

CHAPTER 19

ETHNICITY AS A FACTOR

KIMBERLY S. JOHNSON AND RAMONA L. RHODES

INTRODUCTION

If projections are correct, by 2050 non-Hispanic whites will no longer make up a majority of the US population. Due primarily to higher birth rates and immigration, the growth in the minority population will substantially outpace that of non-Hispanic whites over the next four decades. Persons of African American (or black) race and Hispanic (or Latino) ethnicity, the two largest minority groups, currently make up 13% and 16% of the US population, respectively. By 2050, Hispanics are expected to represent 30% of the US population (Ortman and Guarneri, 2009). This projected increase in racial and ethnic diversity is not limited to children and young adults but also includes older Americans. Over the next two decades, the proportion of older adults who are racial and ethnic minorities will increase from 21% to 28%, with the growth in the proportion of African Americans and Hispanics expected to be two to three times higher than that of older non-Hispanic whites (US Department of Health and Human Services, 2013a).

With an increasingly diverse racial and ethnic population comes a myriad of cultures. “Culture” refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. Because culture significantly influences the experience of serious illness and death, including explanatory models of illness, communication, preferences for care, use of health-care services, and quality of life, attention to cultural beliefs is fundamental to delivering high-quality palliative care. The issue is especially challenging for a number of reasons. First, as the population grows more diverse, clinicians will increasingly find themselves caring for patients whose cultural backgrounds differ from their own. When clinicians lack skills at acknowledging and respecting the importance of cultural considerations in clinical care, such cross-cultural encounters are ripe for misunderstandings, conflict with patients and families, and lower quality care. Another issue is the wide variation in cultural beliefs, values,

and practices that exist even among individuals within the same racial or ethnic group. That is, the extent to which patients and families adhere to common cultural beliefs and practices will vary based on other factors, such as acculturation or socioeconomic status. Because of this variation, there is no substitute for attempting to learn about the values and preferences of individual patients and families in real-time clinical encounters through thoughtful inquiry. Clinicians who make assumptions about individuals based solely on racial or ethnic identity risk stereotyping. However, even with this caveat, given the profound influence of culture on the experience of serious illness, some knowledge of beliefs, practices, and challenges that may be more common for one racial or ethnic group than for another provides an important framework for clinicians caring for culturally diverse groups of patients (Kagawa-Singer and Blackhall, 2001; Crawley et al., 2002).

This chapter focuses on the experience of those of African American (or black) race and Hispanic (or Latino) ethnicity, the two largest minority groups in the United States. For the most part, the term “African Americans” or “blacks” in this chapter refers to those with a shared history who are descendants of enslaved blacks within the boundaries of the present United States. However, some immigrants from African, Caribbean, Central American, and South American nations, and their descendants, may be identified or self-identify with the term. The term “Hispanic” or “Latino” refers to native or foreign-born persons from Latin America. Nearly two-thirds of US Hispanics or Latinos are native born. Those of Mexican ancestry make up two-thirds of Hispanics in the United States with significantly fewer reporting Puerto Rican, El Salvadoran, Cuban, or Dominican Republican, ancestry (Pew Hispanic Center, 2011). Although Latin American culture is diverse and influenced by country of origin and social class, there are some important commonalities of language and culture among US Hispanics or Latinos. In this chapter, we discuss access to and quality of palliative care for African Americans and Hispanics; highlight cultural beliefs, values, and preferences that may influence care; and suggest strategies and future directions for health-care providers, organizations, policymakers, and researchers that may improve care for racially and ethnically diverse populations.

DISPARITIES IN THE QUALITY OF HEALTH CARE

Racial and ethnic disparities in access to and quality of health care are widely documented for African Americans and Hispanics compared to non-Hispanic whites. For example, compared to non-Hispanic whites, both African Americans and Hispanics receive lower quality care and have higher rates of morbidity and mortality from HIV, diabetes mellitus, and some cancers (lung, prostate, stomach, and breast for African Americans; cervical and liver for Hispanics). They are also less likely to receive

appropriate cardiac medications or procedures for coronary artery disease, and African Americans have a lower life-expectancy than non-Hispanic whites (National Research Council, 2003). Although both minority groups are less likely to have health-care insurance or a usual source of care, these factors do not entirely account for health-care disparities. Even when income, health insurance, and access to care are accounted for, many racial and ethnic disparities in health care persist, suggesting that other factors, such as health-care providers' bias, stereotyping, prejudice, and clinical uncertainty, may contribute (National Research Council, 2003). Despite national initiatives to reduce and eliminate health-care disparities, there has been little improvement in many areas and worsening disparities in others (US Department of Health and Human Services, 2013b).

Racial and ethnic disparities in care extend throughout the health-care continuum and include not only disease prevention, early diagnosis, and curative treatment but also the care of patients living with advanced, serious illness. For example, compared to whites, bereaved caregivers of African Americans report less satisfaction with the overall quality of end-of-life care (Welch, Teno, and Mor, 2005). Other research documents lower quality care for minorities across multiple domains, including communication and pain management, lower rates of advance care planning, and lower rates of hospice enrollment (Hofmann, 1997; Gordon, 2006; Smith, 2007; Mack, 2010; Smith, 2009; Cintron, 2006; Carr, 2011; NHPKO, 2013; Medicare Payment Advisory Commission, 2013).

