LA CAJA DE PANDORA:[1] IMPROVING ACCESS TO HOSPICE CARE AMONG HISPANIC AND AFRICAN-AMERICAN PATIENTS

by Alina M. Perez* and Kathy L. Cerminara**

It has been said that end-of-life medical treatment options represent the ultimate Pandora's Box.[2] This metaphor depicts the process most patients face upon learning they are facing terminal illnesses. Many patients, when first learning about their diagnoses and prognoses, will seek more information about the illness and try every available treatment hoping for a cure ("expecting riches"),[3] until finally realizing and accepting the inevitability of their fates (finally

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[1] *Caja* is the Spanish word for "box." MERRIAM-WEBSTER'S SPANISH-ENGLISH DICTIONARY, *available at* http://www.merriam-webster.com/spanish/caja. *See* text accompanying footnotes 2–4 (likening consideration of end-of-life medical treatment options to the process Pandora experienced when considering opening the box the gods had sent to Earth with her).

* Assistant Professor, Nova Southeastern University College of Osteopathic Medicine, Public Health Program. Professor Perez wishes to thank Mario Perez for support throughout her scholarly endeavors.

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[2] *See* Kathy Cerminara, *Pandora's Dismay: Eliminating Coverage-Related Barriers to Hospice Care*, 11 FLA. COASTAL L. REV. 107.

[3] *Id.*

"appreciating the misfortune in the box").[4] During this process, the patient engages in decision-making regarding what treatment to seek, what services to enlist, and what resources to consult in order to cope with such an emotionally devastating threat.

Many patients clinging to hope in the form of potentially curative treatment could benefit from hospice services,[5] but, for the most part, it is not until the patient accepts the finality of his or her condition that the physical, psychological, and social benefits of hospice care[6] become accessible to the patient and his or her family. Under current Medicare regulations and other healthcare payers' policies, patients must abandon the hope of curative treatment before opting for hospice services.[7] As a result, many terminally ill patients access the services late, sometimes a few hours before death.[8]

Scholars have proposed that such a barrier to access, present in Medicare, Medicaid, and other health insurers' coverage rules,[9] may

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[4] *Id.*

[5] Hospice is a philosophy of care that focuses on alleviating pain and other symptoms of patients that are terminally ill. Among other services, hospice teams provide nursing care, social work, and counseling services to patients, their families and any other persons caring for the patients; medications, certain therapies to enhance patient's daily functional skills, medical supplies, short in-patient and respite care, and bereavement services. *See* MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO THE CONGRESS: REFORMING THE DELIVERY SYSTEM 207 (2008) [hereinafter MEDPAC REPORT].

[6] Hospice care emphasizes the psychological well-being of patients in addition to alleviating their physical discomfort and pain. This emphasis on psychological well-being extends to the patients' families and others involved in the patients' care. Through chaplains and social workers, hospice provides both emotional and spiritual support before death and bereavement services to family members for up to a year after a patient's death. NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION, WHAT IS HOSPICE AND PALLIATIVE CARE?, http://www.nhpco.org/i4a/pages/index.cfm?pageid=4648 (last visited Dec. 18, 2009). *See also* Cerminara, *supra* note 2 (discussing benefits of hospice care).

[7] *See generally* Cerminara, *supra* note 2 (discussing barriers posed by current Medicare regulations regarding access to hospice by patients that are not ready to give up curative treatment who could benefit from hospice or palliative care); Randall Krakauer et al., *Opportunities to Improve the Quality of Care for Advanced Illness*, 28 HEALTH AFFAIRS 1357, 1357 (2009).

[8] Krakauer et al., *supra* note 7; *see also* Cerminara, *supra* note 2; David Casarett & Janet L. Abrahm, *Patients with Cancer Referred to Hospice Versus a Bridge Program: Patient Characteristics, Needs for Care, and Survival*, 19 J. CLINICAL ONCOLOGY 2057, 2057 (2001).

[9] Haiden A. Huskamp et al., *Providing Care at the End of Life: Do Medicare Rules Impede Good Care?*, 20 HEALTH AFFAIRS 204, 209 (2001) (reporting that "in six markets studied, coverage of an eligibility for end-of-life services were similar in most commercial health plans and

be responsible for lower utilization of hospice services[10] and late access to hospice services.[11] This problem becomes even more significant, and barriers in addition to coverage rules become apparent, when considering the healthcare needs of racial and ethnic minorities in the United States.[12] Not only do patients in racial and ethnic minority groups access hospice late, like the general population, but they also access it in far fewer numbers.[13] The statistics are especially stark among African-American and Hispanic patients.[14]

Specifically, although studies show that some ethnic and racial minorities suffer disproportionately from certain cancers and serious chronic illnesses,[15] the percentage of minorities that utilize hospice

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[fee-for-service] Medicare."). *But see* Beth Jackson et al., Medstat Group, Hospice Benefits and Utilization in the Large Employer Market 3 (March 2000) (reporting that a minority of private plans follow the Medicare model on hospice benefits).

[10] *See* Alexi A. Wright & Ingrid T. Katz, *Letting Go of the Rope-Aggressive Treatment, Hospice Care, and Open Access*, 357 New. Engl. J. Med. 324, 325 (2007); Timothy E. Quill, *Initiating End of Life Discussion with Seriously Ill Patients: Addressing the "Elephant in the Room"*, 284 JAMA 2502, 2503 (2000).

[11] *See* Cerminara, *supra* note 2; Joan M. Teno et al., *Timing of Referral to Hospice and Quality of Care: Length of Stay and Bereaved Family Members' Perceptions of the Timing of Hospice Referral*, 34 J. Pain & Symptom Mgmt. 120 (2007); Quill, *supra* note 10, at 2503.

[12] Office of Management and Budget, Guidance on Allocation of Data on Race for Use in Civil Rights Monitoring and Enforcement (2002), http://www.whitehouse.gov/omb/bulletins_b00-02.

[13] 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. Geriatric Soc'y 970, 970 (2003) (discussing that minority populations are by no means insignificant in terms of proportion of citizenry or impact on the healthcare system). According to the year 2008 Census Bureau report, 66% of the population in the United States is White, 14% Black, 15% Hispanic, 5.1% Asian, and 1.6% American Indian and Alaskan Natives. Robert Bernstein & Tom Edwards, Public Information Office, *An Older and More Diverse Nation by Midcentury*, U.S Census Bureau News, Aug. 14, 2008, *available at* http://www.census.gov/Press-Release/www/releases/archives/population/012496.html. The growth of some minority groups will be more significant than others, but by 2050, the African-American population is expected to grow from 41 million to 66 million while the population of Hispanics is expected to nearly triple from 47 to 133 million. *See id.*; Sam Roberts, *In a Generation, Minorities May Be the U.S. Majority*, N.Y. Times, Aug. 13, 2008. http://www.nytimes.com/2008/08/14/washington/14census.html.

[14] Nat'l Hospice & Palliative Care Org., NHPCO Facts and Figures: Hospice Care in America 7, tbl.5 (2008) [hereinafter Facts & Figures].

[15] African-Americans have a high cancer mortality rate and higher prevalence of the AIDS virus. Office of Minority Health, U.S. Dept. of Health & Human Serv., Cancer Da-

and palliative services is also disproportionately low. When compared by race, in 2007, only 9 percent of patients accessing hospice were African-Americans;[16] 1.6 percent of such patients were Asians, Hawaiian or other Pacific Islanders; and 0.3 percent of such patients were American Indian or Alaskan natives.[17] When ethnicity was considered, only 5.1 percent of patients accessing hospice were of Hispanic or Latino origin, as compared to 94 percent of non-Hispanics.[18] While no study has identified a single predictor for such behavior, some studies have established significant relationships between minorities' use of hospice and execution of advance directives and certain cultural manifestations,[19] systemic institutional discrimination,[20] and structural barriers.[21] Other studies have identified current poli-

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ta/Statistics, http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=3&lvlid=20 (last visited July 13, 2010); Office of Minority Health, U.S. Dept. of Health & Human Serv., HIV/AIDS Data/Statistics, http://minorityhealth.hhs.gov/templates/browse.aspx? lvl=3&lvlid=70 (last visited July 13, 2010). African Americans are twice as like to have diabetes as whites. Similarly Hispanics, especially, Mexican Americans are most likely to be diagnosed with diabetes than their white counterparts. Both, African Americans and Hispanics are more likely to have diabetes complications, such as end stage renal disease and amputations, than whites. *See* Office of Minority Health, U.S. Dept. of Health & Human Serv., Diabetes Data/Statistics, http://minorityhealth.hhs.gov/templates/browse.aspx?lvl= 3&lvlid=62 (last visited July 13, 2010).

16 Not only are African-Americans underrepresented in hospice care, but they also are more likely to leave hospice care once they have elected it. *See* Kimberly Johnson et al, *Racial Differences in Hospice Revocation to Pursue Aggressive Care*, 168 ARCHIVES INTERNAL MED. 218, 218 (2008).

17 FACTS & FIGURES, *supra* note 14, at 7.

18 *Id.* Hispanics could be of any race or multi-racial. U.S Office of Management and Budget (OBM), Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, http://www.whitehouse.gov/omb/rewrite/fedreg/ombdir15.html. For a discussion of the implications of the methods of measuring race and ethnicity, see Vickie M. Mays, et al., *Classifications of Race and Ethnicity: Implications for Public Health,* 24 ANN. REV. PUB. HEALTH 83 (2003).

19 *See* Sean Morrison et al., *Barriers to Completion of Health Care Proxies*, 158 ARCHIVES INTERNAL MED. 2493, 2496 (1998) (discussing the influence of familism on beliefs among Hispanics that healthcare proxies are not necessary); Eric L. Krakauer et al., *Barriers to Optimum End-of-Life Care for Minority Patients*, 50 J. AMER. GERIATRICS SOC'Y. 182, 183–84 (2002) [hereinafter *Barriers*] (finding that cultural diversity strongly influences end-of-life decision-making processes).

20 "[S]ystemic and individual discrimination can drive care patterns and could cause the hospice care differences observed in this study." Greiner et al., *supra* note 13, at 977.

21 *See Barriers*, *supra* note 19, at 182–83.

cies characteristic of the United States health system that serve as barriers to timely hospice access (or any hospice access) by minorities.[22]

This Article explores these powerful statistics, seeking to shed light on the end-of-life decision-making process for Hispanics and African-Americans, with an eye toward identifying barriers to access and utilization of hospice services among those populations. Part I will discuss the influence of culture on healthcare decision-making, first generally, then specifically examining end-of-life decision-making, and finally zeroing in on the end-of-life decision-making process for African-American and Hispanic populations. Part II will examine the influence of disparities in the healthcare system on healthcare decision-making, particularly end-of-life decision-making, and Part III will focus on inadequate healthcare policies, concluding by proposing ways to bridge the existing gap between Hispanic and African-American patients and hospice services.

Specifically, as other authors have suggested more generally,[23] eliminating the currently existing dichotomy between palliative and curative care at the time of accessing hospice services likely will help some African-American and Hispanic patients access such services more readily.[24] In addition, the hospice providers and the governmental entities that regulate them should revamp legal and institutional rules to avoid disparately impacting Hispanic and African-American patients, do all they can to encourage diversity in the medical professions, and emphasize education about cultural influences on end-of-life decision-making at the institutional and academic levels to improve the cultural proficiency of the healthcare workforce. It

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[22] Cerminara, *supra* note 2*; see also* LAVERA CRAWLEY & MARJORIE KAGAWA-SINGER, CALIFORNIA HEALTHCARE FOUNDATION, RACIAL, CULTURAL, AND ETHNIC FACTORS AFFECTING THE QUALITY OF END-OF-LIFE CARE IN CALIFORNIA 6 (March 2001), http://www.chcf.org/publications/2007/03/racial-cultural-and-ethnic-factors-affecting-the-quality-of-endoflife-care-in-california (discussing issues involving lack of culturally and linguistic services). *See* section III of this Article, which address some of those issues.

[23] *See* Cerminara, *supra* note 2*; see also* Casarett & Abrahm, *supra* note 8; Brad Stuart et al., *CHOICES: Promoting Early Access to End-of-life Care Through Home-Based Transition Management*, 6 J. PALLIATIVE MED. 671, 671–72 (2003); Richard D. Brumley et al., *Effectiveness of a Home-Based Palliative Care Program for End-of-Life*, 6 J. PALLIATIVE MED. 715, 715–16 (2003); Marie Bakitas et al., *Project ENABLE: A Palliative Care Demonstration Project for Advanced Cancer Patients in Three Settings*, 7 J. PALLIATIVE MED. 363, 364–65 (2004).

[24] *See* section III.A.I.a (discussing impact of one study on African-Americans).

is not for any one person, healthcare provider or regulator, to say how any individual should die, but both the law and healthcare providers should do all they can to ensure that all persons, to the extent possible, have meaningful access to services that could ease the dying process for them and their families.

I. THE POWER OF CULTURAL INFLUENCES

Cultural influences abound in healthcare decision-making, especially end-of-life decision-making. While even members of majority racial and ethnic groups reflect their background and experiences in their attitudes toward medical decision-making, this article will focus on the cultural experiences of two groups in particular whose background and experiences have been marginalized in the formation of end-of-life decision-making law and ethics. Specifically, after discussing the influence of culture on medical decision-making in general, this section will examine certain features of Hispanic and African-American cultures that, broadly speaking, render the decision-making processes of patients from those backgrounds different from the decision-making processes of most Caucasian patients.

A. The Influence of Culture on Healthcare Decision-Making in General

Everyone, as a member of one or more racial, ethnic or religious groups, operates within the context of cultural influences, thus raising the issue of what "culture" means. Anthropologists and social scientists have defined the concept of "culture" in many different ways.[25] While some define culture based mainly on the complex set of ideas, values and concepts that some groups share,[26] others include a more intricate set of components in the definition. In 1871, famous anthropologist Edward B. Tylor defined culture as "that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a

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[25] CECIL G. HELMAN, CULTURE, HEALTH AND ILLNESS 2 (5th ed. 2007).

[26] *Id.*

member of society."[27] Some of the manifestations of any person's culture (such as traditional dress, social rituals, and language) are readily observable;[28] others, however, are not so evident and present themselves in the form of beliefs and assumptions common to a particular group.[29] The deepest manifestation of culture is embedded in the unspoken behavior of the group.[30] It is composed of rules that are "implicit, taken for granted, almost impossible for the average person to state as a system, and generally out of awareness."[31]

Considering these definitions, it is easy to understand that cultural influences likely play a prominent role in the development and expressions of beliefs, attitudes, opinions, and behaviors of all people with respect to all aspects of their everyday lives. In the context of healthcare, researchers have found that culture influences how people perceive the symptoms of illness,[32] how they explain the causes of their diseases,[33] and patients' attitudes toward treatment and the use of medications and technology.[34] Studies also show that culture influences patients' perceptions of the role of healthcare professionals[35] and styles of communication between physicians and their patients,[36] as well as the values underlying their relationship and its outcomes.[37] For example, in certain cultures, it is a sign of disrespect to question a doctor regarding treatment options.[38] In such a culture, doctors are

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[27] *Id.*

[28] *Id.* (defining "tertiary level culture").

[29] *Id.* (defining "secondary level culture").

[30] HELMAN, *supra note 25, at 2.* (defining "primary level culture").

