programs).

107. See Ellen Fox, *Predominance of the Curative Model of Medical Care: A Residual Problem*, 278 *JAMA* 761, 761 (1997) (explaining that, while curative care is important, palliative care is also an important goal of medicine).

108. See Daniel Callahan, *Death and the Research Imperative*, 342 *NEW ENG. J. MED.* 654, 654–55 (2000) (quoting William Haseltine, then CEO of Human Genome Sciences, as saying that "[d]eath is a series of preventable diseases" and arguing that research "should not, even implicitly, have eradication of death as its goal" because it supplants emphasis on the importance of relieving suffering at the end of life and it "promotes the idea among the public and physicians that death represents a failure of medicine"). See generally Symposium, *Patient-Centered Law and Ethics*, 45 *WAKE FOREST L. REV.* 1429 (2010) (containing multiple articles that address the value of providing medical care that places the individual patient at the center of health care delivery, rather than letting insurance companies, pharmaceutical companies, and even medical organizations drive).

109. See Albert R. Jonsen, *The God Squad and the Origins of Transplantation Ethics and Policy*, 35 *J. L. MED. & ETHICS* 238, 239–40 (2007) (noting society's reluctance to accept mortality).

utilization of life-prolonging measures constitutes “good health care.” Although attitudes among health care providers are shifting, not long ago it was common to interpret good care as demanding every available, medically relevant treatment.¹¹⁰ Even as more commentators argue against the unthinking presumption in favor of utilizing medical technology simply because it is available, the evidence described above suggests that a systemic overutilization of medical treatments at the end of life persists for all patients and particularly for African American and Hispanic patients.¹¹¹

Improving Data Collection and Usage. Patient distrust of doctors’ motives, suspicion of bias, and language and cultural barriers¹¹² exacerbate all of these challenges in end-of-life communication.¹¹³ Although the prevalence and scope of academic literature on racial disparities in health care delivery suggests widespread awareness among physicians,¹¹⁴ this may not translate into routinely better care and communication in many physicians’ practices.¹¹⁵ One recent commentary recommended that physician practices routinely inquire about their new patients’

110. See Sabatino, *supra* note 105, at 377 (explaining that it is common to spend excessive amounts of money on curative care even when it will not improve the patient’s condition). See generally N. ENG. HEALTHCARE INST., WASTE AND INEFFICIENCY IN THE U.S. HEALTH CARE SYSTEM—CLINICAL CARE: A COMPREHENSIVE ANALYSIS IN SUPPORT OF SYSTEM-WIDE IMPROVEMENTS (2008) (evaluating waste in the health care industry, which the report defines as “health care spending that can be eliminated without reducing the quality of care,” and attributing much of the waste to physicians’ tendency to over-treat patients).

111. See Mack et al., *supra* note 15, at 1533 (noting the over-utilization of life-prolonging treatment, rather than palliative care, by black patients compared to white patients). As Daniel Callahan has so ably argued, medical research should focus on reducing morbidity in the final years of life and assuring that people receive excellent care as they die in order to reduce suffering. See DANIEL CALLAHAN, SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY 52–58 (1987) (arguing that medicine should aim to improve, rather than prolong, lives); DANIEL CALLAHAN, TAMING THE BELOVED BEAST: HOW MEDICAL TECHNOLOGY COSTS ARE DESTROYING OUR HEALTH CARE SYSTEM 152–55 (2009) (“Death itself, part of our biological nature, ought not to be seen as the primary target for health care, particularly when most of us now have the chance to live a full life” and observing that, paradoxically, as our society has become healthier, people have begun to worry more about health and to spend more technological resources on maintaining it); Callahan, *supra* note 108, at 655–56 (2000); see also James F. Fries, *Aging, Natural Death, and the Compression of Morbidity*, 303 NEW ENG. J. MED. 130, 130 (1980) (discussing the common goal of shortening or avoiding, the period of “old age” as much as possible by preserving qualities that society generally associates with youth).

112. See Wendi Norris et al., *Communication about End-of-Life Care Between Language-Discordant Patients and Clinicians: Insights from Medical Interpreters*, 8 J. PALLIATIVE MED. 1016, 1017 (2005) (discussing the fact that communication about end-of-life care is especially difficult when patients and physicians are from different cultures or speak different languages).