COMMUNICATION

Racial and ethnic minorities with serious illness and their families experience lower quality communication than non-Hispanic whites. Compared to whites, bereaved family members of African Americans report more concerns with family support and provider communication, including the extent to which providers share information (Welch et al., 2005). Seriously ill African Americans (versus whites) rate physician communication as less informative, supportive, and partnering and are less likely to report that physicians elicited treatment preferences or listened to their concerns (Hofmann et al., 1997; Gordon et al., 2006; Smith, Davis, and Krakauer, 2007). Even when communication occurs, the outcomes may differ by race. For example, in a study of patients with advanced cancer, end-of-life discussions between African Americans and their doctors were less likely to result in care consistent with patients' stated preferences compared to similar conversations between whites and their doctors (Mack et al., 2010; Loggers et al., 2009). Highlighting the importance of cultural considerations in communication in palliative care and similar to research in primary care settings, patients' ratings of communication quality tend to be higher in race-concordant (African American patient and African American physician) than race-discordant (African American patient and white physician) encounters (Gordon, Street, Sharf, Kelly, et al., 2006; Cooper et al., 2003). Because minorities are significantly underrepresented in the clinician workforce

compared to the general population, these data further underscore the importance of clinicians' knowledge and skills in navigating cross-cultural encounters.

Issues related to the quality of communication are further magnified in encounters between physicians and their Hispanic patients with limited English proficiency (LEP). Nearly three-fourths of Hispanics who live in the United States speak Spanish at home, and fewer than one in four Hispanic immigrants reports being able to speak English very well. In contrast, the vast majority of US-born Hispanics and later generations of Hispanics speak English fluently (Pew Hispanic Center, 2007b). Persons with LEP have less access to health care and are less satisfied with the quality of care. (Ngo-Metzger et al., 2007). In the absence of a readily available interpreter, clinicians may either attempt to communicate in English with Spanish-speaking patients with LEP or use family members or untrained staff. Such practices are more likely to lead to errors in communication than when professional interpreters are used (Flores et al., 2010). These errors, which may include intentional or unintentional omissions of information and alterations in content, are particularly problematic in the types of conversations that are common in palliative care, including those involving breaking bad news and eliciting goals of care or treatment preferences. Therefore, whenever possible and especially during conversations about goals and preferences, encounters with patients of LEP should be facilitated by a professional interpreter (Smith, Sudore, and Perez-Stable, 2009). Although the use of trained interpreters improves communication, even when an interpreter is involved clinicians may still provide less information and emotional support in encounters with language-discordant seriously ill patients and their families, and errors in interpretation may still occur (Ngo-Metzger et al., 2007; Thornton et al., 2009; Pham et al., 2008). As in race-concordant patient-physician interactions, patients with language-concordant physicians report higher satisfaction with care than those with language-discordant physicians (Ngo-Metzger et al., 2007; Fernandez et al., 2004).

PAIN MANAGEMENT

Compared to whites, African Americans and Hispanics across age groups, diagnoses, and settings are less likely to have their pain appropriately assessed and treated. Prescribers are more likely to underestimate pain and less likely to treat pain based on established guidelines in seriously ill patients in these minority groups. Also, opioids may not be as accessible to patients who live in predominantly minority neighborhoods since pharmacies in these areas are less likely to stock adequate supplies of opioids than those in predominantly non-Hispanic white neighborhoods (Anderson, Green, and Payne, 2009; Cintron and Morrison, 2006). Even when opioids are prescribed and available, African Americans and Hispanics may still be unable to obtain them because of lack of insurance and inability to afford the medications. Concerns related to addiction, hastening death, or fear of other side effects may also serve as a barrier to the appropriate use of these medications in seriously ill minorities (Rhodes et al., 2015).

ADVANCE CARE PLANNING

African Americans and Hispanics are less likely than whites to complete an advance directive, to discuss their preferences for end-of-life care with family and friends, or to have a do not resuscitate order during hospitalization (Eleazer et al., 1996; Kiely et al., 2001; Kwak and Haley, 2005; Morrison et al., 1998; Murphy et al., 1996; Carr, 2011; Carrion, Nedjat-Haiem, and Marquez, 2013). One barrier to advance care planning for minorities is lack of knowledge. Compared to whites, African Americans and Hispanics have less knowledge of advance directives, and health-care providers are less likely to engage them in advance care planning (Hofmann et al., 1997; Morrison et al., 1998; Murphy et al., 1996; Carr, 2011; Carrion et al., 2013; Carrion et al., 2013; Cohen et al., 2010; Carr, 2012; Volandes et al., 2008a, b; Fischer et al., 2012; Braun et al., 2008; Morrison and Meier, 2004; Kelley, Wenger, and Sarkisian, 2010; Waters, 2001). Even when minorities want to have discussions about their preferences for end-of-life care, they may not do so if such communication is not initiated by healthcare providers (Hofmann et al., 1997; Morrison and Meier, 2004; Kelley, et al., 2010; Waters, 2001). Language barriers and limited education may further increase the difficulty in completing advance directives for Hispanics (Carr, 2012; Volandes et al., 2008a, b; Fischer et al., 2012). Additionally, certain beliefs that are more common among African Americans than whites may serve as a barrier to advance care planning, including the belief that planning for death may initiate the process of dying; discussions about preferences for end-of-life care should occur close to death; their health-care wishes even if documented in an advance directives will not be honored; and they will receive lower quality care if they have an advance directive (Phipps, True, Harris, et al., 2003; Torke et al., 2005; Caralis et al., 1993; Bullock, 2006). As described later, mistrust of the health-care system, spiritual beliefs, and preferences for care may also contribute to lower rates of advance care planning among minorities.