[31] *Id.*

[32] *See* Lee Pachter, *Culture and Clinical Care: Folk Illness Beliefs and Behaviors and Their Implications for Health Care Delivery*, 271 JAMA 690, 690 (1994) (discussing non-concordant cultural beliefs regarding the origin and treatment of illnesses between patients and their physicians).

[33] *See id. See generally* HELMAN, *supra* note 25, at 121–155 (discussing physician-patient interactions).

[34] *See* Pachter, *supra* note 32, at 690.

[35] *See id.* at 691. *See generally* HELMAN, *supra* note 25, at 121–155.

[36] *See* HELMAN, *supra* note 25, at 121–155.

[37] *Id.*

[38] *See* H. Russell Searight & Jennifer Gafford, *Cultural Diversity at the End of Life: Issues and*

regarded as the experts, with authority that patients should not challenge; therefore, patients accept treatment without questioning its necessity or propriety, or learning its specifics.[39]

Most important, culture has a tremendous impact on how people conceptualize and deal with pain,[40] misfortune, and death.[41] While members of some cultures view pain as a result of others' malintentioned wishes (for example as a result of witchcraft and the evil eye),[42] others see pain as divine punishment for misbehaviors that the patient must stoically endure, rather than seek relief.[43] Additionally, some cultural groups may define pain as a normal part of life, thus influencing when and how their members seek relief for pain,[44] while still other cultures may include psychological and emotional dimensions in the concept of pain.[45] When pain sufferers perceive treatment as not addressing their beliefs, they may consider it to be incomplete and insufficient,[46] negatively impacting their treatment outcomes.

Cultural influences also significantly affect views of death, dying, and care at the end of life.[47] Variations among cultures are evident in

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Guidelines for Family Physicians, 71 AM. FAM. PHYSICIAN 515, 518–19 (2005) (finding some families and patients defer to doctor as an expert for end-of-life decisions).

[39] *See id.* Acceptance of treatment without questioning may also be related to a desire not to know details. Sometimes, for example a patient who suspects a serious diagnosis will refrain from asking questions because it is the duty of family members, not the patient himself or herself, to deal with the diagnosis. Anne Lapine et al., *When Cultures Clash: Physician, Patient, and Family Wishes in Truth Disclosure for Dying Patients*, 4 J. PALLIATIVE MED. 475, 476 (2001). *See also infra* text accompanying notes 154–56.

[40] *See generally* HELMAN, *supra* note 25, at 185–195.

[41] *See generally id.* at 224–244.

[42] *See generally id.* at 185–195; *see also* Linda Farber Post et al., *Pain, Ethics, Culture and Informed Consent to Relief,* 24 J. L., MED. & ETHICS 348 (1996).

[43] HELMAN, *supra* note 25, at 187.

[44] *Id.* at 192 (noting that women in some countries endure labor pains while women in the United States often do not, demanding analgesia to relieve them).

[45] *Id.* at 187 (citing emotional distress and interpersonal conflicts as examples).

[46] *Id.* (discussing that a patient who believes that a terminal illness is a punishment will perceive the use of analgesics alone as insufficient without a redemption act, and he or she may not even believe that pain medication will help in those circumstances).

[47] *See Barriers*, *supra* note 19, at 184.

the conceptualization of death,[48] the way groups deal with approaching death, and funeral and bereavement practices.[49] How people conceptualize and deal with pain, suffering, and death will determine how they deal with decision-making choices as they or their loved ones are facing the possibility of dying from a terminal illness. Understanding cultural manifestations in the context of end-of-life issues is particularly helpful for the practitioner trying to make sense of the seemingly "irrational behavior" of individuals and their families in the face of terminal illness. For example, a terminally ill individual may renounce all "heroic measures" at the end of life, but still request that he or she receive nutrition and hydration, at all costs and in whatever form. Such a situation, which is far from uncommon,[50] may illustrate culturally influenced, yet unspoken beliefs and values. Even aside from wishing to obey certain religious directives,[51] culture

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[48] *See* HELMAN, *supra* note 25, at 40. For example, definitions of death vary. In many Western countries, patients are legally dead when they display no brain activity, but members of other cultures define biological death as a cessation of other bodily functions such as the heart beat or respiration. In some cultures, death is a process that does not become final until the end of a series of rituals conducted by the family and the community. Such rituals may last for several years. *See id.* at 231–33.

[49] *Id.* at 232.

[50] Questions surrounding the withholding or withdrawal of medically supplied nutrition and hydration are especially difficult, as exemplified by the number of legal cases that have addressed the issue. The table listing all the legal cases arising as a result of end-of-life decision-making clashes in the leading treatise on the subject stretches for twenty-three and a half pages; of those cases, four and a half pages' worth involved questions of whether to withhold or withdraw medically supplied nutrition and hydration. Compare section 1.09 (general cases table) with section 6.03[G] (table of cases about medically supplied nutrition and hydration). ALAN MEISEL & KATHY L. CERMINARA, THE RIGHT TO DIE (3d ed. 2004 and annual supplements). For a discussion of some of the difficulties surrounding decisions to withhold or withdraw medically supplied nutrition [hereinafter Right to Die], see Kathy L. Cerminara, *The Schiavo Maelstrom's Potential Impact on the Law of End-of-Life Decision Making*, ETHICS, POLITICS, AND DEATH IN THE 21ST CENTURY: THE CASE OF TERRI SCHIAVO 78, 94–97 (Kenneth W. Goodman ed., Oxford Univ. Press 2009).

[51] The U.S. Conference of Catholic Bishops of the Roman Catholic Church recently strengthened the American Church's position with respect to the provision of medically supplied nutrition and hydration. While qualified in later language, the Conference's Ethical and Religious Directives for Catholic Healthcare Services now state, "In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the 'persistent vegetative state') who can reasonably be expected to live indefinitely if given such care." U.S. CONFERENCE OF

defines the role that food and nutrition plays within the group, carrying specific meanings and in many instances becoming part of the group's identity.[52]

Importantly, although culture may shape the beliefs and values of groups of individuals in general, the results are by no means homogeneous.[53] Within the same cultural or ethnic group, individuals will acquire and express cultural values differently, many times influenced by other social and psychological processes such as acculturation[54] and assimilation,[55] or simply by individual experiences.[56] Furthermore, cultural beliefs and behaviors are neither static nor unchangeable.[57] Factors such as immigration, intercultural marriages, globalization, and world unrest contribute to a "constant process of change and adaptation."[58] Immigrants, refugees, persons who have obtained asylum, and other migrant groups usually find themselves

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CATHOLIC BISHOPS, ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES 31 (2009), *available at* http://www.usccb.org/meetings/2009Fall/docs/ERDS-5th_ed_091118_FINAL.pdf. *See generally* U.S. CONFERENCE OF CATHOLIC BISHOPS, U.S. BISHOPS TO VOTE ON REVISION OF ETHICAL DIRECTIVE ON NUTRITION AND HYDRATION AT NOVEMBER MEETING (2009) *available at* http://www.usccb.org/comm/archives/2009/09-226.shtml. These directives do not govern Catholic patients, but rather "are concerned primarily with institutionally based Catholic healthcare services. They address the sponsors, trustees, administrators, chaplains, physicians, healthcare personnel, and patients or residents of these institutions and services," although individual Catholic healthcare practitioners also may take them into account, since "they express the Church's moral teaching." U.S. CONFERENCE OF CATHOLIC BISHOPS, ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES 4 (2001), *available at* http://www.usccb .org/bishops/directives.shtml. Catholic patients may, indeed, however, take the directives into account for that same reason – "they express the Church's moral teaching." *Id.*

52 HELMAN, *supra* note 25, at 59.

53 *See* Lucy M. Candib, *Truth Telling and Advance Planning at the End of Life: Problems with Autonomy in a Mulitcultural World*, 20 FAMILIES, SYS. & HEALTH 213, 218 (2002).

54 *Id.*; *see also* WEBSTER'S COLLEGIATE DICTIONARY 9 (11th ed. 2004) (defining acculturation as "cultural modification of an individual, group, or people by adapting to or borrowing traits from another culture").

55 WEBSTER'S COLLEGIATE DICTIONARY 74 (11th ed. 2004) (defining assimilate as "to absorb into the culture or mores of a population or group").

56 *See* Barbara J. Noggle, *Identifying and Meeting Needs of Ethnic Minority Patients*, 10 HOSPICE J. 85, 88 (1995) (emphasizing that "each individual and family with any ethnic group is indeed unique").

57 *See* HELMAN, *supra* note 25, at 3.

58 *Id.*

culturally coexisting not only with the different values, norms, languages, and the social structures of new countries or regions, but also with the "acculturated" generations within their own families.

The processes of acculturation and assimilation add one more dimension to the complex set of issues facing people at the end of their lives, sometimes contributing greatly to conflict and miscommunication between patients and physicians. In the case of Hispanics, for example, more acculturated members of the family, who may subscribe to the value of patient autonomy, may want to tell the truth to a patient regarding his or her terminal illness, contrary to the wishes of more traditional family members who still subscribe to the cultural practice of shielding the patients from bad news.[59] This clash, in turn, may engender conflicts with other members of the patient's support group and/or with the healthcare provider(s) attending the patient.

In addition, language and culture are inextricably related.[60] Language is the vehicle that transmits and maintains cultural ties through generations.[61] Members of a cultural group create and share experiences through language that have a special meaning within the culture; many view their language as the symbol of their social identity.[62] For this reason, Dr. Claire Kramsch has said that "language [including its verbal and non-verbal forms] embodies . . . [and] symbolizes cultural reality."[63] The effects of language on social relationships become particularly significant in the context of healthcare and end-of-life issues to the extent that a practitioner may not be accustomed to the ways that culturally diverse patients verbally and non-verbally express pain,[64] suffering, grief and other emotions. Such a misunder-

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[59] *See* Geyla Frank et al., *Ambiguity and Hope: Disclosure Preferences of Less Acculturated Elderly Mexican Americans Concerning Terminal Cancer – A Case Story*, 11 CAMBRIDGE Q. HEALTHCARE ETHICS 117, 124 (2002).

[60] CLAIRE J. KRAMSCH, LANGUAGE AND CULTURE 3 (H.G. Widdowson ed., Oxford Univ. Press 2008); *See also* Lee Sue Kim, *Exploring the Relationship Between Language, Culture and Identity*, 32 GEMA ONLINE J. LANGUAGE STUDIES 1 (2003).

[61] *See* Kim, *supra* note 60, at 1.

[62] *See id*.

[63] KRAMSCH, *supra* note 60, at 3.

[64] For a discussion of pain as a culturally mediated experience, *see supra* text accompanying

standing can create a gap in communication with potentially negative consequences such as prescription of the wrong medicine or treatment or failure to treat an issue that the practitioner did not realize the facts presented.[65] Equally devastating can be the consequences when patients speak the healthcare provider's language less than proficiently or not at all.[66] Language-concordant patient-physician interactions seem to greatly influence patients' perceptions of their disease and their overall health behaviors.[67]

Understanding the dimensions of healthcare decision-making is especially significant in complex societies like the United States, in which groups from all over the world converge and coexist within the same communities. In such complex societies, the concept of culture takes an even broader meaning.[68] Not only is the term associated with ethnic and racial groups, but it is also associated with other well-defined subgroups. The subdivision of the general culture into "subcultures" is a prevalent phenomenon.[69] Most of the cultural influences discussed thus far have been patient-centered, but professionals from different cultures also bring different cultural influences

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notes 41–47.

[65] *See* HELMAN, *supra* note 25, at 148. Physicians may misinterpret the way patients express distress based on cultural expectations. *Id.* at 150. For example, they may interpret somatization, which is the "cultural patterning of psychological and social disorders into a language of distress of mainly physical symptoms and signs," as evidence of real physical problems. *Id.* at 260. Alternatively, physicians may attribute the presence of certain symptoms to psychological or emotional problems, overlooking a real illness, thus misinterpreting symptoms because of preconceptions or stereotypes. *See generally id.* at 189–95. *See also,* Shankar Vedantam, *Racial Disparities Found in Pinpointing Mental Illness*, WASHINGTON POST, June 28, 2005, http://www.washingtonpost.com/wp-dyn/content/article/2005/06/27/AR2005062701496.html.

[66] Not only may patients not seek healthcare due to language barriers, but when they do, miscommunication can be the source of poor compliance with follow up and treatment or outright dissatisfaction with care. LISA A. COOPER & NEIL R. POWE, THE COMMONWEALTH FUND, DISPARITIES IN PATIENT EXPERIENCES, HEALTH CARE PROCESSES, AND OUTCOMES: THE ROLE OF PATIENT-PROVIDER RACIAL ETHNIC, AND LANGUAGE CONCORDANCE 10, 10–12 (2004), http://www.commonwealthfund.org/Content/Publications/Fund-Reports/2004/Jul/Disparities-in-Patient-Experiences--Health-Care-Processes--and-Outcomes--The-Role-of-Patient-Provide.aspx.

[67] *Id.* at 10.

[68] HELMAN, *supra* note 25, at 3.

[69] *Id.*

to their work.

Especially in the medical field, the existence of professional sub-cultures add yet another dimension to the experience of those involved in medical encounters. The terms "medical culture," "nursing culture," and "social work culture" all refer to groups with distinctive characteristics. While these subcultures may share common values with the general culture, some of their specific values and behaviors may conflict with those of other cultures and subcultures. For example, "medical culture" is characterized by the use of medical and technical jargon, which a person from the general culture may not understand.[70] Another example is the use of technology by members of the medical culture to stave off death in circumstances in which members of other cultures would allow nature to take its course.[71]

Whether referring to ethnic, racial, or professional cultures, it is paramount to understand that the identification of particular attitudes and behaviors within a particular ethnic or minority group should never be blindly attributed to every individual in that group. Doing so may lead to stereotyping, discrimination, and stigmatization.[72] Therefore, while general knowledge regarding certain beliefs, attitudes, and practices of particular groups may provide a general framework for analyzing and resolving issues within that group, each individual person must be seen in his or her individual context and reality to appropriately address his or her situation.[73] Only through the use of a culturally sensitive approach and adequate questioning techniques can any individual's problems be properly addressed.

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[70] *Id.* at 151.

[71] *Id.* at 232.

[72] INST. OF MED., REPORT UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 171 (Brian D. Smedley, Adrienne Y. Stith eds., Nat'l; Academies Press 2003) [hereinafter UNEQUAL TREATMENT]; Barbara Koenig & Jan Gates-Williams, *Understanding Cultural Differences in Caring for Dying Patients*, 163 W. J. MED. 244 (1995); CRAWLEY & KAGAWA-SINGER, *supra* note 22, at 8.

[73] Searight & Gafford, *supra* note 38, at 516.

B. The Influence of Culture on End-of-Life Decision-Making

Culture may impact many aspects of healthcare,[74] but researchers have found three major areas in which this impact is most significant at the end of life: the communication of bad news, the locus of decision-making, and attitudes toward advance directives.[75] Underlying these three areas are the medical ethical values of autonomy,[76] beneficence,[77] nonmaleficence,[78] and justice.[79]

While these ethical principles have become basic tenets of Western medicine,[80] they may conflict or hold different weight when applied to end-of-life issues in other cultures.[81] Some cultural practices may downplay one while emphasizing another, contrary to the Caucasian beliefs that have formed the bulk of healthcare ethics theorizing.[82] For example, although in the United States the principles of autonomy and informed consent[83] are most valued in the decision-making process,[84] members of other cultures may place more impor-

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74 For example, some cultures use folk healers instead of physicians, some differ in their willingness to use medical technology and in help-seeking patterns. *See generally* HELMAN, *supra* note 25.