113. See LaVera Crawley, *Strategies for Culturally Effective End-of-Life Care*, 136 ANNALS INTERNAL MED. 673, 675–76 (2002) (using a case study to demonstrate minorities’ mistrust of physicians, explaining that such mistrust is associated with historical events, and suggesting methods for effective response by physicians).

114. See Nicole Lurie et al., *Racial and Ethnic Disparities in Care: The Perspectives of Cardiologists*, 111 CIRCULATION 1264, 1264 (2005).

115. See *id.* at 1265 (noting that only 34 percent of cardiologists polled believed that health care differed for people of different racial or ethnic backgrounds).

race, ethnicity and language in order to facilitate data gathering on racial variations in utilization patterns.¹¹⁶ The simple act of gathering this information can help to focus attention on issues of racial bias and cultural differences,¹¹⁷ providing a reminder to physicians to consider their recommendations in light of the data on differential utilization patterns.

Removing Coverage Barriers. In addition, several commentators also have strongly endorsed efforts to remove structural barriers to the utilization of hospice and palliative care, including addressing absent or limited health insurance coverage.¹¹⁸ Perhaps most importantly, given the emotional, religious, and cultural challenges inherent in confronting mortality,¹¹⁹ removing the requirement that hospice patients forego all therapeutic care will, at least for some patients, make opting for hospice care more acceptable. The Medicare hospice benefit requires that patients have a life expectancy of no more than six months without life-supportive care and that they agree to forego life-sustaining treatment.¹²⁰ As part of the Obama administration's health care reforms, the Affordable Care Act of 2010 ("the Act") requires that the Centers for Medicare & Medicaid Services investigate the feasibility of allowing patients to continue therapeutic care while receiving hospice services.¹²¹ Because the Act requires budget neutrality, the concurrent care model must result in overall savings, or at least no additional cost, to the Medicare program.¹²² The evaluation of concurrent care also requires consideration of other

116. See Editorial, *Demographic Data: Reducing Disparities Starts with a Question*, AM. MED. NEWS, July 4, 2011, <http://www.ama-assn.org/amednews/2011/07/04/edsa0704.htm> (endorsing a recent report by the Commission to End Health Care Disparities that recommends gathering such data that, together with electronic medical records, can simplify the process of detecting patterns and variations that are inconsistent with good practice standards); see also HEALTH RES. & EDUC. TRUST, HRET DISPARITIES TOOLKIT: A TOOLKIT FOR COLLECTING RACE, ETHNICITY, AND PRIMARY LANGUAGE INFORMATION FROM PATIENTS 3 (2005) (providing guidelines for systematically collecting race, ethnicity, and primary language data from patients with attention to explaining to patients the purposes and goals for collecting this information).

117. See HEALTH RES. & EDUC. TRUST, *supra* note 116, at 10.

118. See, e.g., Cerninara, *supra* note 49, at 108–09 (describing barriers inherent in the Medicaid and Medicare coverage of hospice services).

119. See *id.* at 125 (explaining that some patients resist hospice because they are not ready to confront death or because they fear that entering hospice will reduce their quality of care).

120. 42 C.F.R. § 418.24 (2010).

121. 42 U.S.C.A. § 1395d (d), (e) (Supp. 2011). See also David J. Casarett, *Rethinking Hospice Eligibility Criteria*, 305 JAMA 1031, 1031 (2011) (describing the Act's requirement of a three-year demonstration project allowing concurrent care). If these initiatives are successful, it seems likely that care that is typically labeled and reimbursed as "hospice" will expand to include home delivery of palliative care to patients who still wish to continue with active therapy to combat their disease. *Id.* at 1032 ("Life-prolonging treatment could increase survival relative to typical hospice care, and the addition of palliative care to life-sustaining treatment may improve survival compared with usual care.").