African Americans and Hispanics place great value on the importance of family, which may include not only nuclear family but also distant relatives and fictive kin—friends or nonrelatives who have similar status to blood relatives. Both groups are more likely than whites to feel that decisions about end-of-life care should be made by their family, which is counter to the emphasis on patient autonomy in US culture (Smith et al., 2009; Kwak and Haley, 2005; Carrion, Nedjat-Haiem, Martinez-Tyson, et al., 2013; Carr, 2012; Phipps, True, Harris, et al., 2003; Torke et al., 2005; Bullock, 2006; Born et al., 2004; Phipps, True, and Murray, 2003). Because African Americans and Hispanics more often defer decision-making to family, they may believe that formal documents are not needed and that family will use their own judgment “when the time comes” (Smith et al., 2009; Torke et al., 2005; Phipps, True, and Murray, 2003). As such, a large number of family and friends may be present at the bedside or in family meetings and may make decisions about the patient’s care collectively.

USE OF HOSPICE AND PALLIATIVE CARE SERVICES

African Americans and Hispanics enroll in hospice at lower rates than whites. Although African Americans currently make up 13.1% of the population, they account for only 8.6% of hospice patients nationwide. Hispanics make up 16.9% of the US population but only 6.9% of total hospice patients (US Census Bureau, 2012; National Hospice and Palliative Care Organization, 2013). Similarly, among Medicare beneficiaries, the largest group of hospice enrollees, 47% of whites who died in 2011 used hospice compared to 35% of African Americans and 38% of Hispanics (Medicare Payment Advisory Commission, 2013). A number of factors may explain the lower use of hospice services by minorities. First, African Americans and Hispanics have less knowledge of hospice services than whites, including information about services provided, eligibility, and how hospice care is funded (Born et al., 2004; Colon, 2005; Selsky et al., 2012; Rhodes, Teno, and Welch, 2006; Reese et al., 1999; Ludke and Smucker, 2007; Johnson, Kuchibhatla, and Tulsy, 2009). Research also suggests that African Americans are often not informed about hospice as an option for end-of-life care and as a group have less favorable beliefs about hospice care, including the belief that hospice causes one to die before one's time and the beliefs that those who enroll in hospice get "no treatment" (Rhodes et al., 2006; Reese et al., 1999; Ludke and Smucker, 2007; Johnson et al., 2009; Rosenfeld et al., 2007). For Hispanics with LEP, language may limit providers' abilities to communicate with and provide comfort and support to patients and families, which may lead to underutilization of services. For both groups, the expectation that family members and friends will provide care at the end of life may also serve as a barrier to hospice enrollment because of concerns about hospice staff interfering with this care (Born et al., 2004). Additionally, although they are a tremendous source of assistance with physical care and provide a great deal of psychosocial and emotional support, sometimes family members themselves may serve as a barrier to hospice enrollment, especially when their preferences for care differ from that of the patient. For example, even when patients are ready to move forward with care focused on comfort, they may continue to pursue aggressive treatment because they do not wish to disappoint family members. Finally, because of mistrust of the health-care system and spiritual beliefs, African American and Hispanic patients and their family members may be less willing to accept a poor prognosis, which may make discussions about end-of-life care and hospice even more challenging (Smith et al., 2009; Rhodes et al., 2015).

Given improved outcomes for patients and families who enroll in hospice compared to those who receive conventional care, increasing hospice enrollment for minorities may reduce some disparities in the quality of end-of-life care (Baer 2000; Teno, Clarridge, et al., 2004)). For example, among African Americans who enroll in hospice, some disparities in care, such as family ratings of overall satisfaction and concerns about spiritual or emotional support and communication, are reduced when compared to the

general population (Rhodes, Teno, Connor, 2007). Additionally, hospice enrollment may provide minorities with access to services that may otherwise be difficult for them to obtain. African American cancer patients, for example, endorse a greater need than whites for the kinds of services that hospice provides (Fishman, 2009).

Although African American and Hispanic hospice enrollees have similar or longer lengths of stay than whites, there is some evidence that the experience of minority hospice enrollees, specifically African Americans, may differ from that of whites (Park et al., 2012; Colón and Lyke, 2003; Johnson, Kuchibhatla, and Tulsy, 2011). African Americans are more likely to disenroll from hospice to pursue potentially life-prolonging interventions like CPR, mechanical ventilation, and invasive medical therapies (Johnson, Kuchibhatla, Tanis, et al., 2008; Kapo, MacMoran, and Casarett, 2005). This is important because there is evidence that receipt of such interventions, while common among hospice disenrollees, may not significantly increase life expectancy but may reduce quality of remaining life (Carlson et al., 2010). Also, hospices with a large proportion of African American enrollees receive lower ratings from bereaved family on care coordination and overall quality (Rhodes, Xuan, and Halm, 2012). While there is currently little data, small studies of home-based and in-patient palliative care suggest similarly favorable outcomes for whites and African Americans who use these services, including increased satisfaction, greater rates of home deaths and hospice referrals, and increased documentation of treatment preferences (Ciemins et al., 2006; Zaide et al., 2012; Holley et al., 2009).