75 Searight & Gafford, *supra* note 38, at 516.

76 Kenneth V. Iserson, *Principles of Biomedical Ethics*, 17 EMERGENCY MED. CLINICS N. AM. 284 (1999) (stating that "[a] person should be free to make his or her own decisions").

77 *Id.* at 293 ("doing good").

78 *Id.* ("do no harm").

79 *Id.* at 294 ("fairness in the allocation of resources").

80 Globally, Western medicine is politically and geographically dominant among ethnomedical systems. It is characterized by its reliance on modern science and rational and empirical study of physical phenomena. It also relies heavily on technology, focusing on the individual person and emphasizing medical efficiency in its approach to healthcare organization. JEANNINE COREIL ET AL., *Comparative Health Cultures, in* SOCIAL & BEHAVIORAL FOUNDATIONS OF PUBLIC HEALTH 167, 176–77 (Jeannine Coreil ed., Sage Pub'l, Inc. 2009).

81 *See* Searight & Gafford, *supra* note 38; *see generally* Dayna Bowen Matthew, *Race, Religion, and Informed Consent – Lessons from Social Science*, 36 J.L. MED. & ETHICS 150 (2008).

82 *See* Matthew, *supra* note 81, at 157–158.

83 *Id.* at 150, 156–157.

84 The right to refuse even life-prolonging treatment is an example of the primacy of autonomy and informed consent. The law of end-of-life medical decision-making, for example, is rooted in the concept of protecting individuals from unwanted bodily contact. MEISEL & CERMINARA, *supra* note 50, at § 1.07[A] (even if the treatment in question will benefit the pa-

tance on nonmaleficence. Family members of a patient suffering from a catastrophic or terminal illness may ask the patient's doctor not to tell the patient of his or her diagnosis.[85] In doing so, the family may be operating out of a belief that learning of his or her condition will harm the patient emotionally and even physically.[86] This behavior directly conflicts with current truth-telling practices in medicine, which emphasize the patient's values of autonomy and self-determination.[87]

With the competent patient thus unaware of the terminal diagnosis, family members operating within this belief system envision controlling decision-making regarding treatment options. Yet, under Western, Caucasian law and ethics, permitting the family to make decisions without the competent patient's participation violates the principle of informed consent.[88] This approach is anathema to most U.S physicians as, ethically and legally, informed consent is considered the cornerstone of medical treatment.[89] Furthermore, since many cultures consider illness to be a family event rather than an individual occurrence,[90] not one but several members of the patient's family are likely to become involved, resulting in group decision-making[91] and inviting into the decision-making process multiple levels of idio-

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tient, which applies even if "a patient will likely die as a consequence of refusing treatment.").

85 *See* Searight & Gafford, *supra* note 38, at 515; Frank et al., *supra* note 59, at 122.

86 Searight & Gafford, *supra* note 38, at 515. Some cultures believe the patient will give up on life and start deteriorating faster if they know of a poor prognosis. *Id*. at 518.

87 *See id*. at 517. One example of how important these principles are in the United States is the Patient Self-Determination Act (PSDA), 42 U.S.C. § 1395cc. Congress intended the PSDA to encourage adults to exercise control over medical treatment decisions, requiring healthcare entities to disseminate information about advance directives to satisfy this goal. The PSDA exemplifies the values of autonomy, informed decision-making, truth telling, and control over the dying process. Joyce Giger et al., *Multi-cultural and Multi-Ethnic Considerations and Advanced Directives: Developing Cultural Competency*, 13 J. Cultural Diversity 3, 4 (2006); s*ee 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 (2001).

88 *See* Matthew, *supra* note 81, at 156–164.

89 *Id*. at 152.

90 *See* Searight & Gafford, *supra* note 38, at 518.

91 *See* Giger et al., *supra* note 87, at 5–6 (stating that Koreans, Mexican Americans, and certain Hispanic groups believe in a "family-center[ed] model of decision-making rather than a patient-center[ed] model . . . .").

syncrasies and acculturation issues.[92] Physicians not accustomed to such styles of decision-making may view the process as cumbersome and complicated, as well as inimical to prevailing medical norms.[93]

In addition, patients of some cultures would expect physicians to first inform a particular, designated person or family member, rather than the patient or any other family member, of the gravity of the patient's health situation. In these cultures, the designee is thereafter in charge of making medical decisions on behalf of the patient, even when the patient has capacity to make those decisions.[94] In some other cultural groups (for example Hispanics), respect for hierarchy,[95] combined with trust borne of mutual respect,[96] often results in deferring medical decisions to the patient's physician.[97] Asking a patient's physician to make end-of-life medical decisions on behalf of the patient becomes particularly problematic, resulting in discomfort and tension, when the physician is not trained in cultural sensitivity.[98] In many such cases, physicians may not even be able to consult a patient's advance directive to determine the patient's wishes, as all groups of ethnic and racial minorities exhibit lower rates of advance

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[92] *See supra* text accompanying notes 16 and 55. Conflict among family members or with physicians about end-of-life decision-making is not unique to ethnic and racial minorities. *See generally* Mary Ann Meeker & Mary Ann Jezewski, *Family decision making at the end of life*, 3 Palliative & Supportive Care 131, 137–38 (2005).

[93] Meeker & Jezewski, *supra* note 92, at 138; s*ee also* Jennifer W. Mack et al., *Hope and Prognostic Disclosure*, 25 J. Clinical Oncology 5636, 5640 (2007) (discussing the difficulties of physical and family sympathy).

[94] *See* Kagawa-Singer & Blackhall, *supra* note 87, at 2998. In the Vietnamese culture, for example, the eldest son is the one responsible for taking care of elderly parents, making all care decisions. Joyce Newman Giger & Ruth Elaine Davidhizar, Transcultural Nursing: Assessment and Intervention 502 (Michael S. Ledbetter ed. Mosby, Inc. 2004).

[95] Carlos Sandoval, *Culture and Care*, *in* A Clinical Guide to Supportive & Palliative Care for HIV/AIDS 301, 306 (Joseph F. O'Neill et al. eds., 2003) (stating that "Jerarquismo" means respect for hierarchy).

[96] Victor Alejandro Diaz, Jr., *Cultural factors in preventive care: Latinos*, 20 Primary Care Clinical Off. Practice 503, 504 (2002). In Spanish, *respeto* is "the reciprocal respect between physician (authority figure) and patient." *Id*. Personalismo is "trust borne of mutual respect." Giger et al., *supra* note 87, at 5.

[97] Geiger et al., *supra* note 87, at 5.

[98] *See generally* Searight & Gafford, *supra* note 38.

directive execution than Caucasians.[99]

C. Cultural Influences Among Hispanics and African-Americans: Different Views of End-of-Life Decision-making

Various factors contribute to the relatively low levels of advance directive execution and use of hospice services among racial and ethnic minorities. In the case of Hispanics and African-Americans, studies have linked these statistics with cultural perspectives on death and suffering;[100] systemic individual and institutional discrimination;[101] structural barriers;[102] individual factors such as gender, age, and marital status;[103] and family dynamics such as parent-child relationships.[104] While the influences of individual factors on the rate of completing advance directives and accessing hospice are beyond the scope of this Article, it will next explore the general cultural influences most prevalent among first Hispanics and then African-Americans.

1. Hispanics, Advance Directives and Hospice Care: The Influence of Familism and Language

Although there is a paucity of research, existing studies have shed some light on the cultural influences on Hispanics in the United States with respect to end-of-life issues.[105] The reasons behind the low

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99 Greiner et al., *supra* note 13, at 971.

100 *See infra* text accompanying notes 105–170.

101 *See* Searight & Gafford, *supra* note 38, at 520; *See generally* 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, 191–92 (1996) [hereinafter *Trusting*]; Vernellia Randall, *Racial Discrimination in Health Care in the United States as a Violation of the International Convention on the Elimination of all Forms of Racial Discrimination*, 14 U. Fla. J.L. & Pub. Pol'y 45 (2002) [hereinafter *Racial Discrimination*].

102 Krakauer et al., *supra* note 19, at 186; s*ee also* Crawley & Kawaga-Singer, *supra* note 22.

103 *See* Greiner et al., *supra* note 13, at 970; Theodore J. Iwashyna & V.W. Chang, *Racial and Ethnic Differences in Place of Death in the United States*, 50 J. Amer. Geriatrics Soc'y. 1113, 1115 (1993); Theodore J. Iwashyna et al., *The Lack of Effect of Market Structure on Hospice Use,* 37 Health Services Res. 1531, 1546–47 (2002).

104 Searight & Gafford, *supra* note 38, at 519.

105 *See generally* Frank et al., *supra* note 59; Kagawa-Singer & Blackhall, *supra* note 87; *see gener-*

rates of hospice usage undoubtedly vary, but studies most frequently cite cultural influences in the form of basic beliefs, attitudes, and behaviors, in addition to language and systemic barriers. It is impossible to properly understand these findings, however, without placing them in the context of the socioeconomic realities of Hispanics in the United States. The Hispanic or Latino[106] category in U.S Census Bureau reporting includes people of Cuban, Mexican, Puerto Rican, South or Central American, and other Spanish cultures of origin.[107] Among Hispanics, Mexicans comprise the largest group, at 66.1 percent of the U.S. population, followed by Puerto Ricans (9 percent),[108] Cubans (4 percent), and Central and South American (14.5), with the remaining 6.4 percent being comprised of people of other Hispanic or Latino origins.[109] Hispanic-Americans may be of any race,[110] and the Hispanic population is one of the fastest-growing in the U.S.; according to census projections, the number of Hispanics of all races in the U.S. is expected to triple from 47 to 133 million by 2050.[111]

The Migration Policy Institute has identified two categories of U.S. Hispanics: (1) native Hispanics, or people of Hispanic ancestry or heritage born in the United States, and (2) Hispanics born in other countries who are not U.S. citizens.[112] Due, in part, to an increase in unauthorized immigration, the latter category has experienced the

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ally Morrison et al., *supra* note 19; Leslie J. Blackhall et al., *Ethnicity and Attitudes Toward Patient Autonomy*, 274 JAMA 820 (1995); Sheila T. Murphy et al., *Ethnicity and Advance Care Directives*, 24 J.L. MED. & ETHICS 108 (1996); Leslie J. Blackhall & Frank Murphy, *Bioethics in a Different Tongue: The Case of Truth-Telling*, 78 J. URBAN HEALTH 59 (2001) (perspectives in truth-telling).

[106] The term "Latino" appeared for the first time in the U.S Census in 2000. US CENSUS BUREAU, THE HISPANIC POPULATION (2000), http://www.census.gov/prod/2001pubs/c2kbr01-3.pdf.

[107] *Id.*

[108] *Id.* These include only Puerto Ricans living on the mainland; there are an additional 3.8 million living in the associated territory. *Id.*

[109] *See* U.S. CENSUS BUREAU, THE HISPANIC POPULATION IN THE UNITED STATES 1 (2000), *available at* http://www.census.gov/population/socdemo/hispanic/p20-535/p20-535.pdf.

[110] The federal government considers race and ethnicity to be distinct concepts. CDC OFFICE OF MINORITY HEALTH, HISPANIC OR LATINO POPULATIONS, http://www.cdc.gov/omhd/Populations/HL/HL.htm#1 (last viewed Dec. 19, 2009).

[111] *Id.*

[112] *Id.*

most growth in the last few decades.[113] Hispanics are dispersed throughout the United States, with the highest concentrations in the states of New Mexico, California, Texas, Arizona, Nevada, Colorado, and Florida.[114]

Cultural variations exist among Hispanics from different countries of origin, just as cultural subgroups vary in terms of their levels of acculturation.[115] While the different groups may share a common language and emphasis on the importance of the family, [116] differences in cultural practices and acculturation levels may account for variation in health status and healthcare practices.[117] For example, one study shows that Puerto Ricans are more likely than Mexican-Americans and persons of Central-American/Caribbean descent to visit an ambulatory care center but are the most likely to have any emergency department visits.[118] The same study found that Puerto Ricans and Mexicans are more likely than persons of Central-American/Caribbean descent to have any inpatient hospital admissions.[119] Equally diverse is the approach of Hispanic subgroups to preventive care. Mexicans, for example are the least likely of all Hispanic groups to have heard of the Pap test;[120] among Mexican-American women, lower preventive screening behaviors correlate

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[113] *See generally* Pew Hispanic Center, A Portrait of Unauthorized Immigrants in the United States, *available at* http://pewhispanic.org/reports/report.php?ReportID=107 (last visited Dec. 19, 2009). One estimate, by the Pew Hispanic Center in 2008, projected a total of 11.9 million undocumented immigrants living in the United States, the majority (59 percent or 7 million) from Mexico and another quarter (26 percent or 3 million) from other Latin American countries. *Id*.

[114] Urban Institute, Undocumented Immigrants: Facts and Figures, http://www.urban.org/url.cfm?ID=1000587&renderforprint=1 (last visited Dec. 19, 2009).

[115] *See generally* Robin M. Weinick et al., *Hispanic Healthcare Disparities: Challenging the Myth of a Monolithic Hispanic Population*, 42 MED. CARE 313 (2004); Sandoval, *supra* note 95, at 302.

[116] Diaz, *supra* note 96, at 503; *see also* Sandoval, *supra* note 95.

[117] *See generally* Weinick et al., *supra* note 115.

[118] *Id*. at 316.

[119] *Id*.

[120] Diaz, *supra* note 96, at 506. A Papanicolaou (Pap) smear is a method for detecting cervical cancer. *See* MERRIAM WEBSTER'S MEDICAL DICTIONARY, *available at* http://www.merriam-webster.com/medical/pap%20smear.

highly with anxiety over a cancer diagnosis.[121]

    With respect to end-of-life issues, studies have found that His-
panics are less likely to have advance directives than whites,[122] per-
haps in part because, generally speaking, Hispanic cultures view life
as a gift from God. Because death is part of life,[123] adherents to such a
belief system would say that death, like life, should be in God's
hands. A study exploring factors influencing decisions to formulate
advance directives among minority and non-minority seniors[124]
found that some participants, in particular Hispanics and African-
Americans, linked their decisions about end-of-life care to their reli-
gious beliefs. A Hispanic woman summarized her beliefs in God as
the decision maker at the end of life by saying that "because you
serve God your whole life, [He] will take you when you've had
enough."[125] In addition, Hispanic cultures tend to emphasize main-
taining hope in the face of terminal illness,[126] so Hispanics are less
likely than whites and African-Americans to believe that a patient
should learn about a terminal diagnosis.[127] For the same reason, His-
panics are less likely to place the burden of decision-making on the
patient with a terminal illness.[128] Members of this group tend to favor
use of life support even in hopeless circumstances,[129] and to value dy-
ing at home in the care of the family.[130]

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[121] Diaz, *supra* note 96, at 506.

[122] Giger et al., *supra* note 87, at 7 (explaining that the cultural orientation of living in the pre-
sent ("presentism") is most common among Hispanics and contributes to lack of advance
planning).