122. See Casarett, *supra* note 121, at 1032 (adding that it is possible that decreased acute care utilization and the cost savings of palliative home health programs might make budget neutrality achievable).

factors such as timing of hospice access, rates of departure from hospice to seek therapeutic care, the possible reduction of racial disparities in hospice use and the overall impact on quality of care.¹²³

Developing Additional Legal Support Mandates. Apart from the removal of these legal barriers, there is little that the law can do to change differential patterns of hospice and end-of-life care utilization, except to exhort physicians to avoid bias and to take culture into account in discussing patient preferences at the end of life.¹²⁴ Continuity of care regulations for the transition from hospital to hospice provide guidance about coverage but do little to promote the utilization of hospice.¹²⁵ Specific legal mandates have only limited impact on individual physician-patient relationships.¹²⁶ For example, in 2000, the Department of Health and Human Services' Office of Minority Health promulgated a variety of standards applicable to institutions for culturally appropriate health care delivery.¹²⁷ The mandated standards focus primarily on institutional obligations to provide language assistance and interpreter services and related requirements.¹²⁸ Although laudable,

123. *See id.* at 1032 (noting that measures of access, quality, and survival should be considered in a comprehensive evaluation); *see also* Cerminara, *supra* note 49, at 138–48 (advocating the abandonment of the false dichotomy between therapeutic and palliative care, and explaining why concurrent care and increased hospice utilization will benefit patients, providers, families, and the health care system).

124. *See* Noah, *supra* note 10, at 156–77 (reviewing legal strategies to combat racial discrimination in health care delivery and concluding that existing legal remedies provide only limited recourse to victims of discrimination in health care delivery and that non-legal avenues including education and research provide the best option for addressing racial inequalities in health care, whatever their source).

125. *See generally* 42 C.F.R. § 418 (2010) (including regulations concerning hospice care for Medicare beneficiaries). *See also id.* § 418.110 (stating that participating hospices must provide 24-hour services to *all* patients); *id.* § 418.52 (requiring informed consent from the patient or patient's representative about the type of care and services that may be provided as part of hospice).

126. *See* DEP'T HEALTH & HUMAN SERVS., OFFICE OF MINORITY HEALTH, NATIONAL STANDARDS FOR CULTURALLY AND LINGUISTICALLY APPROPRIATE SERVICES IN HEALTH CARE xiii–xiv (2001) (describing concerns that the CLAS standards will not address all of the problems related to cultural competence). *But see* *The Compelling Need for Cultural and Linguistic Competence*, NAT'L CTR. FOR CULTURAL COMPETENCE, <http://nccc.georgetown.edu/foundations/need.html> (last visited May 20, 2012) (noting that State and Federal agencies rely on organizations such as the National Committee for Quality Assurance to ensure that legal mandates are complied with and that managed care organizations and behavioral health managed care organizations “support standards that require cultural and linguistic competence in health care”).

127. *See National Standards on Culturally and Linguistically Appropriate Services (CLAS)*, U.S. DEPT. HEALTH & HUMAN SERVS., <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15> (last visited May 20, 2012) (setting out 14 standards for culturally appropriate health care for institutions and explaining that compliance with four specific standards (numbers 4-7) is a condition of federal funding for recipient institutions).

128. *See id.* (outlining several standards for health care providers to comply with). The four mandated standards state that:

Standard 4 Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation; Standard 5 Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their

none of these mandates address issues of individual cultural competence or communication skills, nor do any of the mandates or suggested steps provide avenues to address racial bias in individual health care providers. Formal legal efforts to encourage cultural competence can only have a limited effect, because they depend on the understanding and cooperation of individual health care providers who work within institutions¹²⁹ and because most of these standards permit paper compliance at the institutional level with limited accountability or training of individuals who practice within the institution's walls.¹³⁰

Improving Physician-Patient Communication. In the health care context, commentators refer to inter-cultural communication skills as "cultural competence"¹³¹ although the term contemplates much more than simply achieving a practical understanding of, for example, "Black culture" or "Hispanic culture" or "Muslim religion."¹³² In fact, although some unifying cultural or religious

right to receive language assistance services; Standard 6 Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer); Standard 7 Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.

Id.

129. See Joseph R. Betancourt, *Cultural Competence—Marginal or Mainstream Movement?*, 351 NEW ENG. J. MED. 953, 954 (2004) (framing cultural competence not as a concept that will eliminate all disparities but as a "set of skills for physicians who *wish* to deliver high-quality care to all patients") (emphasis added).