CULTURAL BELIEFS, VALUES, AND PREFERENCES

As in other areas of health care, racial and ethnic disparities in the quality of palliative and end-of-life care are multifactorial. Provider factors such as bias, stereotypes, and poor communication, as well as health-care policies that fail to consider cultural diversity, may contribute to disparities in health-care access and quality (National Research Council, 2003). Patient factors are also important. Compared to whites, African Americans and Hispanics have lower incomes, lower levels of education, lower rates of health insurance coverage, and lower levels of health literacy—all of which are associated with poorer health outcomes and less access to care (National Research Council, 2003; US Department of Health and Human Services, 2014a, 2014b; National Center for Education Statistics, 2006). Health literacy is the degree to which individuals are able to obtain, process, and understand basic health information and services needed to make appropriate health decisions (National Center for Health Statistics, 2012). Lower levels of health literacy are associated with less use of preventive services, less knowledge of medical conditions and treatments, higher rates of uninsurance, higher rates of hospitalization, and poorer self-reported health status (Williams et al., 1998; Baker et al.,

1998; Baker et al., 1997; Scott et al., 2002; Bennet et al., 1998). In fact, there is some evidence that education and health literacy are more strongly associated with preferences for end-of-life care than race and that the use of video images in advance care planning may address these factors (Vollandes et al., 2008a, 2008b). Patient factors, which limit access to palliative care, are further compounded by language barriers and immigration status for some Hispanics. Those who are undocumented may not be as forthcoming with medical information or health concerns because of fear of deportation (Smith et al., 2009).

In addition to sociodemographic factors, cultural beliefs, values, and preferences are also important determinants of health and use of health-care services. These factors often shape the experience of illness and death and guide medical decision-making (US Department of Health and Human Services, 2014c). Among those that are especially relevant to palliative and end-of-life care for minorities are preferences for care, spiritual beliefs, and mistrust of the health-care system (Kagawa-Singer and Blackhall, 2001; Crawley et al., 2002; Smith et al., 2009; Crawley et al., 2000; Krakauer, Crenner, and Fox, 2002; Johnson, Kuchibhatla, and Tulsky 2008).

Preferences for End-of-Life Care

Compared to whites, African Americans and Hispanics are more likely to want life-sustaining therapies, such as cardiopulmonary resuscitation and mechanical ventilation, in the face of poor prognosis, including brain damage or if experiencing a terminal illness with very limited life-expectancy (Krakauer et al., 2002; Barnato et al., 2009; Blackhall et al., 1999). Additionally, these minority groups are more likely than whites to want to die in the hospital and less likely to want potentially life-shortening palliative drugs. These differences persist even when controlling for sociodemographic factors and beliefs about effectiveness of resuscitation (Barnato et al., 2009). Similar preferences for more aggressive care in the event of catastrophic illness exist among African American physicians compared to white physicians, further highlighting how issues of shared culture rather than solely differences in sociodemographics and medical knowledge may impact end-of-life decision-making (Mebane et al., 1999).

Consistent with preferences for more aggressive therapies at the end of life, African Americans and Hispanics incur higher costs and receive more expensive, life-prolonging care in the last months of life despite less expensive, preventive, or cure-directed therapies earlier in the life-course. Specifically, they are more likely to die in the hospital, be admitted to the intensive care unit (ICU), and receive intensive therapies such as ICU care and gastrostomies than whites (Hanchate et al., 2009). Because hospice focuses on comfort rather than cure and advance directives tend to direct healthcare providers to limit life-prolonging therapies, greater preferences for life-prolonging therapies may partly explain the lower use of hospice care and completion of advance directives by these minority groups (Johnson, Kuchibhatla, and Tulsky, 2008).

Although much has been written about the more aggressive treatment preferences of minorities at the end of life, a few important points are worth noting. First, while African Americans and Hispanics as a group are more likely to endorse preferences for more aggressive end-of-life care than whites, many endorse preferences consistent with the hospice and palliative care philosophy of care. For example, in a national study of Medicare beneficiaries, more African Americans and Hispanics than whites reported wanting to die in the hospital; however, 82% of African Americans and 85% of Hispanics did not want to die in the hospital (Barnato et al., 2009). Second, expressed preferences for care may not always match the care received, especially for minorities. Research suggests that African Americans may be less likely to receive the end-of-life care they state they would prefer regardless of whether those preferences are for aggressive care or care focused primarily on comfort (Loggers et al., 2009; Borum, Lynn, and Zhong, 2000).

Spiritual Beliefs

Spirituality and faith are tenants that are especially central to many members of the African American community, and some African American patients rely heavily on their faith in God during times of illness and distress. African Americans are more likely than whites to participate in religious activities and to use religion to cope with illness (Sahgal and Smith, 2009). African Americans are also more likely to believe that God is responsible for physical and spiritual health, that divine intervention and miracles occur, and that there are religious prohibitions against physician-assisted death or advance directives limiting life-sustaining therapies (Johnson, Elbert-Avila, and Tulsy, 2005). As such, they may believe that completing an advance directive conflicts with their belief that God will take care of them or that it will go against God's will. Spiritual beliefs may also guide African Americans in their decisions about hospice and may be perceived to conflict with the hospice philosophy of care (Johnson, Kuchibhatla, and Tulsy, 2008). Choosing hospice may be viewed as giving up on or losing faith in God's ability to heal or to perform miracles, and poor health or death may be viewed as a consequence of this loss of faith (Bullock, 2006; Reese et al., 1999; Crawley et al., 2000; Krakauer et al., 2002; Johnson et al., 2005).