[123] *Id.* (citing E.L. Mitty, *Ethnicity and End of Life*, 27 REFLECTIONS ON NURSING LEADERSHIP 29
(2001)).

[124] *See generally* Crystal Dea Moore & Susan Sherman, *Factors that Influence Elders' Decisions to
Formulate Advance Directives*, 31 J. GERONTOLOGICAL SOCIAL WORK 21 (1999).

[125] *Id.* at 36.

[126] *See generally* Frank et al., *supra* note 59.

[127] *See generally* Blackhall et al., *supra* note 105.

[128] *Id.*

[129] Leslie J. Blackhall et al., *Ethnicity and Attitudes Towards Life Sustaining Technology*, 48 SOC.
SCI. & MED. 1779 (1999). This same study, however, found that many in this same group of
Mexican-Americans supported the withdrawal of life support "under certain circum-
stances." *Id.* at 1785.

[130] The Kaiser Family Foundation, *Coverage, Access and Quality, Hispanics' Low Use of Hospice*

In addition to demonstrating differences among persons of various Hispanic cultures, studies illustrate gender-specific differences within cultures. A recent qualitative study using focus groups with several ethnic groups found that most of the Hispanic women studied did not believe in withdrawing life support ("pulling the plug"),[131] but that the Hispanic men studied wanted "the least amount of intervention at the end of life."[132]

Focusing narrowly on hospice as a sub-category of end-of-life treatment preferences reveals evidence that the concept of hospice faces some cultural barriers of its own. A 2009 study of patients from all races and ethnicities suffering from metastatic lung cancer found that Hispanic patients were less likely than White or Asian patients to have discussed hospice with their physicians.[133] While such a lag in discussing end-of-life care may exist due to the previously discussed cultural reasons, it also may be attributable to language issues. In Spanish, a "hospice" is a place for orphaned children,[134] so that a person who speaks Spanish or who is more proficient in Spanish than English may misunderstand the term entirely when hearing it. This is significant because the Pew Hispanic Center has reported that more than 20 million Hispanics eighteen years of age and older in the United States speak English with less proficiency than "very well."[135] Moreover, the word "hospice" may evoke the wrong concept even for those who speak English; studies indicate that some Hispanics in the United States believe that a hospice is a place where patients go and die alone.[136]

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care related to Cultural Barriers, Misconceptions, May 3, 2007, http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=44684.

[131] *See generally* Sonia A. Duffy et al., *Racial/Ethnic Preferences, Sex Preferences, and Perceived Discrimination Related to End of Life Care*, 54 J. AMER. GERIATRICS SOC. 153 (2006).

[132] This study also found a similar pattern of differences regarding life support between African-American men and women. *Id.* at 153.

[133] *See generally* Haiden A. Huskamp et al., *Discussion with Physicians about Hospice Among Patients with Metastatic Lung Cancer*, 169 ARCHIVES INTERNAL MED. 955 (2009).

[134] *Id.*

[135] The Pew Hispanic Center, *Statistical Portrait of Hispanics in the United States – Table 19,* 2007, http://pewhispanic.org/files/factsheets/hispanics2007/Table-19.pdf.

[136] Kaiser Family Foundation, *Kaiser Health Disparities Report: A Weekly Look at Race, Ethnicity and Health,* http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=44684

Indeed, studies reveal that language barriers have a consistent negative impact on healthcare processes and patient ratings of care[137] and that language concordance between patients and healthcare providers positively impacts health outcomes. For example, one study of Hispanic outpatients with asthma indicated that patients whose doctors spoke the same language as they did had significantly better rates of appointment-keeping and medication adherence.[138] Similarly, in another study, Spanish-speaking Latinos who visited same-language physicians asked more questions and had greater recall of the physicians' instructions than did Latinos who did not have language-concordant physicians.[139] Another study demonstrated that, among Hispanic patients, language concordance and the use of interpreters greatly affected patients' perceptions about their diseases.[140]

Language as an expression of cultural heritage[141] can also add positive dimensions to the patient-doctor relationship. Patients in race/ethnicity-concordant relationships with their doctors are more likely to rate their physicians as "excellent" across different categories, including the provision of care, treating them with respect and being accessible.[142] This may result from the shared values and beliefs that may accompany race/ethnicity-concordance, or it may result from the physicians' increased cultural sensitivity when coming from

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(last visited Dec. 21, 2009). This misunderstanding is not limited to Hispanics, at least insofar as it involves viewing hospice as a "place you go to die." *See* JOSEPH J. FINS, A PALLIATIVE ETHIC OF CARE 134 (2006).

[137] *See generally* COOPER & POWE, *supra* note 66.

[138] *Id*. at 12 (citing Aaron Manson, *Language Concordance as a Determinants of Patient Compliance and Emergency Room Use in Patients with Asthma*, 26 MED. CARE 1119–28 (1988)).

[139] *Id*.

[140] In the United States, however, ethnic minorities are poorly represented among physicians and other healthcare professionals. *See infra* text accompanying notes 305–09, in addition, there are too few trained and available translators in all sectors of healthcare. *See infra* text accompanying note 210. Importantly, when patients used family or *ad hoc* interpreters, they were significantly less satisfied with care. CRAWLEY & KAGAWA-SINGER, *supra* note 22.

[141] *See generally* Lee Kim, *Exploring the Relationship Between Language, Culture and Identity*, 3 GEMA ONLINE J. LANGUAGE STUD. (2003), *available at* http://myais.fsktm.um.edu.my/515/1/GemaCol3.2.2003No4.pdf (reviewing existing studies and theories about the relationship between language, culture and identity and concluding that the relationship is distinctively inseparable).

[142] UNEQUAL TREATMENT, *supra* note 72, at 132.

the same racial or ethnic background.[143] It also may result from the fact that concordance promotes communication; poor communication and miscommunication may engender mistrust,[144] especially among ethnic minorities who are also exposed to institutional racism and stereotyping attitudes on the part of healthcare professionals.[145]

Finally, but perhaps primary in consideration, is familism, one of the most-cited reasons for the failure to access or the refusal of hospice services among Hispanics, as well as for the low rates of completion of advance directives among Hispanics.[146] Familism, "a social pattern in which a focus on family assumes a position of ascendance over individual interests,"[147] is common among Hispanic groups and colors the major interactions in Hispanic patients' lives.[148] It emphasizes the centrality of the family and dictates filial obligations among its members.[149] It can thus influence the willingness of Hispanic patients to execute advance directives and to elect hospice services in at least two ways. First, familism is believed to influence the completion of advance directives[150] by encouraging patients to avoid appointing healthcare surrogates because of the existence of a strong family network.[151] Delegating surrogate responsibilities to one, two, or even a few persons may work against the family unit.[152] Familism also can influence the likelihood of a hospice election because of the cultural

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[143] *Id.*

[144] Morrison et al., *supra* note 19, at 2497.

[145] *See infra* text accompanying notes 220–29 (describing African-Americans' experiences with medical institutional racism and segregation). *See also supra* text accompanying note 94 (noting physicians' reactions to styles of decision-making that do not accord with the traditional Western style).

[146] Morrison et al., *supra* note 19, at 2496; Murphy et al., *supra* note 105, at 114.

[147] Merriam-Webster's Dictionary, *available at* http://www.merriam-webster.com/dictionary/familism.

[148] Diaz, *supra* note 96, at 503; Morrison et al., *supra* note 19, at 2493 (examining cultural factors influencing different rates of advance directive use in different segments of the American population).

[149] Morrison et al., *supra* note 19, at 2496.

[150] *Id.*

[151] *Id.*

[152] *Id.*

belief that disclosing a terminal diagnosis to a patient may harm him or her.[153] That belief not only influences truth-telling practices and decision-making practices among Hispanics, but it also, especially when combined with the family system approach to healthcare decision-making,[154] can leave the patient (the one responsible for electing hospice care under the current system)[155] out of the decision-making process.

2. African-Americans, Advance Directives and Hospice Care: The Influence of Faith and Mistrust

The narrative of ethnic and racial minorities who face end-of-life decisions and who may wish to access hospice takes on a specific political and social twist when discussing African-Americans.[156] While African-Americans may not experience many of the immigration issues Hispanics do, their attitudes and behaviors toward end-of-life care generally have been shaped by a history of healthcare discrimination[157] and overall racism.[158]

African-Americans comprise only 8 percent of hospice patients in the United States, consistent with their tendency to complete advance directives at lower rates[159] and to be more likely to choose aggressive treatment at the end of life[160] than Caucasians. Studies show that some of African-Americans' reluctance to even discuss end-of-life care and rejection of advance directives may stem from religious beliefs and philosophical differences with prevailing values related to

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[153] Jung Kwak & William E. Haley, *Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups*, 45 THE GERONTOLOGIST 634, 638 (2005).

[154] Blackhall et al., *supra* note 105; Kagawa-Singer & Blackhall, *supra* note 87. *See supra* text accompanying notes 151–153.

[155] *See infra* Part III.A.1.a.

[156] *See Barriers*, *supra* note 19; UNEQUAL TREATMENT, *supra* note 72. *See generally Trusting*, *supra* note 101. *See also Racial Discrimination*, *supra* note 101 (section III discussing racial disparity in health status of the U.S. Population and section IV discussing institutional racism and racial discrimination in the U.S. healthcare system).

[157] UNEQUAL TREATMENT, *supra* note 72, at 131; *see generally Trusting*, *supra* note 101.

[158] UNEQUAL TREATMENT, *supra* note 72, at 131; *see generally Trusting*, *supra* note 101.

[159] Murphy et al., *supra* note 105, at 112, tbl.2.

[160] *See generally Trusting*, *supra* note 101.

death and dying.[161] Existing health disparities, however, may also frame social and economic issues that have an even greater direct impact on such end-of-life decisions.[162]

As in the case of Hispanics, generalizations about African-Americans are unwise and dangerous; the "Black Experience" is diverse.[163] In his article *Death and Dying in the Black Experience*, Dr. Richard Barrett, an expert on African-American funerary customs and practices, cautions that ". . . generalizing about 'culture, race, and ethnicity' with regard to black experience overall is very difficult, if not somewhat misleading."[164] That said, however, examination of various studies can begin to establish the broad outlines of individually divergent beliefs and practices within this group.

For example, studies indicate that African-Americans tend to be less comfortable discussing death,[165] more likely to want life-prolonging therapies,[166] and more likely to agree that those who believe in God should not have to plan for end-of-life care[167] than Caucasians. African-Americans usually prefer to die at home,[168] but in

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161 *See* Kimberly Johnson et al., *What Explains Racial Differences in the Use of Advance Directives and Attitudes Toward Hospice Care?*, 56 J. Amer. Geriatrics Soc. 1953, 1956 (2008) [hereinafter Attitudes]; *see generally* Catherine M. Waters, *Understanding and Supporting African Americans' Perspectives of End-of-Life Care Planning and Decision Making*, 11 Qualitative H. Res. 385 (2001).

162 Searight & Gafford, *supra* note 38, at 519.

163 Ronald K. Barrett & K. S. Heller, *Death and Dying in the Black Experience: An interview with Ronald K. Barrett*, 3 Innovations End-of-Life Care (2001), *available at* http://www2.edc.org/lastacts/archives/archivesSept01/intlpersp.asp.

164 *Id.* For example, although the authors of this Article have chosen to use the term "African-American" as an overall descriptor, according to Dr. Barrett, "African-Americans" and "Blacks" are distinct groups, with the first label describing "[a]ll persons of African descent genealogically connected to Africa, in particular West Africa." *Id.* at 2. The later label describes "people whose sociocultural roots are in the North American Experience, but who are of African descent." *Id.* Both the Institute of Medicine and the federal Office of Management and Budget use the terms "African-American" and "black" interchangeably. *See* Unequal Treatment, *supra* note 72, at 32 n.2.

165 Attitudes, *supra* note 161, at 1956.

166 *Id.*

167 *Id.*

168 This changes, however, if dying at home causes hardship to family. *See* Frances Jackson, et al., *Barriers to Hospice Care for African Americans: Problems and Solutions*, 2 J. Hospice and

fact most die in the hospital,[169] perhaps correlating with their prefer-
ence for more aggressive treatment at the end of life.[170]

While most of the available literature locates the reason for Afri-
can-Americans' under-use of hospice care in mistrust of the health-
care system,[171] the literature has virtually ignored some of the possi-
ble cultural factors affecting participation in hospice services. Only a
few studies have found that, along with mistrust of the healthcare
system and of healthcare professionals from different racial back-
grounds,[172] their religious and philosophical views of death and dy-
ing could account for the low rate at which African-Americans access
hospice services.[173]

It seems, however, as though such cultural influences likely play
significant roles. Similar to Hispanics, studies have shown that com-
munication patterns in physician-patient relationships play a signifi-
cant role in end-of-life decision-making among African-Americans. In
one qualitative study conducted by Jenkins *et al.* in 2005,[174] for exam-
ple, focus group participants stressed the importance of healthcare

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PALLIATIVE CARE 65, 70 (2000); Carolyn Jenkins et al., *End-of-Life Care and African Americans: Voices from the Community*, 8 J. PALLIATIVE CARE 585, 587 (2005). In a study among hospice users, being African-American or Latino was associated with a higher likelihood of dying at home versus at the inpatient hospice unit. Susan C. Miller et al., *How Does the Timing of Hospice Referral Influence Hospice Care in the Last Days of Life?*, 51 J. AMER. GERIATRICS SOC'Y. 798, 799 (2003) (citing a study from 1983). *But see* Duffy et al., *supra* note 131, at 154, tbl.3 (a quali-tative study finding that Blacks were more likely than Hispanics, Arabs, or Whites to prefer to die in a hospital-type setting).

169 Ann Berger, et al., *A Commentary: Social and Cultural Determinants of End-of-Life Care for Eld-erly Persons*, 42 THE GERONTOLOGIST 49, 49 (2002).

170 *Cf.* Johnson et al., *supra* note 16, at 221 (stating that "African American patients are more likely than white patients to request life-sustaining therapies, including cardiopulmonary resuscitation and mechanical ventilation, at the end of life regardless of prognosis").

171 *See generally* Malcom A. Cort, *Cultural Mistrust and Use of Hospice Care: Challenges and Reme-dies*, 7 J. OF PALLIATIVE MED. 63 (2004); LaVera Crawley, *Palliative Care in African American Communities*, 3 INNOVATIONS END OF LIFE CARE (2001), *available at* http://www2.edc.org/lastacts/archives/archivesSept01/editorial.asp; Robert L. Ludke & Douglas R. Smucker, *Racial Differences in the Willingness to Use Hospice Services*, 10 J. PALLIATIVE MEDICINE 1329, 1329 (2007).

172 Karla T. Washington et al., *Barriers to Hospice Use Among African Americans: A Systematic Re-view*, 33 HEALTH & SOCIAL WORK 267, 267 (2008).

173 Waters, *supra* note 161, at 396 n. 97.

174 Jenkins et al., *supra* note 168, at 585.

providers' familiarity with the particular cultural metaphors African-Americans use to discuss death[175] and with cultural signs of respect such as the need to address others by last name until given permission to use another form of address.[176]

Additionally, and again similar to Hispanics, African-Americans place utmost importance on the community and honoring the family; therefore, African-American patients value the input of others, especially family members, when making end-of-life care decisions.[177] Such family-centered values call for a departure from the patient-centered, autonomy-guided, healthcare values predominant in the American healthcare system.