130. See *National Standards on Culturally and Linguistically Appropriate Services*, *supra* note 127 (stating that its standards were "primarily *directed* at health care organizations" and that individual providers were "encouraged to use that standards to make their practices more culturally and linguistically accessible") (emphasis added).

131. See Lisa C. Ikemoto, *Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS U. L.J. 75, 97–98, 100–01 (2003) (arguing that the goals and effects of cultural competency training are to counter "racially and ethnically exclusive health care" by identifying racism as a problem in health care and addressing its effects at both the institutional level and by individual providers and suggesting that such training, by creating self-awareness about individual and institutional values, can improve the quality of health care for minority patients); see also Chen et al., *supra* note 70, at 140–42 (finding that African American and Latino patients who perceived racism in the health care system were more likely to prefer a physician of their own race and were more likely to express satisfaction about care received from a racially-concordant physician).

132. See Betancourt, *supra* note 129, at 953 (criticizing efforts to teach "dos and don'ts for caring for 'the Hispanic patient'" and arguing that although learning about particular cultures can be helpful, "but when broadly applied, this approach can lead to stereotyping and oversimplification of culture"); cf. Michael Selmi, *The Facts of Affirmative Action Reviewing The Shape of the River: Long-Term Consequences of Considering Race in College and University Admissions*, 85 VA. L. REV. 697, 729–30 (1999) (discussing the "contentious" argument about whether African Americans share a particular viewpoint which contributes to diversity in institutions of higher education). Selmi explains that Bowen and Bok's data instead supports the conclusion that a diverse student body benefits all students on campus by increasing the likelihood that student will become community leaders rather than simply justifying diversity by treating "black students as objects for the school's own purposes" or expecting

principles may predominate across a particular race or religion, the key to true cultural competence lies in the ability to communicate with patients as individuals, while being attentive to the potential impact of cultural issues. In a truly functional doctor-patient relationship, the physician is able to address end-of-life issues with the patient through a respectful understanding of each patient's individual beliefs, preferences, and concerns.¹³³ Overall, improving doctor-patient communication will help patients of all races to trust their physicians and to encourage discussion of options for the end of life.¹³⁴

Utilizing Patient Advocates. Several elements of communication require specific attention in order to promote meaningful discussion about end-of-life options between minority patients and their physicians. First, because patients with terminal illness may be struggling with depression, denial, pain or discomfort, and related feelings that distract them from fully focused discussions about end-of-life care,¹³⁵ selecting an available, willing advocate to help navigate the bureaucracy of the health care system is helpful.¹³⁶ When available, such an advocate (typically a spouse, adult child or other responsible family member or friend) can also serve as a second pair of ears, helping the patient to understand medical information as it is presented.¹³⁷

Developing Physician-Patient Trust. The medical literature addressing end-of-life communication also recommends that physicians focus on several communication goals, including assessing the patient's understanding that the illness is terminal,¹³⁸ ascertaining the patient's treatment preferences, and helping

black students "to give the black perspective on affirmative action or to instruct white students on black culture". *Id.*

133. See Kagawa-Singer & Blackhall, *supra* note 62, at 2994 ("[C]ulture is not an independent, homogeneous, dichotomous variable."); cf. Betancourt, *supra* note 129, at 953 (describing the evolution of cultural competence as initially assuming things about patients solely based on their background, and evolving to focus on the values of patient-centered care).

134. See Barbara A. Noah, *A Prescription for Racial Equality in Medicine*, 40 CONN. L. REV. 675, 714-18 (2008) (explaining that one way trust can be built between doctor and patient by training doctors to better understand and empathize with issues of racism and racial disparities that currently affect potential patients); James A. Tulsky, *Beyond Advance Directives: Importance of Communication Skills at the End of Life*, 294 JAMA 359, 362-64 (2005) (emphasizing that advance directives alone cannot adequately address specific goals and treatment decisions for dying patients, suggesting that physicians focus on the emotional needs of the patient and family by acknowledging the difficulty of making decisions and providing specific examples of good communication techniques).