Similar to African Americans, a majority of Hispanics endorse the importance of religion, and some religious beliefs may influence preferences for more aggressive care at the end of life (Pew Hispanic Center, 2007a). For example, common to both African Americans and Hispanics is a belief that suffering is redemptive and should be endured as part of a test of faith (Smith et al., 2009; Crawley et al., 2000). Such beliefs may seem to conflict with the hospice philosophy of care, which emphasizes the importance of aggressive symptom management and comfort. In general, research suggests that those who endorse greater religious coping or faith receive more aggressive care at the end of life, even in analyses adjusting for racial and ethnic differences (Phelps et al., 2009).

Mistrust in the Health-Care System

Mistrust in the health-care system has been identified as a barrier to use of hospice care and completion of advance directives by some African Americans (Crawley et al., 2002; Crawley et al., 2000; Johnson, Kuchibhatla, and Tulskey, 2008; Cort, 2004). Compared to whites, minorities endorse less trust in the health-care system (Smith et al., 2009; Born et al., 2004; Boulware et al., 2003; LaVeist, Nickerson, and Bowie, 2000; Rose et al., 2004; Lillie-Blanton et al., 2000). African Americans and Hispanics are more likely to believe that they receive lower quality care than whites (Lillie-Blanton et al., 2000). For African Americans, historical occurrences such as the Tuskegee Syphilis Study and other negative experiences may create a sense in some patients that health-care providers do not always have their best interests in mind (Crawley et al., 2000; Gamble, 1997). As a result, some African Americans may feel that completion of an advance directive or living will is an indication that options for treatment will not be offered, that they will be withdrawn, or that their wishes, though documented, will not be honored or respected (Wicher and Meeker, 2012). Historical racial segregation, discrimination, denial of services, and ongoing disparities in care may also influence African Americans patients to choose aggressive treatment despite its futility, instead of care that is focused on comfort, symptom management, and support such as hospice. They may feel that health-care providers are not offering all options available or limiting treatment because of their race (Crawley et al., 2000; Krakauer et al., 2002; Wicher and Meeker, 2012). A significant proportion of Hispanics also report that they have experienced discrimination in health care and describe negative patient-provider interactions. This perceived discrimination along with additional challenges imposed by language barriers and cultural insensitivity may engender mistrust in hospice providers and lead to underutilization of hospice services and a reluctance to complete advance directives (Smith et al., 2009; Lauderdale et al., 2003).

NAVIGATING CROSS-CULTURAL ENCOUNTERS: STRATEGIES FOR HEALTH-CARE PROVIDERS

Communication with patients about advance care planning, palliative care, and end-of-life care requires an examination of patient preferences and overall goals of care. This can be further nuanced by the consideration of specific racial, ethnic, or cultural beliefs, values, and practices. Given that a lack of cultural sensitivity is a potential barrier to high-quality end-of-life care for members of the African American and Hispanic/Latino communities, health-care providers must make efforts to provide culturally sensitive care to patients of diverse racial and ethnic backgrounds (Kagawa-Singer and Blackhall, 2001; Crawley et al., 2002; Smith et al., 2009). The following recommendations are also summarized in Table 19.1.

Table 19.1 Strategies for Effective Cross-Cultural Care

Goals of Care and Treatment Options	Strategies
ACP (living will, advance directive, medical power of attorney)	<p>Describe the goals of ACP, emphasizing that</p> <ul style="list-style-type: none"> • ACP helps patients to make their wishes for care known to their loved ones and health-care providers. • ACP helps make decision-making less difficult and stressful for loved ones because the patient's wishes are known and documented. • ACP does not hasten death. Everyone should have an advance care plan regardless of age or health status. <p>Initiate discussions as early as possible and before a crisis develops (i.e., early in the disease trajectory, at routine health-care visits)</p> <p>Even if patients are reluctant to complete a formal document,</p> <ul style="list-style-type: none"> • Include information about their stated preferences for care in the medical record. • Encourage them to choose a family member or trusted friend to make decisions for them if they become incapacitated and to share their wishes for care with that person. • Emphasize the importance of having an advocate or spokesperson.
Palliative Care	<p>Describe the goals of palliative care, emphasizing that</p> <ul style="list-style-type: none"> • Palliative care helps to treat symptoms that are associated with certain illnesses and their treatment, such as pain, shortness of breath, nausea, and vomiting. • Palliative and curative care can be complementary; they can work together to improve health and well-being.
Hospice	<p>Describe the goals of hospice, emphasizing that</p> <ul style="list-style-type: none"> • Hospice is not a withdrawal of all care; it is a change in the focus of care from cure to comfort. • Hospice uses a team approach to provide care and support to the patient and the patient's family, including doctors, nurses, social workers, nurse aids, etc. • Hospice is not "giving up" or "losing faith" in God. In fact, spiritual support is a main component of hospice care. A chaplain is available for spiritual support should the need arise. • Hospice staff will not take the place of care provided by family but will support the family as they care for the patient
<i>Specific Barriers</i>	
Conflict with Spiritual Beliefs	<p>Take a spiritual history.</p> <p>Ask the patient about spiritual beliefs that may influence decision-making.</p> <p>Ask the patient and/or family how the health-care team can best support and meet their spiritual needs.</p> <p>Offer a visit from pastoral care or a chaplain</p> <p>Be open to involvement of members of patients' religious community if the patient requests this.</p>