II. The Flawed Healthcare System: Race, Ethnicity and Healthcare Disparities

In addition to possibly stemming from cultural influences, low rates of hospice use among ethnic and racial minorities may reflect existing disparities in the U.S healthcare system.[178] Although they are different concepts, health disparities and healthcare disparities are intrinsically related.[179] Disparities in healthcare can accentuate and perpetuate health disparities among different groups.

Racial and ethnic variations in health outcomes may stem from biological,[180] environmental,[181] socioeconomic,[182] and behavioral dif-

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175 *Id.* at 586–587. *See also* Crawley, *supra* note 171, at 2–3 (describing some of those metaphors and cultural language).

176 Jenkins et al., *supra* note 168, at 587.

177 Barrett & Heller, *supra* note 163, at 4.

178 Greiner et al., *supra* note 13, at 977.

179 Kaiser Family Foundation, Policy Challenges and Opportunities in Closing the Racial/Ethnic Divide in Health Care 4 n.1 (2005) (stating that the term "health disparity" refers to the burden of disease experienced among populations while the term "health care disparities" reflects inequities in how these populations experience the healthcare system including, access, coverage, and other utilization issues).

180 Hani K Atrash & Melissa D. Hunter, *Health Disparities in the United States: A Continuing Challenge, in* Multicultural Medicine and Health Disparities 3, 4 (David Satcher & Rubens J. Pamies eds., 2006).

181 *Id.*

ferences.[183] Although race[184] and ethnicity[185] are not the ultimate causes of particular health outcomes, researchers do consider them to be risk factors associated with varying mortality and morbidity rates among the population.[186] Because race and ethnicity are usually strongly associated with known health risk factors such as poverty,[187] use of tobacco and alcohol,[188] inadequate healthcare access,[189] and other disadvantages,[190] they also may serve as "prox[ies] for un-measured social factors," such as cultural, social, and environmental influences on the distribution of disease.[191]

Racial and ethnic disparities in health and their multifactorial causes are well-documented in the literature.[192] Disparities exist not only in the distribution of disease,[193] but also in access to services,[194]

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[182] *Id.; see also* UNEQUAL TREATMENT, *supra* note 72.

[183] Mays et al., *supra* note 18, at 85.

[184] The Institute of Medicine has defined race as a "social and cultural construct...'of human variability based on perceived differences in biology, physical appearance, and behavior.'" Gerald M. Oppenheimer, *Paradigm Lost: Race, Ethnicity, and the Search for a New Population Taxonomy*, 91 AM. J. PUB. HEALTH 1049, 1050 (2001) (citing M.A. HAYNES & B.I. SMEDLEY, THE UNEQUAL BURDEN OF CANCER: AN ASSESSMENT OF NIH RESEARCH AND PROGRAMS FOR ETHNIC MINORITIES AND THE MEDICALLY UNDERSERVED 38 (Nat'l Acad. Press 1999)) [herein-after UNEQUAL BURDEN].

[185] According to the Institute of Medicine, ethnicity "involves how one sees oneself and how one is `seen by others as part of a group on the basis of presumed ancestry and sharing a common destiny.'" Oppenheimer, *supra* note 184, at 1050 (*citing* UNEQUAL BURDEN, *supra* note 184, at 35).

[186] *See generally* Atrash & Hunter, *supra* note 180.

[187] Jeannine Coreil, *Social Epidemiology, in* SOCIAL AND BEHAVIORAL FOUNDATIONS OF PUBLIC HEALTH 47, 57–59 (2009) [hereinafter SOCIAL & BEHAVIORAL].

[188] *See generally* Beny J. Primm et al., *Tobacco, Alcohol, and Drugs, in* MULTICULTURAL MEDICINE AND HEALTH DISPARITIES 321 (David Satcher & Rubens J. Pamies eds., 2006).

[189] *See infra* section III.

[190] *See generally* Atrash & Hunter, *supra* note 180 (discussing the various sources of health dis-parities in the United States).

[191] Mays et al., *supra* note 18, at 86; *see also* SOCIAL & BEHAVIORAL, *supra* note 187.

[192] Joseph R. Betancourt et al., *Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Health Care*, 118 PUB. HEALTH REPORTS 293, 294 (2003).

[193] *See* U.S. DEPT. HEALTH & HUMAN SERVS., NATIONAL HEALTHCARE DISPARITIES REPORT 176–182 (2008), *available at* http://www.ahrq.gov/qual/nhdr08/nhdr08.pdf. The 2008 DHHS report on health disparities shows that Hispanics and African Americans continue to suffer

quality of care,[195] treatment of various conditions,[196] insurance status,[197] and health outcomes.[198] While some of those disparities have been attributed to cultural factors,[199] others have been blamed on a deficient healthcare system.[200]

A deficient healthcare system manifests itself in the form of inadequate resources and services in the provision of hospice care in minority neighborhoods. A recent study, for example, showed that African-Americans and Hispanics who lived in census tracts with a greater percentage of minorities were less likely to use hospice services than those who lived in areas in which the minority population was less than 30 percent.[201] The findings of this study suggest that

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disproportionately from diseases such as HIV/AIDS and to experience a wider gap in access to care [hereinafter Disparities Report 2008].

194 *See, e.g.*, Daniel L. Howard et al., *Distribution of African Americans in Residential Care/Assisted Living and Nursing Homes: More Evidence of Racial Disparity?*, 92 Amer. J. Pub. Health 1272 (2002) (examining racial separation in long-term care).

195 *See, e.g.,* Disparities Report 2008, *supra* note 193, at 78, Fig.2.26. (discussing a report by the U.S. Department of Health and Human Services, the *National Health Care Disparities Report,* that revealed, as compared to their white counterparts, Hispanics and African-Americans are more likely to have received potentially inappropriate prescription medication and to experience poor provider-patient communication).

196 Kaiser Family Found. & Am. Coll. of Cardiology Found., Racial and Ethnic Differences in Cardiac Care:The Weight of the Evidence (2002). A review of 81 studies evaluating cardiac care among minorities found evidence of racial/ethnical disparities even among patients with comparable health insurance. The review found lower rates of diagnostic and revascularization procedures for at least one minority group. Kaiser Family Report, Issue Brief: Policy challenges and Opportunities in Closing the Racial/Ethnic Divide in Health Care 1, fig.1 (2005) [hereinafter Kaiser Family Foundation Issue Brief].

197 Disparities Report 2008, *supra* note 193, at 105, fig.2.48.

198 *Id*. at 124 tbl.2.1a.

199 *See* section I.C.

200 Lisa A. Cooper et al., *Designing and Evaluating Interventions to Eliminate Racial and Ethnic Disparities in Health Care*, 17 J. Gen. Intern. Med. 477, 477 (2002) (stating that "[h]ealth care, in contrast to health status, reflects the total societal effort, whether public or private, to provide, organize, and finance services that promote the health status of individuals, and the community"). Examples of efforts that would promote the health status of minority individuals and communities would include making culturally sensitive care available and providing an adequate number of healthcare facilities and pharmaceutical and other medical resources within the community. *Id*. at 483.

201 Jennifer S. Haas et al., *Lower Use of Hospice by Cancer Patients who Live in Minority Versus*

minority neighborhoods may lack the necessary resources and infra-structure, including: hospice facilities, adequate pharmaceutical re-sources to treat end-of-life pain, and hospice workers willing to travel to such neighborhoods[202] to provide hospice services at home.[203]

Additional evidence of a healthcare system that fails to address the needs of minorities is the lack of providers in underserved com-munities and the lack of providers from minority groups. A report from the Kaiser Family Foundation revealed that "28% of Latinos and 22% of African-Americans report having little or no choice in where to seek care, while only 15% of whites report this difficulty."[204] More-over, even when able to access some type of care, minority patients may experience language and cultural barriers in attempting to ac-cess it.[205] As might be expected, Hispanics of limited English profi-ciency encounter more difficulties communicating with their doctors than do Hispanics for whom English is the primary language.[206]

White Areas, 22 J. GEN. INTERN. MED. 396, 398 (2007).

[202] *Id.*

[203] *Id.*

[204] KAISER FAMILY FOUNDATION ISSUE BRIEF, *supra* note 196, at 3 (citing the Commonwealth Fund Health Care Quality Survey, 2001). For a discussion of the cultural beliefs of Hispanics and African-Americans, *see* section I.C.

[205] *See* MICHELLE M. DOTY, THE COMMONWEALTH FUND, HISPANIC PATIENT'S DOUBLE BURDEN: LACK OF HEALTH INSURANCE AND LIMITED ENGLISH at vii (2003), http://commonwealthfund.org/Publications.aspx (search "Michelle Doty"; scroll down, click on article hyperlink, and then click on the "funding report" hyperlink).

[206] *Id.* Language barriers may strongly contribute to health disparities and poor access to healthcare on the part of Hispanics and some African-American patients (for example, Hai-tians). The presence of these barriers highlights another issue: the need for more trained medical interpreters to appropriately serve these patients. The existing shortage of trained interpreters is actually broad-based; the system lacks interpreters who can serve a wide va-riety of minorities, not simply these two groups, and the problem affects access to health-care in general as well as access to end-of-life care, including hospice services. *See* CRAWLEY & KAGAWA-SINGER, *supra* note 22, at 36. After judicial interpretation of Title VI of the Civil Right Act, 42 U.S.C. § 2000d *et seq.*, as prohibiting discrimination against persons with lim-ited English proficiency (LEP) as a form of national origin discrimination, President Bill Clinton issued Executive Order 13166, Improving Access to Services for Persons with Lim-ited English Proficiency, 65 Fed. Reg. 50121 (August 16, 2000). Correspondingly, the De-partment of Justice (DOJ) set forth principles various governmental agencies could use to develop guidelines to assist persons of Limited English Proficiency (LEP). *See* "Enforcement of Title VI of the Civil Rights Act of 1964 National Origin Discrimination Against Persons With Limited English Proficiency," 65 Fed. Reg. 50123 (August 16, 2000). In response, the

Here, the issue of culturally and linguistically congruent care surfaces again, this time in the institutional context. Although few studies have examined how race concordance between patients and physicians affects health services utilization or health outcomes, existing evidence associates it with higher satisfaction of patients with their medical care, better physician communication and better health outcomes.[207] Culturally and linguistically appropriate[208] end-of-life care is paramount to assure not only access to care but also quality of care for patients at the end of life.[209] In the United States, however, ethnic minorities are poorly represented among physicians and other healthcare professionals,[210] and only a limited number of trained and available translators exist in all sectors of healthcare.[211]

Another flaw of the current system is the inability to provide insurance or healthcare for the uninsured. In this sense, immigration status plays a pivotal role in the ability of Hispanics to access and benefit from hospice services.[212] In 2006, 62 percent of Hispanics, or

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U.S. Department of Health and Human Services developed guidelines requiring that interpreters be provided to persons of LEP. *See* U.S. Dept. of Health & Human Servs., Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons,

http://www.hhs.gov/ocr/civilrights/resources/specialtopics/lep/policyguidancedocument.html (last visited April 10, 2010). The federal mandate is unfunded, however. Siddharth Khanijou, *Rebalancing Healthcare Inequities: Language Service Reimbursement May Ensure Meaningful Access to Care for LEP Patients*, 9 DePaul J. Health Care L. 855, 856–57 (2005). This puts hospice service providers and other institutions that accept Medicare payment at an extreme financial disadvantage because they must provide interpreters but cannot seek reimbursement for the cost of the interpreters' services. *Id*. Many facilities have limited resources, so some have resorted to other solutions such as educating bilingual staff to provide medical interpretation. *Id*.

207 *See supra* text accompanying notes 139–41, 143, 176–77.

208 "Cultural and linguistic competence is a set of congruent behavior, attitudes and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations." Office of Minority Health, U.S. Dept. of Health & Human Servs., National Standards for Culturally and Linguistically Appropriate Services in Health Care 4 (2001).

209 *See* Crawley & Kagawa-Singer, *supra* note 22, at 6.

210 Unequal Treatment, *supra* note 72, at 114–15.

211 Crawley & Kagawa-Singer, *supra* note 22, at 41.

212 For a discussion of structural barriers affecting Hispanic's access to hospice and palliative care see *supra* section III.

15 million persons of Hispanic origin, were uninsured,[213] in part due to the undocumented status of a growing percentage of the persons in this category. Most undocumented immigrants do not qualify for government assistance.[214]

Perhaps the most important sign of an inadequate healthcare system is racism. A significant amount of literature addresses the existence of health disparities from a theory of racial inequities supported by social institutions.[215] Systematic discrimination at the provider level occurs as the result of unjust conscious or unconscious stereotyping.[216] Many studies show that, while African-Americans are more likely to require healthcare services than other groups, they are less likely to receive them.[217] Racism at the institutional level is expressed through policies that result in inadequate resources, lower quality of care and unequal access to care.[218]

With respect to African-Americans in particular, slavery, segregation and racism have shaped attitudes and beliefs about the use of advance directives, palliative care and hospice services.[219] Fear and mistrust of the medical establishment seem to be logical outcomes of a century of unethical experimentation,[220] and studies show that fear and mistrust are reasons African-Americans most cite for not using

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[213] Press Release, The Commonwealth Fund, *Hispanic and African American Adults are Uninsured at Rates One-and-a Half to Three Times Higher Than White Adults* (Aug. 1, 2006), *available at* http://commonwealthfund.org/Newsroom.aspx (search "adults are uninsured" in quotations, click on the press release name hyperlink).

[214] CRAWLEY & KAGAWA-SINGER, *supra* note 22, at 25.

[215] *See* David R. Williams & Toni D. Rucker, *Understanding and Addressing Racial Disparities in Health Care*, 21 HEALTH CARE FINANCING REV. 75, 87 (2000).

[216] *Id.* Even medical providers who are consciously opposed to racist behavior may fall back on unconscious negative racial attitudes and stereotypes when diagnosing and treating patients, particularly given the time pressures and complexity of clinical settings. UNEQUAL TREATMENT, *supra* note 72, at 162–64.

[217] *See Racial Discrimination*, *supra* note 101, at 57–58 (discussing how disparities exist between Whites and African-Americans with regard to treatment for several medical conditions, the amount of time doctors spend with minority patients, the number of doctor's visits and the aggressiveness of the doctors' treatment).

[218] *See infra* section III describing and discussing some of those policies.

[219] *Trusting*, *supra* note 101, at 193.

[220] *See, e.g.,* Vanessa Northington Gamble, *Under the Shadow of Tuskegee: African Americans and Health Care*, 87 AMER. J. PUB. HEALTH 1773, 1773–74 (1997).

hospice services.[221] Such fear is accentuated if there are few or no African-Americans among hospice workers, as is the case.[222] Similarly, many African-Americans distrust treatment choices that may imply that "less care [will be] provided;"[223] as a result, they favor more aggressive medical treatment when facing terminal illness and have fewer advance directives and living wills.[224] A hospice, with the accompanying termination of curative efforts, represents a decrease in care from at least one perspective, thus likely representing an unacceptable choice to persons who resist decreases in care.