135. See Tulsky, *supra* note 134, at 362 (explaining that when most people receive bad news related to terminal illness, they are so shocked that they have difficulty understanding the details of the treatment plan for their illness).

136. See Grudzen & Grady, *supra* note 22, at 1202.

137. See John Hardwig, *What About the Family*, HASTINGS CENTER REP., Mar.-Apr. 1990, at 5, 9 (explaining that family members can have a very large stake in medical decision making and that they can intervene and help a patient understand and make the right decision).

138. See Tulsky, *supra* note 134, at 360 (stating that setting clear goals and coming to informed and explicit decisions on plan of treatment directly impacts the patient's quality of life in the final stage end of life).

the patient to take steps to complete advance care planning.¹³⁹ Particularly in doctor-patient relationships in which there may be concerns about trust, the physician must take the time to convey a continued desire to care for the patient while at the same time disclosing the lack of additional therapeutic options.¹⁴⁰ With these goals in mind, commentators have recommended that physicians address the trust issue directly by asking the patient whether it is difficult to trust a physician who is not of the same race or cultural background.¹⁴¹ Knowing details of the patient's life and history may also help the physician to learn more about him- or herself in the sense of identifying and understanding potentially false assumptions about the patient.¹⁴²

Developing Physician-Patient Cultural Insight. With regard to situations in which cultural misunderstandings or tone-deafness may be affecting physician-patient communication, commentators have suggested specific types of information that physicians should seek out.¹⁴³ For example, inquiries into the general beliefs and approaches to disclosure of prognosis for people of the patient's race, and into the patient's religious beliefs or concerns about the medical system in particular,¹⁴⁴ can help physicians to assess the impact of culture on the patient's preferences. Similarly, inquiries into the cultural group's typical decision-making style and the particular patient's approach can be helpful in understanding the patient's willingness and comfort level to participate in decisions about end-of-life care.¹⁴⁵

139. *See id.* (explaining that confusion about the goals of care or the treatment preferences of a patient and her family can lead to an "inability to make certain [medical] decisions" that can lead to unnecessary suffering for the patient).

140. *See* Pantilat, *supra* note 89, at 1279–80 (suggesting, for example, that physicians replace the phrase "[t]here is nothing more to do" to cure the illness with "I wish there were something we could do to cure your illness. . . . Let's focus on what we *can* do to help you"); *see also* Tulsky, *supra* note 134, at 364, box 3 (suggesting language for communicating with hope when cure is no longer possible).

141. *See* Kagawa-Singer & Blackhall, *supra* note 62, at 2995 tbl.1 (adding that physicians should generally honor patients' treat decisions but utilize respectful negotiation techniques when requests for aggressive care would prove to be "medically futile").

142. *See id.* at 2993–96 (providing excerpts from an interview with an African American patient dying of lung cancer who provides insight into how to improve the physician-patient relationship when the two are from different cultural backgrounds, including the suggestion that when patients share details of their lives, it helps the physician to know more not only about the patient but about the physician himself).

143. *See, e.g.,* Mack et al., *supra* note 15, at 1533 (stating that black patients have less knowledge about end-of-life directives and are less likely to speak with their doctors about these directives). Because of this lack of understanding, physicians should be more deliberate in providing such information to black patients. *Id.* at 1533–34.

144. *See* Kawaga-Singer & Blackhall, *supra* note 62, at 2999 tbl.2 (displaying information about the level of cultural influence on patients and what physicians can do to accommodate those beliefs).

145. *See id.* (noting the importance of ascertaining whether the patient is comfortable with making decisions individually or prefers a family-centered approach).

Some research suggests that effective communication of this sort has a positive impact on the quality of end-of-life care, especially on hospice utilization.¹⁴⁶

Training More Minority Physicians. As a general matter, minority physicians are more likely than their white counterparts to provide care to patients of different races.¹⁴⁷ Unfortunately, certain minority groups, including African Americans and Hispanics remain significantly underrepresented in medical schools.¹⁴⁸ More specifically, with respect to African American and other racial and ethnic minority patients, research suggests that race concordance between physician and patient provides benefits to patients, including improved communication and trust.¹⁴⁹ It is

146. See, e.g., Mack et al., *supra* note 15, at 1538 (discussing how communication can lead to better end-of-life care, and noting that more African American patients utilized hospice care when they had better communication with their physician).