(continued)

Table 19.1 Continued

Goals of Care and Treatment Options	Strategies
Cultural Beliefs	Ask the patient and/or family if there are specific cultural traditions that they would like to practice or observe and allow them to observe those practices if possible.
Family Involvement	Ask patients how they would like health information and medical decision-making communicated to them. If patients defer to family, identify one family member who will act as point person for communication about the care plan and medical decision-making. Arrange a family meeting to discuss prognosis, goals of care, and treatment strategies.
Language Barriers/Health Literacy	Ask about preferred language for communication. Use a medical interpreter for all communication if not fluent in the patient's primary language. When available, provide written materials in the patient's preferred language. Avoid complicated medical terminology when explaining things to the patient and/or family. Ask the patient and/or family if they have questions about their condition, prognosis, treatment, etc. Ask the patient and/or family their understanding of what is going on (i.e., severity of illness, treatment plan, etc.). This may help to gauge their level of comprehension.
Desire for Aggressive Treatment Despite Poor Prognosis/Medical Mistrust	Have open and honest communication with the patient and family about prognosis and goals of care. Make the patient and/or family members aware of their options for care at the end of life (palliative care, hospice, etc.). Do not pressure patients into making decisions but revisit the discussion periodically, particularly as the patient's condition worsens or symptoms progress. Respect the patient and/or family's wishes for treatment. The goal is for them to make an informed decision, which may not always be congruent with the provider's recommendations. Negotiate common goals of care Discuss and consider time-limited trials of aggressive care based on patient/family goals and preferences.

Note: ACP = advance care planning.

Avoiding Stereotyping: A Tailored Approach

The strategies discussed here are general recommendations that health-care providers may employ to address the concerns of patients of diverse racial and ethnic backgrounds who may benefit from palliative or hospice care. However, providers should

tailor their approach to the specific cultural, spiritual, or religious beliefs, values, needs, and concerns of individual patients and families in real time. To identify these important cultural and spiritual beliefs, providers should take a cultural and spiritual history (Kagawa-Singer and Blackhall, 2001). This includes asking patients and families how the medical team can best meet their cultural and spiritual needs, inquiring about specific cultural practices that are observed, and enlisting the services of pastoral care or chaplaincy if needed or desired. Providers should also be open to involvement of members of the patient's religious community (i.e., the patient's pastor, priest, rabbi, etc.) and allow or facilitate patients' observance of specific cultural or spiritual practices if possible.

Discussing Advance Care Planning

Advance care planning and treatment options such as palliative care and hospice services should be discussed with patients and families in a way that informs them of appropriate options for care, allays fears, and addresses previously identified barriers. For instance, patients should know that the goal of advance care planning is to assist them in making their preferences for care known not only to family members but to health-care providers. Providers should emphasize that advance care planning does not hasten death. Patients may be more open to advance care planning when it is addressed early in the disease trajectory and during routine office visits—preferably with a provider with whom the patient has had a long-standing, trusting relationship (Waters, 2001). Even if patients are reluctant to complete formal documents (i.e., living will, advance directive, or medical power of attorney), health-care providers should document their discussions with patients in the medical record. They should also encourage patients to choose a family member or trusted friend to make decisions for them, should they not be able to do so. To demonstrate support and respect for patients' interests, providers may explain the importance of having someone who can advocate on their behalf, knows their preferences for care, and can communicate those wishes to the health-care team.

Discussing Hospice and Palliative Care Services

Some strategies may also help health-care providers communicate with patients and families about palliative care and hospice care and dispel some of the myths that are associated with these services. Providers should emphasize that the goals of palliative care are to alleviate symptoms that are associated with certain illnesses and their treatment, including pain, dyspnea, nausea, vomiting, and anxiety. Palliative care can be complementary to curative or ongoing treatment; these treatment alternatives can work together to improve the patient's overall health and well-being. If and when the patient's disease progresses beyond curative treatment, hospice can be introduced to the patient and family as an option for care. Hospice should never be referred to as a withdrawal of all care, as patients may view this as being abandoned or fear that clinicians are not

offering appropriate care because of their race or ethnicity. Instead, it should be referred to as a change in focus of care from cure to comfort. Patients and families should be made aware that hospice consists of a multidisciplinary team of doctors, nurses, nurses aids, and social workers who work together to provide the patient and family with care and support. Those who have an objection to hospice based on religious or spiritual beliefs should be informed that spiritual support is also a component of hospice care and that chaplains are available for spiritual support when needed.