Closely related to all of these concerns is another hypothesized reason for African-Americans' general reluctance to execute living wills: their perception of the healthcare industry as representative of the "microcosm of societal and historical events" they have endured.[225] For example, a study of African-American perspectives on end-of-life care and decision-making produced the following statements: "How good is a living will when it can be usurped by other laws or by doctors who are playing 'god'[?]," and "I am concerned about White people making decisions for me because I know the decisions they've made over the last 300 years concerning Black people."[226] The evidence thus tends to indicate that, at least among African-Americans, racism and discrimination have contributed to a belief system some have characterized as "fatalistic and pessimistic,"[227] one in conflict with the hospice philosophy.[228]

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[221] *See, e.g.,* Jackson et al., *supra* note 168. Donna J. Reese et al., *Hospice Access and Use by African Americans: Addressing Cultural and Institutional Barriers through Participatory Action Research*, 44 SOCIAL WORK 549, 551, 554 (1999).

[222] *See* Jackson et al., *supra* note 168, at 70; *see also* Reese et al., *supra* note 221, at 554.

[223] Timothy P. Daalerman et al., *An Exploratory Study of Advance Care Planning in Seriously Ill African-American Elders*, 100 J. NAT'L MED. ASS'N 1457, 1457 (2008).

[224] *See* Greiner et al., *supra* note 13, at 977; Washington et al., *supra* note 172, at 268.

[225] Waters, *supra* note 161, at 391.

[226] *Id. See also* Nicholas A. Christakis & Theodore J. Iwashyna, *Impact of Individual and Market Factors on the Timing of Initiation of Hospice Terminal Care*, 38 MED. CARE 528, 536 (2000) (suggesting that some minorities may be seen as less appropriate for more expensive curative care).

[227] Reese et al., *supra* note 221, at 552 (citing Sohail R. Rana, *Cancer Knowledge and Attitudes Of African American and White Adolescents: A Comparison Of Two Secondary Schools*, 3 J. ASS'N MINORITY PHYSICIANS 13 (1992)).

III. FLAWED HEALTHCARE POLICY CHOICES: THE PERPETUATION OF UNDER-UTILIZATION OF HOSPICE CARE

Separate from, but intertwined with, both the cultural influences addressed in section I and the disparities identified in section II, Hispanics and African-Americans share common policy barriers to end-of-life care in the form of hospice services. To the extent that income and healthcare coverage govern access to end-of-life care, much as they govern access to all types of care throughout the American healthcare system, the rules controlling coverage clash with cultural influences and disparities in a way that precludes—or at least places huge barriers in the way of—access for some African-American and Hispanic patients.[229] Moreover, institutional and academic barriers to cultural sensitivity existing within the healthcare professions reflect healthcare policy choices that have disadvantaged Hispanic and African-American patients in end-of-life decision-making.

A. The Clash With Payer Policies

Hospice care is covered by Medicare,[230] Medicare-managed health plans, and by Medicaid[231] in some states.[232] In addition, some private insurers pay for hospice benefits.[233] Furthermore some not-

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228 *Id.*

229 UNEQUAL TREATMENT, *supra* note 72, at 84 (stating that "[i]nsurance status, perhaps more thananany other demographic or economic factor, determines the timeliness and quality of healthcare, if it is received at all"). Income becomes relevant because a person with enough income can pay for care even in the absence of insurance coverage. *See* INST. OF MED., COVERAGE MATTERS: INSURANCE AND HEALTH CARE 28 (2001) [hereinafter COVERAGE MATTERS].

230 42 C.F.R. § 418.1; *see also* CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE & YOU 2009 5-1 to 5-26 (2009), *available at* http://lee.house.gov/uploads/10050.pdf.

231 NAT'L HOSPICE & PALLIATIVE CARE ORG., ISSUE BRIEF: MEDICAID AND HOSPICE CARE 1, 2 (2003) [hereinafter NHPCO ISSUE BRIEF]. *See also* 42 C.F.R. § 430.0 (describing Medicaid as a shared federal and state venture, with the federal government establishing general standards and states each determining their own eligibility standards).

232 *See* Lainie Rutkow, *Optional or Optimal?: The Medicaid Hospice Benefit at Twenty*, 22 J. CONTEMP. HEALTH L. & POL'Y 107, 123 n.102 (2005) (listing forty-seven states, plus the District of Columbia, that as of 2005 offered a Medicaid hospice benefit).

233 *See* OFFICE OF DISABILITY, U.S. DEPT. OF HEALTH & HUMAN SERVS., AGING AND LONG TERM CARE POLICY, HOSPICE BENEFITS AND UTILIZATION IN THE LARGE EMPLOYER PLAN 6 (2000)

for-profit and freestanding hospices may provide charity care for a limited number of patients.[234] At first glance, it appears as if Hispanics and African-Americans can access hospice services with equal ease as the majority population, as long as they have coverage through such a payer. However, Hispanics and African-Americans must hurdle substantial barriers buried within the healthcare payment structure to access such care; the same coverage rules apply to all, but those rules clash with the Hispanic and African-American cultural, socioeconomic and political experiences in ways that they do not with other patients' experiences.

This section explores how existing Medicare and Medicaid policies, in addition to the variance among states in Medicaid policies, may more significantly impact Hispanics and African-Americans than the general population. After identifying the existing policies and issues, this section proposes solutions and a modest agenda for further research that could reconcile Hispanics' and African-Americans' cultural beliefs and social attitudes with the benefits hospice care can offer.

1. Medicare Policies That Present Barriers

In at least two ways, current Medicare policies impose substantial hurdles in the paths of Hispanic and African-American patients who are eligible for and may wish to access hospice care. Specifically, patients must renounce curative care for their terminal illnesses to elect to receive Medicare-funded hospice services and must have primary care physicians who refer them to hospice care before Medicare will pay for that care.

a) Forgoing Curative Treatment[235]

Medicare is a health insurance program for people over 65, people with certain disabilities and people of all ages who suffer from

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(exploring the use of hospice services by the privately insured and finding that hospice benefits were offered in a wide variety of models across employers and plans).

[234] Karl A. Lorenz et al., *Charity for the Dying: Who Receives Unreimbursed Hospice Care?*, 6 J. PALLIATIVE MED. 585, 585 (2003) (finding from a National Home and Hospice Care Survey that only 3% of hospice patients received charity care).

[235] MEDPAC REPORT; *supra* note 5, at 172.

end-stage renal disease.[236] Through its parts A and B, and its pre-scription drug coverage, Medicare covers most of the healthcare needs of people under the program, and hospice care is included.[237] The Medicare rules provide, however, that hospice services will be covered only if no curative treatment for the terminal condition is sought at the same time.[238]

As discussed in section I, certain cultural characteristics of His-panics and African-Americans influence their views about end-of-life treatment choices.[239] Asking patients from these groups to choose comfort care to the exclusion of life-prolonging treatment may be in-congruent with their beliefs and could impose a barrier to access even for those who would want to experience the benefits of hospice, such as pain control and symptom management, social and emotional support and spiritual services. Similarly, asking patients to choose between the two presumes that patients are ready to embrace dying. Accepting death may be particularly problematic for groups who re-sist truth-telling to patients, such as those Hispanics whose families have requested that physicians refrain from revealing terminal diag-noses to patients.[240]

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[236] 42 U.S.C § 1395c; 42 C.F.R §§ 406.12 to .13.

[237] Medicare Handbook 2009, An Introduction to Medicare Coverage and Appeals, §§ 1.01–.08.

[238] The regulation only requires that the curative treatment waived be related "to the treatment of the terminal conditions for which hospice care was elected or a related condition." 42 CFR § 418.24(d)(2). *But see* Patient Protection and Affordable Care Act, § 3140(a) (2010) (es-tablishing, as part of healthcare reform, a demonstration program "under which Medicare beneficiaries are furnished, during the same period, hospice care and any other items or services covered under Medicare").

[239] *See supra* section I.C.

[240] *See supra* section I.A. for a description of some common beliefs and practices among His-panic groups. For this same reason, the requirement of many hospice providers that pa-tients with capacity must sign their own enrollment forms may be contrary to cultural val-ues. Consistent with Western medicine's values, law and ethics, the principles of autonomy and informed consent are implicit in the requirement that the patient him or herself sign the enrollment forms that will allow the receipt of hospice services. It is only in cases in which the patient lacks capacity that the next of kin or a patient representative may sign enroll-ment forms. This requirement may constitute a barrier to access among groups in which familism is an important value. *See supra* text accompanying notes 147–56 for a discussion of familism. Even if wanting to utilize hospice, family members may want to sign the papers without the patient's knowledge to protect the patient not only from the burden of decision-making at the end of life, but also from the pain of knowing about the terminal illness.

Eliminating the dichotomy between curative and palliative care, as some scholars and policy analysts have proposed,[241] thus may have a positive impact on at least some minorities. Doing so would not only help with coverage issues,[242] but it could also increase access to hospice services by accommodating the beliefs and practices of some Hispanics and African-Americans. One of the steps toward eliminating such a dichotomy is through the implementation of palliative care transition programs.[243]

Palliative care transition programs[244] or "bridge" programs[245] create a smooth path from hospitalization or home healthcare to hospice by offering an array of home-based services, including education in advance care planning, avoidance of unnecessary urgent hospitalizations, aggressive pain and symptom control, and facilitation of hospice enrollment.[246] Transition programs could not only encourage physicians to refer patients to palliative care earlier in the disease process,[247] but they also could have a positive psychological impact on those patients who refuse palliative care exclusively out of fear and mistrust of the healthcare system.[248]

Specifically, being able to receive both spiritual and counseling services and desired curative care may ease a patient's fear of being deprived of needed care because of prejudice or racism; this interme-

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241 *See generally* Wright & Katz, *supra* note 10, at 325–27; Cerminara, *supra* note 2; Huskamp et al., *supra* note 9, at 211; Stuart, *supra* note 23, at 671. *See also* Patient Protection and Affordable Care Act, § 3140(a) (2010) (establishing, as part of healthcare reform, a demonstration program "under which Medicare beneficiaries are furnished, during the same period, hospice care and any other items or services covered under Medicare").

242 *See* Cerminara, *supra* note 2, at 110.

243 *Id.*; Stephen R. Connor, *Development of Hospice and Palliative Care in the United States*, 56 Omega 89, 96 (2007).

244 *See* Elizabeth L. Ciemins et al., *An Evaluation of the Advanced Illness Management (AIM) Program: Increasing Hospice Utilization in the San Francisco Bay Area*, 9 J. Palliative Med. 1401, 1403 (2006).

245 Casarett & Abrahm, *supra* note 8, at 2057.

246 Ciemins et al., *supra* note 244, at 1404.

247 *See* Casarett & Abrahm, *supra* note 8, at 2062 (suggesting that they do not need to wait for a diagnosis that they have six months or less to live).

248 See *supra* section II (discussing African-Americans attitudes' regarding the healthcare system).

diate step, as a transition toward full hospice services with an attendant rejection of curative care, could result in more acceptance of hospice and increased utilization of hospice services.[249] A San Francisco Bay area study seems to support this analysis.[250] In this study, the implementation of a palliative care transition program[251] among patients whose life expectancy was six months or less, but who were not yet eligible for or ready to accept hospice, resulted in a notable increase of hospice utilization, especially among African-American patients.[252]

These findings seem to suggest that creating more palliative care transition programs may be a positive step toward eliminating the dichotomy between palliative and curative care to benefit Hispanics and African-Americans. Palliative care programs in hospitals emphasize the care of the "whole person,"[253] focusing on both physical pain and symptoms and "the person's goals of care"[254] through "direct involvement of the patient's family and healthcare providers."[255] Such emphasis on family involvement likely would be concordant with the family-centered style of decision-making characteristic of many Hispanics and African-Americans.[256]

A recent report on access to palliative care in the United States,[257] however, indicates that there are "notable disparities in geographical availability" of such programs, observing "strikingly low rates of pal-

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[249] *See* Johnson et al., *supra* note 16, at 222–23.

[250] *See generally* Ciemins et al., *supra* note 244.

[251] *Id*. at 1404 (utilizing home care and hospice staff to provide patients who were not ready for hospice but were eligible for home care with an array of home-based services including education in advance care planning, avoidance of unnecessary urgent hospitalizations, aggressive pain and symptom control and facilitation of hospice enrollment).

[252] *Id*. at 1409.

[253] R. SEAN MORRISON, NAT'L PALLIATIVE CARE RESEARCH CTR., AMERICA'S CARE OF SERIOUS ILLNESS: A STATE BY STATE REPORT CARD ON ACCESS TO PALLIATIVE CARE IN OUR NATION'S HOSPITALS 8 (2008), *available at* http.www.capc.org/reportcard/state-by-state-report-card.pdf [hereinafter REPORT CARD].

[254] *Id*.

[255] *Id*.

[256] *See supra* notes 147–56 (Hispanics) and 175 (African-Americans) and accompanying text.

[257] *See generally* REPORT CARD, *supra* note 253.

liative care programs in public and sole community provider hospitals."[258] In many instances, those hospitals are the only option for most of the uninsured population in need of healthcare,[259] and Hispanics and African-Americans tend to be uninsured in larger numbers than many other racial and ethnic groups.[260] There is a need for further research on availability to and the impact of palliative care transition programs on Hispanic and African-American patients, with a possible eye toward adoption of such programs in underserved areas.

b) Necessity That an Attending Physician Certify Terminal Condition

Another potential barrier to access that the Medicare hospice regulations indirectly create is the requirement that the hospice medical director consult with the patient's attending physician to certify the patient's terminal diagnosis.[261] Without a certification from an at-

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[258] *Id*. at 19.

[259] *Id*.

[260] U.S. Census Bureau, Income, Poverty and Health Insurance Coverage in the United States: 2008 at 22, (Sept. 10, 2009), http://www.census.gov/Press-Release/www/releases/income_wealth/014227.html. In 2008, 19.1 percent or 7.3 million of African Americans and 30.7 percent or 14.6 million of Hispanics were uninsured as compared to 10.8 percent or 21.3 million of white non-Hispanics.

[261] 42 C.F.R. § 418.3 (defining attending physician as "a doctor of medicine or osteopathy or a nurse practitioner whom the patient identifies as having the most significant role in determining and delivering his or her care at the time of hospice election"). *See also* Centers for Medicare and Medicaid Services, *Coverage of Hospice Services Under Hospital Insurance*, Medicare Benefit Policy Manual, Ch. 9, § 20.1, *available at* http://www.cms.hhs.gov/manuals/Downloads/bp102c09.pdf. Physicians at rural health clinics and federally qualified healthcare clinics are included in the definition of "attending physician". The Medicare regulations actually provide: "The hospice admits a patient only on the recommendation of the medical director in consultation with, or with input from, the patient's attending physician *(if any)*." 42 C.F.R. § 418.25(a) (emphasis added). The inclusion of the parenthetical "if any" should indicate that a medical director need only consult with an attending physician if the patient has an attending physician. *See* Centers for Medicare and Medicaid Services, *Coverage of Hospice Services Under Hospital Insurance*, Medicare Benefit Policy Manual, Ch. 9, § 10, [hereinafter Medicare Benefit Policy Manual] (explaining that "certification of terminal illness for hospice benefits shall be based on the clinical judgment of the hospice physician and the individual's attending physician *if he/she has one* or the medical director regarding the normal course of the individual's illness" (emphasis added)). In practice, however, in the experience of Professor Perez, who worked in hos-

tending physician that the patient is terminally ill, Medicare will not pay for hospice care.[262] Regulatory concerns about the costs of hospice care have even led to recent calls for more extensive physician involvement in the certification process than Medicare had required previously,[263] thus indicating that this requirement is not going to disappear any time soon. Such a requirement, however, may be particularly troublesome for Hispanic and African-American patients. An "attending physician," in Medicare parlance, is "a doctor of medicine or osteopathy . . . or nurse practitioner" that the patient identifies as having "the most significant role in the determination and delivery of . . . [that patient's] care."[264] Yet statistics demonstrate that Hispanics and African-Americans are more likely to depend on emergency room and clinic care for their healthcare needs,[265] thus lacking continuity of care with the same doctor. Some may not visit the doctor at all. For instance, key findings of a Commonwealth Fund survey from 2003[266] revealed that, when compared with whites and African-Americans, only 69 percent of Hispanic adults with health problems had at least one medical visit during the prior year, as compared to 83 and 84 percent respectively of the other groups.[267]

Some of these statistics are intrinsically related to being uninsured.[268] Lacking health insurance reduces the likelihood of having a regular doctor.[269] Moreover, language barriers may multiply the

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pice care for several years, an attending physician's participation often is required.