147. For example, one study found that African American physicians practice in areas where the percentage of African American residents was nearly five times higher than in areas where white physicians practice. See Miriam Komaromy et al., *The Role of Black and Hispanic Physicians in Providing Health Care for Underserved Populations*, 334 NEW ENG. J. MED. 1305, 1307–09 (1996) (noting that similar to African American physicians, Hispanic physicians also tend to locate their practice in areas with twice the percentage of Hispanic residents than other physicians' practices); see also Joel C. Cantor et al., *Physician Service to the Underserved: Implications for Affirmative Action in Medical Education*, 33 INQUIRY 167, 174–76 (1996) (discussing research that found that minority patients receive the highest level of service from physicians of the same race or ethnicity). More recent research confirms this trend. See, e.g., Howard K. Rabinowitz et al., *The Impact of Multiple Predictors on Generalist Physicians' Care of Underserved Populations*, 90 AM. J. PUBLIC HEALTH 1225, 1225 (2000) (noting studies that found that minority physicians are twice as likely to practice in underserved areas with more minority patients). Another study found that minority patients are four times more likely than white patients to obtain treatment from minority physicians. See Ernest Moy & Barbara A. Bartman, *Physician Race and Care of Minority and Medically Indigent Patients*, 273 JAMA 1515, 1517 (1995). Put another way, over a third of minority patients received care from nonwhite physicians, compared with just 11 percent of white patients. *Id.* Another study found that 22 percent of physicians provided about 80 percent of primary care to African American patients. See Bach et al., *supra* note 11, at 579 (surveying over 150,000 primary care visits by African American and white Medicare beneficiaries to 4355 primary physicians). Bach et al. found that "visits by black patients were markedly more likely than visits by white patients to be to black physicians" and that physicians who treated African American patients "provided more charity care, derived a higher percentage of their practice revenue from Medicaid, more often practiced in low-income neighborhoods, and were less likely to have obtained board certification in their primary specialty . . . than physicians treating white patients." *Id.*

148. See Komaromy et al., *supra* note 147, at 1309; Noah, *supra* note 138, at 698–700 (describing statistical findings that show the underrepresentation of African Americans and Hispanics in the medical field).

149. See Noah, *supra* note 134, at 709 (discussing how minority patients are more comfortable with minority physicians). Although the data described previously primarily support the argument that patients prefer to receive care from physicians of the same race and that cultural competence improves quality of care, Bach's data raises a separate and unsettling possibility—that lower rates of board certification among African American physicians and differences in quality of clinical training between African American and white physicians may separately contribute to inferior quality of care for African American patients. See Bach et al., *supra* note 11, at 582–83. This supposition, if correct, suggests that medical schools must not only make an effort to train more URM physicians, but also ensure that these physicians successfully obtain residencies that position them to provide high-quality care for the population where their practices are located and that emphasize the importance of pursuing board certification.

important, however, to consider the benefits of race concordance within the broader context of efforts to improve physician-patient communication for all parties involved, including physicians, regardless of race.

To this end, the medical education system, with cooperation from relevant regulatory bodies, should continue its efforts to train more under-represented minority physicians. Diversity in medical education promotes two separate but related goals. First, admitting students of diverse backgrounds opens up the field of medicine to members of diverse racial groups, and these physicians more often choose to work in medically underserved areas.¹⁵⁰ Thus, diversity in medical education can increase access to care for underserved communities and provide more patients of diverse races with the opportunity to receive care from a physician with whom they are more likely to communicate effectively and whom they trust. Second, diversity in medical education breaks down racial, cultural, and religious stereotypes by exposing all members of the medical school class to the different perspectives and experiences of their classmates.¹⁵¹ This experience of educational immersion, together with explicit training in cultural competence,¹⁵² can improve the quality of communication between physicians and patients and, ultimately, the quality of medical care.¹⁵³

150. See Noah, *supra* note 134, at 707–08 (describing and discussing data on patterns of physician practice in underserved areas).