Caring for Patients with Limited English Proficiency and Low Health Literacy

Because of the importance of adequate communication to the care of patients with serious illness, health-care providers must work to overcome barriers imposed by limited health literacy and LEP, both of which are more common for minorities. The preferred language for communication should be identified for patients who are not native English speakers. For those with LEP or who prefer to communicate in a language other than English, a medical translator—not a family member or friend—should be used for all communication. Patients should be informed of their legal right to a trained medical interpreter at no cost (Smith et al., 2009; US Department of Health and Human Services, 2001). If printed information is available in the patients' preferred language, it should be provided. In all instances, complicated medical terminology should be avoided. To gauge patients' and families' knowledge of the treatment plan, providers should ask the patients their understanding of the disease process or plan of care. One way to do this is to ask the patient to describe the treatment plan in his or her own words.

Responding to Requests for Aggressive Treatment Despite Poor Prognosis and Limited Life Expectancy

Patients and families sometimes have a desire for aggressive treatment despite limited life expectancy and poor prognosis. Health-care providers must engage in open and honest communication with them about the overall prognosis and goals of care and attempt to negotiate common goals of care when conflicts arise. Patients and families should be made aware of their options for end-of-life care; however, they should not feel pressured into making decisions. Goals of care should be revisited periodically—particularly as the patient's condition worsens. Sometimes a mutually agreed-on, time-limited trial of aggressive care may help to build trust and reduce conflict between the medical team and family members regarding the use of life-sustaining therapies. Arrangement of a family meeting may be helpful and allow providers to discuss prognosis, goals of care, and treatment strategies with family members involved in decision-making. Any consultants or subspecialist providers, clergy, social workers, and other

health-care team members should be invited to participate, as they can provide an overview of the care plan from their perspectives. Health-care providers should work to accommodate the preferred decision-making process of patients and families, which in some cases may include consensus of a large number of relatives and nonrelatives. While large numbers of family members may attend family meetings for formal updates, it is appropriate for clinicians to identify one person to contact for more frequent updates. Ultimately, the goal should be for patients and families to make an informed decision about the care that they receive; health-care providers must understand and realize that, in some instances, this will not be congruent with their recommendations.

FUTURE DIRECTIONS

Disparities in end-of-life care among members of the African American and Hispanic/Latino communities have been identified throughout the literature, and, as noted previously, many reasons for these disparities exist. Health-care provider strategies for addressing these racial and ethnic disparities in care have been discussed; however, moving forward, a concerted effort should be made by health-care organizations, researchers, and policymakers to address these barriers as well.

Health-Care Organizations

Organizations and health systems can aid in reducing barriers to end-of-life care among persons of diverse racial and ethnic backgrounds. The US Department of Health and Human Services has developed Standards for Culturally and Linguistically Appropriate Services, which mandate that health-care organizations work to improve access to care for diverse populations by establishing policies that reduce barriers to care, practices that enhance patients' knowledge of available services, staff that reflect the diversity of the service area, and community partnerships that facilitate service delivery (US Department of Health and Human Services, 2001). Based on these standards, organizations and health systems should provide educational programs to staff on cultural sensitivity at the end of life and institute hiring practices that will increase racial and ethnic diversity among health-care providers across the spectrum of care. Organizations and health systems may also consider creating outreach programs that target members of diverse communities that will educate them about advance care planning and options for care at the end of life or working with community leaders to create these programs. These initiatives may increase cultural sensitivity among providers and address issues of medical mistrust and have been conducted successfully in some settings (Phipps, True, and Murray, 2003; Lyke and Colon, 2004; Reese, Melton, and Ciaravino, 2003).

Research and Policy

Although many studies that have identified racial and ethnic disparities in completion of advance directives, use of palliative care, and hospice enrollment and identified reasons for the underutilization of these services in African Americans and Hispanics/Latinos communities, few studies have focused on the design and implementation of interventions that can combat disparities in end-of-life care. Some research has been promising, and targeted interventions have been developed to address disparities in advance care planning and palliative care for seriously ill African Americans and Latinos, including patient navigation, peer support, and video education materials (Vollandes et al., 2008a, b; Bullock, 2006; Vollandes et al., 2008a, b; Fisher, Sauaia, and Kutner, 2007; Hanson et al., 2013); however, more efforts are needed to design, implement, test, and disseminate effective, culturally sensitive interventions that address these disparities. These interventions could then inform policy regarding end-of-life care for the underrepresented and underserved.

REFERENCES

- Anderson, K. O., C. R. Green, and R. Payne. (2009). "Racial and ethnic disparities in pain: Causes and consequences of unequal care." *Journal of Pain* 10(12): 1187–1204.
- Baer, W. M., and L. C. Hanson. (2000). "Families' perception of the added value of hospice in the nursing home." *Journal of the American Geriatrics Society* 48(8): 879–882.
- Baker, D. W., R. M. Parker, M. V. Williams, and W. S. Clark. (1997). "The relationship of patient reading ability to self-reported health and use of health services." *American Journal of Public Health* 87(6): 1027–1030.
- Baker, D. W., R. M. Parker, M. V. Williams, and W. S. Clark. (1998). "Health literacy and the risk of hospital admission." *Annals of Internal Medicine* 13(12): 791–798.
- Barnato, A. E., D. L. Anthony, J. Skinner, P. M. Gallagher, and E. S. Fisher. (2009). "Racial and ethnic differences in preferences for end-of-life treatment." *Annals of Internal Medicine* 24(6): 695–701.
- Bennet, C. L., M. R. Ferreira, T. C. Davis, et al. (1998). "Relation between literacy, race, and state of presentation among low-income patients with prostate cancer." *Journal of Clinical Oncology* 16(9): 3101–3104.
- Blackhall, L. J., G. Frank, S. T. Murphy, V. Michel, J. M. Palmer, and S. P. Azen. (1999). "Ethnicity and attitudes towards life sustaining technology." *Social Science & Medicine* 48(12): 1779–1789.
- Born, W., K. A. Greiner, S. E. Butler, and J. Ahluwalia. (2004). "Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos." *Journal of Palliative Medicine* 7(2): 247–256.
- Borum, M. L., J. Lynn, and Z. Zhong. (2000). "The effects of patient race on outcomes in seriously ill patients in SUPPORT: An overview of economic impact, medical intervention, and end-of-life decisions. Study to understand prognoses and preferences for outcomes and risks of treatments." *Journal of the American Geriatrics Society* 48(Suppl. 5): S194–S198.
- Boulware, L. E., L. A. Cooper, L. E. Ratner, T. A. LaVeist, and N. R. Powe. (2003). "Race and trust in the health care system." *Public Health Report* 118: 358–365.