[262] 42 C.F.R. § 418.20(b).

[263] *See* 74 Fed. Reg. 18918 (proposing, in response to concerns about cost, regulatory amendments that would "encourage greater physician engagement in the certification process by focusing attention on the physician's responsibility to set out the clinical basis for the terminal prognosis indicated in the patient's medical records") *See also* Medicare Program; Hospice Wage Index for Fiscal Year 2010, 74 Fed. Reg. 39384 (Aug. 6, 2009) (codifying the proposal at 42 C.F.R. pt. 418.22).

[264] 42 C.F.R. § 418.3. *See* MEDICARE BENEFIT POLICY MANUAL, *supra* note 261, at § 20.1.

[265] UNEQUAL TREATMENT, *supra* note 72, at 29; CRAWLEY & KAGAWA-SINGER, *supra* note 22.

[266] MICHELLE M. DOTY, THE COMMONWEALTH FUND, HISPANIC PATIENTS' DOUBLE BURDEN: LACK OF HEALTH INSURANCE AND LIMITED ENGLISH (2003).

[267] *Id.* at vii.

[268] *Id.*

[269] *Id.* at 8–9 (survey indicated that across all racial and ethnic groups, those without insurance were more than twice as likely as those with insurance to not have a regular doctor).

problem; uninsured Hispanics who speak only Spanish lack regular physicians in greater percentages than do uninsured whites, with 66 percent of the former population reporting having no regular physician while 37 percent of the latter population reports the same.[270]

Having health insurance however, does not resolve the issue. Insured African-Americans and Hispanics are twice as likely as whites to rely upon a hospital clinic or outpatient department rather than on a private physician or other office-based provider as their regular source of care[271] for many reasons other than insurance status.[272] These include patients' preferences regarding racially and linguistically concordant physicians, geographical availability of resources, distrust of the healthcare environment,[273] and the existence of laws and policies that indirectly impact access.[274]

The answer is not to eliminate the requirement that a physician certify a patient's terminal condition; to suggest this is to ignore the real concerns that exist about devoting scarce healthcare resources to patients who do not require them.[275] The answer, however, may be to adjust the certification requirement so that some other healthcare provider, not necessarily an "attending physician," may certify the patient's eligibility for hospice services. It may be possible, for exam-

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[270] *Id.* at 9.

[271] UNEQUAL TREATMENT, *supra* note 72, at 110; *see also* Marsha Lillie-Blantin et al., *Site of Medical Care: Do Racial and Ethnic Differences Persist?* 1 YALE J. HEALTH POL'Y L. & ETHICS 15, 25, 28 (2001) ("Only 39 percent of Spanish speaking Hispanics reported that they used a doctor's office as their regular source of care, compared with 71 percent of English speaking Hispanics, 65 percent of African Americans and 80 percent of whites"). DOTY, *supra* note 266, at 11.

[272] *See generally* UNEQUAL TREATMENT, *supra* note 72 (exploring the causes of healthcare disparities in regard to access, and healthcare utilization among ethnic and racial minorities).

[273] *Id.*

[274] *See* Denise Burnette & Ada C. Mui, *Physician Utilization by Hispanic Elderly Persons: National Perspective*, 37 MED. CARE 362, 365–66 (1999) (listing studies that have found associations between race, ethnicity and physician utilization). *See also* Kathryn Pitkin Derose & David W. Baker, *Limited English Proficiency and Latino's Use of Physician Services*, 57 MED. CARE RES. & REV. 76, 84–86 (2000) (finding that the patients with limited English proficiency had a similar reduced number of physician visits than those who had no insurance or no regular source of care).

[275] *See* Cerminara, *supra* note 2 (In fact, far from being predisposed to limit physician involvement, the Department of Health and Human Services Centers for Medicare and Medicaid Services recently proposed increasing physician accountability for hospice admissions).

ple, for a broader range of providers, including nurse-practitioners or physician assistants, to provide the necessary certification, if research were to show that Hispanic or African-American patients are more likely to visit such intermediate-level providers than physicians.

Alternatively, the answer may lie in efforts to encourage Hispanic and African-American patients to see physicians more regularly, so that they have physicians who meet the definition of "attending physician" under the law. One option is to work on building the supply of physicians they are most likely to see,[276] and another may be to expand healthcare coverage so that more patients can establish regular physician-patient relationships. Current efforts at healthcare reform may resolve, at least to some extent,[277] the problems engendered by lack of health insurance, but they will not be satisfactory alone.

2. Barriers Inherent in the Medicaid System

The Medicaid program, an income-based government program administered by the states but partly funded by the federal government,[278] covers certain medical expenses of individuals meeting eligibility criteria.[279] The joint state-federal structure of this program likely negatively impacts access to hospice services by Hispanics and African-Americans. Although the federal government requires that states cover certain services through their Medicaid programs, coverage of hospice care is optional.[280] Each state determines which hos-

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[276] See generally Donald L. Gabard, *Increasing Minority Representation in the Health Care Professions*, 36 J. ALLIED HEALTH 165, 165 (2007); MISSING PERSONS: MINORITIES IN THE HEALTH PROFESSIONS, THE SULLIVAN COMMISSION ON DIVERSITY IN THE HEALTHCARE WORKFORCE (2003).

[277] See generally Adrianne Ortega, Note and Comment, *…And Health Care For All: Immigrants in the Shadow of the Promise of Universal Health Care*, 35 AM. J. L. & MED. 185, 186 (2009). Current efforts would not, for example, cover undocumented immigrants to any extent other than that to which they are already covered.

[278] See 42 C.F.R. § 430.0.

[279] Id.

[280] NHPCO ISSUE BRIEF, *supra* note 231. *See also* Rutkow, *supra* note 232, at 123 n.2 (At that time, forty-seven states and the District of Columbia covered hospice services to some extent) (listing states that cover hospice services before 2009). See CENTERS FOR MEDICARE & MEDICAID SERVICES, MEDICAID AT-A-GLANCE 1, 10 (2005), *available at*

pice services it will cover and the groups eligible to receive those services through Medicaid. Existing variations in requirements and eligibility among the states contribute to a fragmented system in which hospice is not equally accessible to minorities.[281] This sets the stage for a series of issues affecting Hispanics and African-Americans, as both groups are disproportionately enrolled in Medicaid as compared to other groups.[282]

One example lies within the requirements imposed by states that use Medicaid waiver programs.[283] In this context, waiver programs allow states to use Medicaid funds to cover long-term care services in the community instead of in nursing homes or other institutional settings.[284] Many of those waiver programs not only keep patients in the community with their families, but also provide more extensive services than hospices otherwise provide. However, access to hospice for terminally ill patients enrolled in Medicaid waiver programs may result in the loss of those additional benefits. For example, the Channeling waiver program,[285] available for residents of Miami-Dade and

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http://www.cms.hhs.gov/MedicaidGenInfo/Downloads/MedicaidAtAGlance2005.pdf. In 2009, New Hampshire became the forty-ninth state to cover hospice care through its Medicaid program. *See* N.H. Rev. Stat. Ann. § 126-A:4-e (2009).

[281] A. W. Dick et al., *Fragmentation of coverage and Patterns of Enrollment in Medicaid for Young Children: The Roles of Managed Care and Race/Ethnicity*, 17 ACAD. HEALTH SERV. RES. HEALTH POL'Y MEET (2000) (abstract), *available at* http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102272417.html.

[282] UNEQUAL TREATMENT, *supra* note 72, at 84.

[283] U.S. DEPT. OF HEALTH & HUMAN SERVS., MEDICAID STATE WAIVER PROGRAM DEMONSTRATION PROJECTS – GENERAL INFORMATION, http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/01_Overview.asp (last visited February 23, 2010) ("The Social Security Act authorizes multiple waiver and demonstration authorities to allow states flexibility in operating Medicaid programs.").

[284] THE KAISER FAMILY FOUNDATION, MEDICAID AND THE UNINSURED, MEDICAID HOME AND COMMUNITY-BASED SERVICE PROGRAMS: DATA UPDATE, http://www.kff .org/medicaid/upload/7720-03.pdf (last visited February 23, 2010) ("[d]eveloping home and community-based service (HCBS) alternatives to institutional care has been a priority for many state Medicaid programs over the last three decades").

[285] Florida Agency for Health Care Administration, *Alternatives to Nursing Homes*, *available at* http://ahcaxnet.fdhc.state.fl.us/nhcguide/alternatives.shtml#ChannelingWaiverProgram (last visited December 21, 2009) (describing the Channeling program as "a home and community-based services program that was implemented on July 1, 1985, and is operated through an annual contract with an organized health care delivery system in Dade and Broward Counties"). *See* Florida Agency for Health Care Administration, Home and Com-

Broward counties in the state of Florida, provides myriad services including case management, chore services, companion services, counseling, home health aides, personal care services and many other custodial and skilled services at the patient's residence; but Medicaid waiver recipients cannot receive those services (at least not with Medicaid paying the bill) once they access hospice services.[286]

For working caregivers, a reduction in supportive services is many times untenable and makes the difference between keeping the patient at home and having to place him or her in a nursing home.[287] Having to choose between services in this context, similar to the curative treatment context, again could constitute a barrier to early access to hospice care, or even a barrier to access to such care at all. Among patients for whom the involvement of family members in medical matters is important,[288] forcing this choice of services seems untenable. Thus, to permit access of one of these forms of services without the exclusion of the other, studies should focus on the feasibility and impact of integrating hospice care with the additional benefits available through some Medicaid waiver policies.

B. The Clash With Institutional and Academic Realities

Sections I and II of this Article explore the cultural and systemic factors that may influence the lower rate of utilization of hospice care by Hispanics and African-Americans. The foregoing portion of this section has discussed coverage-related barriers within the Medicare

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munity-Based Services (HCBS) Waivers, http://www.fdhc.state.fl.us/Medicaid/hcbs_waivers/index.shtml (last visited December 21, 2009) (describing the variety of home and community-based waiver programs in effect in the state of Florida).

[286] Interoffice Memorandum from Pamela Anne Thomas, Chief of Bureau of Managed Health Care, State of Florida Agency for Health Care Administration (Feb. 28, 2001), *available at* http://www.fdhc.state.fl.us/mchq/managed_health_care/mhmo/docs/Policy_Transmittals/01_04_Segments.pdf.

[287] *See generally* Ezekiel J. Emanuel et al., *Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and Their Caregivers*, 132 ANN. INTERNAL MED. 451, 451–58 (2000) (investigating the causes of the economic and emotional burdens imposed by terminal illness on patients and caregivers).

[288] *See supra* text accompanying notes 147–56 (discussing importance of familism to Hispanic patients); *see also* text accompanying note 178 (explaining that African-American patients "value the input of others, especially family members, in making end-of-life care decisions").

and Medicaid payment systems.[289] Additionally, even aside from coverage-related barriers, hospices as institutions have put into place policies that adversely affect these populations. Finally, a main issue discussed in both sections I and II was the importance of providing language and race-congruent physician-patient relationships. There is a lack of congruence between hospice policies and the realities of caregiving in many Hispanic and African-American households, a shortage of minority physicians and other healthcare professionals in the system, a general failure to appreciate cultural differences among healthcare professionals, and a shortage of interpreters who deal with the end-of-life issues of the United States' culturally diverse population.

1. The Need For An In-Home Primary Caregiver[290]

Institutional barriers may exist in the form of provider rules that have no connection with coverage requirements. For example, in at least one way, some hospices as institutions have adopted internal rules that might negatively impact access to their services among Hispanic and African-American patients.[291] Specifically, some hospices require the presence of a caregiver at the patient's home as a condition of providing services or may not admit patients without caregivers or whose caregivers are frail.[292]

This policy may impact Hispanics and African-Americans more than others because of many factors, including financial ability or in-

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[289] As noted earlier, most private insurance carriers impose the curative/palliative choice upon patients they cover, so that barriers exists in most private insurance coverage situations as well. *See* Huskamp et al., *supra* note 9, at 209.

[290] While neither Medicare nor Medicaid rules impose such a requirement, most hospices require the presence of a primary caregiver in the home, especially as the end nears. Robin Turner & Drew A. Rosielle, End of Life/Palliative Education Resource Center, #087 Medicare Hospice Benefit Part II: Places of Care and Funding 2nd ed, (2007), *available at* http://www.mcw.edu/fastFact/ff_87.htm.

[291] Such rules could also negatively impact the general population, but minorities are most likely to feel the impact.

[292] MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO THE CONGRESS: MEDICARE BENEFICIARIES ACCESS TO HOSPICE 1, 6 (2002) (citing an unpublished paper by J. Mahoney, Summit Business Group LLC., Beneficiaries' Access to the Medicare Hospice Benefit) (noting that "informants . . . reported that some hospices, as a policy, do not admit beneficiaries without competent caregivers").

ability to pay a caregiver outside of the family, the existence or non-existence of a solid family support system and the employment and health status of the family (or informal) caregivers that might volunteer to satisfy this hospice-imposed requirement. While Hispanic and African-Americans generally may have more family and social network support, they also may be more likely to have lower incomes[293] or be in poverty. Hispanic and African-American families thus likely depend more on paid employment to make ends meet, and are more likely to be unable to provide full-time caregiving at home themselves.[294]

In addition, as one study found, working African-Americans and Hispanics are more likely to reduce their employment hours or otherwise take a reduction in employment status in order to assist with a family member's care at home.[295] On one hand, this fact would tend to make it more likely that Hispanic and African-American patients could satisfy hospice requirements that a primary caregiver be in the home before services will be provided, but on the other hand, this means that doing so produces hardship for those populations. Hospice rules are more likely to burden Hispanic and African-American families with reduced employment as a result.[296]

2. Lack of Adequate Numbers of Healthcare Professionals From the Same or Similar Cultural Backgrounds

A good patient/doctor relationship is pivotal to building trust

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[293] CARMEN DENAVAS-WALT ET AL., U.S. CENSUS BUREAU, INCOME, POVERTY, AND HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2008, at 15 (2009), *available at* http://www.census.gov/hhes/www/poverty/poverty08.html.