151. See *id.* at 703–11 (describing how the medical education experience is enriched by a diverse class of students). As I have suggested previously:

Because so much of medical professionalism centers around the physician's ability to communicate with the patient and because so many physicians provide care for patients whose backgrounds differ from their own, the informal learning that occurs in the interstices of the formal medical curriculum can only be enriched by the interaction of students with diverse backgrounds and experiences.

Id. at 705; see also Ikemoto, *supra* note 134, at 100–01 (arguing that the goals and effects of cultural competency training are to “counter[] racially and ethnically exclusive health care” by identifying racism as a problem in health care). Ikemoto suggests addressing its effects at both the institutional level and at the individual provider level. *Id.* Such training can improve the quality of health care for minority patients by creating self-awareness about individual and institutional values. *Id.*

152. KAISER FAMILY FOUND., COMPENDIUM OF CULTURAL COMPETENCE INITIATIVES IN HEALTH CARE 6 (2003) (defining cultural competence as “a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations”); see also *id.* at 14 (providing a list of various public and private sector initiatives to promote cultural competence in health care). The Association of American Medical Colleges' accreditation standards require that both medical school faculty and students have an understanding of diverse cultures and beliefs that may affect health care and those students become aware of their own cultural biases. See LIAISON COMM. ON MED. EDUC., FUNCTIONS AND STRUCTURE IF A MEDICAL SCHOOL: STANDARDS FOR ACCREDITATION OF MEDICAL EDUCATION PROGRAMS LEADING TO THE M.D. DEGREE ACCREDITATION STANDARDS 10 (2011).

153. See Ikemoto, *supra* note 131, at 100–01 (discussing that better communication and training can improve the quality of medical care for minority patients).

The debate about the constitutionality of affirmative action in higher education admissions is now back in the Supreme Court.¹⁵⁴ After the Fifth Circuit Court of Appeals voted against rehearing a challenge to the University of Texas at Austin's use of racial preferences in admissions decisions,¹⁵⁵ the Supreme Court granted certiorari in the case. The new justices who have joined the court since the last major case in this area was decided may opt to make important changes to affirmative action law.¹⁵⁶ Meanwhile, medical schools should continue to recruit minority applicants and to work with high schools and colleges to provide support for potential applicants as they consider careers in medicine.¹⁵⁷ Encouraging minority race students to enter the health care professions in greater numbers will help to create a culture of trust between the health care system and its minority patients, with the ultimate goal to train all physicians to communicate well with their patients.

While it may be true that minority patients trust and communicate more effectively with minority physicians, an ideal of racial concordance between physician and patient is short-sighted.¹⁵⁸ The long-term goal is to teach and support communication skills at the end of life that will foster understanding and trust between physician and patient, regardless of the race of either. In this sense, the diversification of the physician workforce represents a step along a path to improved end-of-life care, but quality care ultimately should not depend on the race of either patient or physician.

Living the Golden Rule. Finally, the consistent implementation of the Golden Rule would go a long way to ameliorating some of the underlying biases, presumptions, and stereotypes that perpetuate health disparities. The Golden Rule,

154. See *Fisher v. Univ. of Tex. at Austin*, 631 F.3d 213 (5th Cir. 2011), cert. granted, 80 U.S.L.W. 3475 (U.S. Feb. 21, 2012) (No. 11-345) (granting the certiorari petition for reconsidering the use affirmative action in college admissions).

155. *Fisher v. Univ. of Tex. at Austin*, 644 F.3d 301, 303 (5th Cir. 2011) (per curiam).

156. See Richard Kahlenberg, *Is Affirmative Action Headed Back to the Supreme Court?*, CHRON. HIGHER ED., (June 21, 2011, 5:07 PM), <http://chronicle.com/blogs/innovations/is-affirmative-action-headed-back-to-the-supreme-court/29699>. The most recent affirmative action decision to uphold race-conscious admissions policies in higher education admissions, *Grutter v. Bollinger*, affirmed classroom diversity to be a compelling governmental interest justifying the consideration of race and ethnicity at the University of Michigan's law school. 539 U.S. 306 (2003).

157. See Noah, *supra* note 10, at 171–72 (making the case for continued affirmative action in medical school admissions, at least for as long as the underlying causes and effects of societal discrimination render it necessary).

158. In fact, some commentators dispute the notion that physician-patient racial concordance promotes communication or improved quality of care at all. See SALLY SATEL, PC, M.D.: HOW POLITICAL CORRECTNESS IS CORRUPTING MEDICINE 175–76 (2000) (describing studies that suggest physician-patient racial match was less important than factors such as reputation, convenient location, and good communication style); see also *id.* at 182–83 (“[I]n this era of managed care’s fifteen-minute doctor visit, what much of the research [on the effect of cultural differences on the doctor/patient relationship] tells us is that most patients attach more value to the amount of time they can spend with their doctor than to the doctor’s race or ethnicity.”).

in its secular or religious form, simply states that one should treat others as one would wish to be treated.¹⁵⁹ In the health care context, this rule does *not* mean that physicians should provide treatments to patients that they themselves would want, except to the extent that these treatments are consistent with the patients' preferences. What it does mean is that physicians should accord patients of all races the same measure of respect, care, and communication that they themselves would wish if the roles were reversed. Such care requires self-reflection. Physicians should carefully examine their own attitudes and behaviors in order to detect their own internal biases and move beyond them to understanding the individual needs of their patients.¹⁶⁰

Some may find this final recommendation rather naive. Of course, many people will continue to act in ways that further their self-interest over the interests of others in contexts where such behavior is wrong. Other people will, consciously or unconsciously, persist in believing that the color of their skin makes them somehow superior to those of other races. But, to the extent that much of the problem of health disparities flows from a lack of understanding of others who are different and hold different beliefs, and a lack of training to promote that understanding (and thus promote the genuine communication that depends on understanding), health care providers have the opportunity as individuals to ameliorate the problem of disparities in the provision of health care. It will take effort—a willingness on the part of individuals to change and to endure the disruption that comes with change, and a willingness on the part of each one of us,

159. See JEFFREY WATTLES, *THE GOLDEN RULE 5* (Oxford Univ. Press, 1996) (suggesting that “[t]here is enough continuity of meaning in its varied uses to justify speaking of *the Golden Rule*” and that “the rule’s unity is best comprehended not in terms of a single meaning but as a symbol of a process of growth on emotional, intellectual, and spiritual levels”); see also Matthew 7:12 (King James Version) (“Therefore all things whatsoever ye would that men should do to you, do ye even so to them.”); cf. Allan S. Detsky & Mark O. Baerlocher, *Do Nice Patients Receive Better Care?*, 306 *JAMA* 94, 94-95 (2011) (discussing variation in physician responses to patients based on patients’ abilities to communicate, adhere to treatment plans, make decisions, and express appreciation).

160. See H. Jack Geiger, Editorial, *Race and Health Care: An American Dilemma?*, 335 *NEW ENG. J. MED.* 815, 816 (1996). Dr. Geiger suggests that physicians confront the following questions:

What choices are black patients and white patients actually offered by their physicians? What do they hear? Do their physicians make specific recommendations? Do the patients participate fully in the decision-making process? What criteria do physicians use in making these clinical judgments? Are they applied equitably, or are they subtly influenced by racial stereotyping on the part of time-pressured physicians, reinforced both by institutional attitudes and by unwarranted assumptions about prevalences and outcomes?

Id.; see also Elysa Gordon, *Multiculturalism in Medical Decisionmaking: The Notion of Informed Waiver*, 23 *FORDHAM URB. L.J.* 1321, 1355 (1996) (suggesting practice guidelines and incentives that “encourage physicians to approach patients about their cultural values”); Michelle van Ryn & Somnath Saha, *Exploring Unconscious Bias in Disparities Research and Medical Education*, 306 *JAMA* 995, 995 (2011) (explaining that “the paradox of well-intentioned physicians providing inequitable care” may arise from conflicts between physicians’ conscious and explicit beliefs and attitudes and the rapid and automatic judgment applied unconsciously during patient encounters).

health care providers or not, to look carefully at our attitudes and behaviors in order to address the deficiencies that we find in ourselves.