[294] Kenneth E. Covinsky et al., *Reduced Employment in Caregivers of Frail Elders: Impact of Ethnicity, Patient Clinical Characteristics and Caregiver Characteristics*, 56 J. GERONTOLOGY 707, 711 (2001).

[295] *Id.*

[296] *Id.* This burden is not small. The Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatment (SUPPORT) confirms that, among families caring for a seriously ill patient, 20 percent had to stop working completely and 31 percent of families lost most of their savings. Donald J. Murphy & Leighton E. Cluff, *SUPPORT: Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments: Study Design*, 43 (1) J. CLINICAL EPIDEMIOLOGY V–X (1990).

and continuity of care.[297] As discussed in sections I and II, key factors positively contributing to this relationship are doctor-patient language[298] and cultural congruence.[299] Congruence in the patient-physician relationship is important in many domains;[300] however, perhaps the most influential domains of consideration in terms of providing good end-of-life care are those that involve ethnicity, language, beliefs about health and illness, values and method of decision-making. Healthcare providers with culturally discordant backgrounds from their patients may not possess the necessary linguistic and guidance skills to effectively address their patients' concerns.[301]

There are not enough minority physicians to address the needs of the population. In the case of African-Americans, historical events and developments within the medical profession effectively limited the access of African-Americans to medical education until the 1960s.[302] Although the number of minority medical school matriculants initially improved intermittently for a few decades, since the mid 1990s, the proportion of underrepresented minorities among medical school applicants had significantly decreased.[303] Today, minority physicians from all racial and ethnic groups comprise only nine percent of the country's physicians.[304]

The situation is no better among other healthcare professions. Findings of the 2004 report of the Sullivan Commission on Diversity in the Healthcare Workforce (the "Sullivan report")[305] show that,

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[297] COOPER & POWE, *supra* note 66, at 17–18.

[298] *See supra* notes 61–68 and accompanying text.

[299] *See supra* notes 38–41, 146–55 and 174–77 and accompanying text.

[300] COOPER & POWE, *supra* note 66, at 3. Socioeconomic status, gender, and age are among others. *Id*.

[301] *Id*. It is important to emphasize, however, that although race concordance may be positively associated with certain health benefits, it does not merit a conclusion that patients should only and always see practitioners of the same race as theirs.

[302] *See generally* UNEQUAL TREATMENT, *supra* note 72, at 105–108.

[303] *Id*. at 121–22. According to the Institute of Medicine report, some evidence indicates that shifts in policies regarding affirmative action and higher education admissions procedures may explain some of this change. *Id*.

[304] *Id*. at 114.

[305] MISSING PERSONS: MINORITIES IN THE HEALTH PROFESSIONS, THE SULLIVAN COMMISSION ON

while minorities in general[306] make up about twenty-five percent of the population in the United States, only nine percent of the nation's nurses and five percent of dentists are from such minorities. This gap extends to academia where only ten percent of baccalaureate nursing faculty, 8.6 percent of dental and 4.2 percent of medical faculty belong to a minority group.[307]

Although no studies establish a definite association between health professions diversity and health outcomes,[308] it is still imperative to develop policies to facilitate the training of minority physicians and other healthcare providers. Research shows that minority professionals are more likely to practice in minority and medically underserved communities,[309] are more likely to accept Medicaid patients, and tend to serve other disadvantaged populations to a greater extent than non-minority professionals.[310] Additionally, minority professionals may experience less difficulty than members of the healthcare professions from other backgrounds in understanding the cultural influences operating on patients of their same racial or ethnic backgrounds. Non-minority healthcare professionals may learn to appreciate such influences through exposure to them and training about them,[311] but patients requiring hospice services are still more likely to interact with healthcare professionals in a meaningful way if they share their own racial or ethnic background.[312]

While several national programs, partnerships, and professional organizations have joined forces to expand the presence of minorities

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DIVERSITY   IN   THE   HEALTHCARE   WORKFORCE   (2004), *available at* http://www.jointcenter.org/healthpolicy/docs/SullivanExecutiveSummary.pdf [hereinafter THE SULLIVAN COMMISSION].

306 *Id.* at 2. These include African-Americans, Hispanics and American Indians.

307 *Id.*

308 U.S. DEPT. OF HEALTH & HUMAN SERVS., THE RATIONALE FOR DIVERSITY IN THE HEALTH PROFESSIONS: A REVIEW OF THE EVIDENCE 6 (2006) [hereinafter RATIONALE FOR DIVERSITY].

309 UNEQUAL TREATMENT, *supra* note 72, at 115.

310 RATIONALE FOR DIVERSITY, *supra* note 308, at 9.

311 *See infra* section III.B.3.

312 *See e.g., supra* text accompanying notes 142–46 (discussing positive results of race/ethnicity concordance among patients and physicians); 219–28 (discussing mistrust of attempts to reduce intensiveness of care among African-Americans related to historical discrimination by other groups).

in the healthcare workforce,[313] some extrinsic barriers remain. For example, in the primary and secondary education levels, minority students lag behind compared to non-minority students in both academic skills and rates of high school completion.[314] At higher educational levels, minority students also lag behind non-minority students in both college enrollment and college graduation rates.[315] Other barriers also exist at the college level. For example, "first-generation college students often face unique adaptation and retention needs"[316] such as development of specific achievement goals, development of academic related skills, self confidence and motivation.[317] In addition, current college admission practices discourage enrollment of students from two-year college programs, which are traditionally attended by minorities seeking careers in the health professions.[318]

In sum, several policy changes must coalesce to remediate the lack of minority professionals in the healthcare system. As recommended in the Sullivan report, the starting point should be the investment of resources in elementary and secondary public education to assure a solid educational foundation among minorities.[319] Beyond that level, colleges should increase programs aimed at providing support to enable the successful transition of two-year college students to four-year colleges. They also should provide additional services to assist minorities, such as scholarship information, and other support services that could help better pave the way for minority students to enter the healthcare professions.

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[313] *See* RATIONALE FOR DIVERSITY, *supra* note 308, at 2 (describing programs and initiatives pioneered and funded by various organizations and the federal government).

[314] THE SULLIVAN COMMISSION, *supra* note 305, at 73.

[315] *Id*.

[316] *Id*. at 76. Needs of those students are different from the needs of other students whose parents or grandparents are able to share college experiences with them. *Id*.

[317] *See* VERONICA A. LOTKOWSKI, THE ROLE OF ACADEMIC AND NON-ACADEMIC FACTORS IN IMPROVING COLLEGE RETENTION, at vii (2004), *available at* http://www.act.org/research/policymakers/pdf/college_retention.pdf.

[318] THE SULLIVAN COMMISSION, *supra* note 305, at 77.

[319] *Id*. at 75.

3. Failure to Appreciate Cultural Influences Among Majority Healthcare Professionals

Added to the lack of minority professionals, the United States' healthcare system confronts yet one more serious problem in trying to care for ethnic and racial minorities. Lack of (or a perceived lack of) sensitivity toward minorities among majority healthcare professionals, especially physicians, underlies many of the issues presented in sections I and II of this article. While this lack of (or perception of lack of) sensitivity may arise from application of the existing principles of the dominant value system,[320] it also may be due to lack of knowledge regarding cross-cultural issues.[321]

Cultural competence[322] has been equated in importance to scientific competence in the delivery of healthcare.[323] It refers to a complex set of knowledge base, attitudes and skills of healthcare practitioners, and also to "specific organizational, system or service attributes."[324] The National Institute of Medicine, in its report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health*, recommends the integration of cross-cultural education into the training of healthcare professionals as means of providing quality care and reducing healthcare disparities.[325]

In spite of this, studies confirm that efforts to educate current and future healthcare professionals regarding cross-cultural issues, especially in end-of-life care, may still be inadequate. Although charitable foundations such as Robert Wood Johnson and others dedicate

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320 *See supra* text accompanying notes 81–82.

321 *See generally* UNEQUAL TREATMENT., *supra* note 72; Searight & Gafford, *supra* note 38; Kawaga-Singer & Blackhall, *supra* note 87, at 2994. Provider bias and stereotypical beliefs may play a role in decision-making.

322 Pamela Wish Garrett et al., *What do Non-English-Speaking Patients Value in Acute Care? Cultural Competency from the Patient's Perspective: A Qualitative Study*, 13 ETHNICITY & HEALTH 479, 479 (2008).

323 *See generally* Association of Medical Colleges, http://www.aamc.org. *See also* The Office of Minority Health, What is Cultural Competence?, http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=11 (last visited Dec. 21, 2009).

324 Garrett et al., *supra* note 322, at 480.

325 UNEQUAL TREATMENT, *supra* note 72, at 214.

considerable funds to educate medical students on palliative care and other end-of-life issues,[326] studies show that medical education about palliative and end-of-life care is insufficient. One study collecting the opinions of deans of medical schools in the United States found that sixty-seven percent of those deans supported medical students' and residents' beliefs that medical schools did not spent adequate time learning about palliative care or end-of-life issues.[327] Other studies have reported that very few schools offer palliative care courses.[328] Yet another study found that among those medical schools that did offer such courses, the time dedicated to the subject in the curriculum was less than twelve hours on average, across the entirety of a student's medical education.[329]

With regard to cultural training, some courses on sociocultural issues exist in medical schools, and some integrate education about sociocultural issues into the general curriculum,[330] but there is limited information on the specifics, such as the number of hours of study or the requirements of such courses.[331] The extent of cross-cultural education on graduate and continuing medical education is unknown.[332]

Overall, the system should include more education of this sort, as well as more incentives to participate in such education if offered at the graduate and continuing medical education level. To effectively

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[326] *See generally* Robert Wood Johnson Foundation, *Workshops Instruct Osteopathic Medical School Faculty on End-of-Life Care* (Mar. 16, 2004), *available at* http://www.rwjf.org/pr/product.jsp?id=16630; *see also* Med. College of Wisconsin, *Medical School Palliative Care Education Project*, http://www.mcw.edu/palliativecare/medschoolproject.htm (last visited Dec. 21, 2009) (describing a program funded by charitable foundations).

[327] Amy M. Sullivan et al., *End of Life Care in the Curriculum: A National Study of Medical Education Deans*, 79 ACADEMIC MED. 760, 763 (2004).

[328] Porter Williamson et al., *Improving Knowledge in Palliative Medicine with a Required Hospice Rotation for Third Year Medical Student*, 79 ACADEMIC MED. 777, 778 (2004). Of 126 medical schools surveyed, only four offered such programs.

[329] George E. Dickinson, *End of Life and Palliative Care Issues in Medical and Nursing Schools in the United States*, 31 DEATH STUDIES 713, 717–18 (2007).

[330] *See* UNEQUAL TREATMENT, *supra* note 72, at 202 (discussing the findings of four literature searches conducted since 1978). As recently as 1999, only seventeen programs teaching cultural diversity were identified in the U.S, the U.K, Canada and Australia.

[331] *Id*.

[332] *Id*.

educate professionals and other healthcare professionals about cul-
turally sensitive end-of-life care, it is necessary to constantly reevalu-
ate existing educational training models and actively seek new in-
formation through research to develop effective new models.[333]
Quality end-of-life care may require "embracing the cultural differ-
ences and perspectives of patients and staff alike"[334] and conducting
further research into healthcare delivery models that support a range
of preferences at the end of life while ensuring access to hospice by
minorities whose values are not congruent with the current system.
Efforts at the policy level should emphasize cultural training, either
including it as a mandatory requirement of licensure[335] or creating a
system of rewards[336] for healthcare providers affirmatively pursuing
such educational opportunities.

IV. Conclusion

All patients bring a complex mix of cultural influences to any
discussion of healthcare decision-making, especially end-of-life care.
Generally speaking, patients of Hispanic and African-American

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[333] *Id.*

[334] Crawley & Kagawa-Singer, *supra* note 22, at 41.

[335] *E.g.*, N.J. Stat. Ann. § 45:9-7.3 (West 2005); *see* Joseph R. Betancourt et al., *Cultural Compe-tence and Health Care Disparities: Key Perspectives and Trends*, 24 Health Aff. 499, 502 (2005) (describing state-level imposition of continuing medical education requirements in cultural competence).

[336] *See, e.g.*, A Multi-Pronged Approach to Meeting the Needs of Limited English Proficient Enrollees in a Medicaid Managed Care Organization, Presentation at the Third National Conference on Quality Health Care for Culturally Diverse Populations: Advancing Effective Health Care Through Systems Development, Data, and Measurement (October 3, 2002), *available at* http://www.diversityrx.org/ccconf/02/w_c6.htm (last visited December 21, 2009) (describing presentation by employees of a Medicaid managed care organization pro-viding financial incentives for language proficiency in certain non-English languages). *Cf.* U.S. Dept. of Health & Human Servs., *Overall System Standards and Implementation Guide-lines*, in Cultural Competence Standards in Managed Care Mental Health Services: Four Underserved/Underrepresented Racial/Ethnic Groups, http://mentalhealth.samhsa.gov/publications/allpubs/sma00-3457/default.asp (last vis-ited December 21, 2009) (detailing as a cultural competence plan implementation guideline the "[d]evelopment of rewards and incentives (e.g., salary, promotion, bonuses) for cultural competence performance, as well as sanctions for culturally destructive practices (e.g., dis-crimination)").

backgrounds in particular differ in significant ways from Caucasian patients, around whose values and belief systems Western medicine and law generally have developed. In the area of end-of-life decision-making, the differing perspectives of Hispanic and African-American patients seem to have contributed to a much lower rate of hospice usage than among the Caucasian population, and this Article has identified some of the institutionalized ways in which the healthcare system could discourage patients from accessing, rather than encourage them to access, the physical, psychological and social benefits that hospice care can offer.

Specifically, this Article has demonstrated that a number of features of the current hospice system, ranging from payer rules to institutional barriers, clash with the cultural influences and socio-political systemic realities of many Hispanic and African-American patients. Hispanics are influenced by familism and language barriers; African-Americans are influenced by faith and mistrust. Both, along with other racial and ethnic minorities, suffer from the healthcare disparities pervading America's deeply flawed healthcare system.

Research should be conducted to investigate whether certain changes in the existing system could help alleviate the under-utilization of hospice services among Hispanic and African-American patients. Palliative care transition programs deserve further study, as does the idea that someone other than an attending physician might be able to consult with the hospice medical director to certify a patient's terminal illness for patients who have no attending physician. Policymakers should re-examine state-specific Medicaid waiver programs to ensure that the provisions governing payment for hospice services do not require the foregoing of other services available as part of end-of-life care. Studies should investigate and attempt to identify alternatives to hospice-specific rules that require in-home primary caregivers before providing in-home services to a patient because of the negative impact that requirement might have on Hispanic and African-American patients and their families. Finally, increasing the cultural sensitivity of the healthcare professions–whether through expanding the number of minority healthcare professionals, increasing the cultural competency of majority healthcare professionals, assuring accurate communication through adequate interpreter services, or some combination of these steps–deserves se-

rious consideration.

    Patients of Hispanic and African-American backgrounds should not be left to grapple with the tragedy of terminal illness without support, as Pandora was without support when opening her box.[337] Rather, policymakers and healthcare providers should concentrate on assuring fairness in access to hospice care, an important resource at the end of life, as a way to help such patients and their families cope.

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[337] *See supra* text accompanying notes 2–4.