- Braun, U. K., R. J. Beyth, M. E. Ford, and L. B. McCullough. (2008). "Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making." *Annals of Internal Medicine* 23: 267-274.
- Bullock, K. (2006). "Promoting advance directives among African Americans: A faith-based model." *Journal of Palliative Medicine* 9: 183-195.
- Caralis, P. V., B. Davis, K. Wright, and E. Marcial. (1993). "The influence of ethnicity and race on attitude toward advance directives, life-prolonging treatments, and euthanasia." *Journal of Clinical Ethics* 4(2): 155-165.
- Carlson, M. D., J. Herrin, Q. Du, et al. (2010). "Impact of hospice disenrollment on health care use and Medicare expenditures for patients with cancer." *Journal of Clinical Oncology* 28(28): 4371-4375.
- Carr, D. (2011). "Racial differences in end-of-life planning: Why don't blacks and Latinos prepare for the inevitable?" *Omega* 63: 1-20.
- Carr, D. (2012). "Racial and ethnic differences in advance care planning: Identifying subgroup patterns and obstacles." *Journal of Aging and Health* 24: 923-947.
- Carrion, I. V., F. R. Nedjat-Haiem, and D. X. Marquez. (2013). "Examining cultural factors that influence treatment decisions: A pilot study of Latino men with cancer." *Journal of Cancer Education* 28: 729-737.
- Carrion, I. V., F. R. Nedjat-Haiem, D. Martinez-Tyson, and H. Castaneda. (2013). "Advance care planning among Colombian, Mexican, and Puerto Rican women with a cancer diagnosis." *Support Care in Cancer* 21: 1233-1239.
- Ciemins, E. L., B. Stuart, R. Gerber, J. Newman, and M. Bauman. (2006). "An evaluation of the Advanced Illness Management (AIM) Program: Increasing hospice utilization in the San Francisco Bay area." *Journal of Palliative Medicine* 9: 1401-1411.
- Cintron, A., and R. S. Morrison. (2006). "Pain and ethnicity in the United States: A systematic review." *Journal of Palliative Medicine* 9(6): 1454-1473.
- Cohen, M. J., J. B. McCannon, S. Edgman-Levitan, and W. A. Kormos. (2010). "Exploring attitudes toward advance care directives in two diverse settings." *Journal of Palliative Medicine* 13: 1427-1432.
- Colon, M. (2005). "Hospice and Latinos: A review of the literature." *Journal of Social Work in End-of-Life & Palliative Care* 1(2): 27-43.
- Colón, M., and J. Lyke. (2003). "Comparison of hospice use and demographics among European Americans, African Americans, and Latinos." *American Journal of Hospice & Palliative Care* 20(3): 182-190.
- Cooper, L. A., D. L. Roter, R. L. Johnson, D. E. Ford, D. M. Steinwachs, and N. R. Powe. (2003). "Patient-centered communication, ratings of care, and concordance of patient and physician race." *Annals of Internal Medicine* 139(11): 907-915.
- Cort, M. A. (2004). "Cultural mistrust and use of hospice care: Challenges and remedies." *Journal of Palliative Medicine* 7(1): 63-71.
- Crawley, L. M., P. A. Marshall, B. Lo, and B. A. Koenig. (2002). "Strategies for culturally effective end-of-life care." *Annals of Internal Medicine* 136(9): 673-679.
- Crawley, L., R. Payne, J. Bolden, T. Payne, P. Washington, and S. Williams. (2000). "Palliative and end-of-life care in the African American community." *JAMA* 284(19): 2518-2521.
- Eleazer, G. P., C. A. Hornung, C. B. Egbert, et al. (1996). "The relationship between ethnicity and advance directives in a frail older population." *Journal of the American Geriatrics Society* 44: 938-943.

- Fernandez, A., D. Schillinger, K. Grumbach, et al. (2004). "Physician language ability and cultural competence. An exploratory study of communication with Spanish-speaking patients." *Journal of General Internal Medicine* 19(2): 167-174.
- Fischer, S. M., A. Sauaia, S. J. Min, and J. Kutner. (2012). "Advance directive discussions: Lost in translation or lost opportunities?" *Journal of Palliative Medicine* 15: 86-92.
- Fisher, S. M., A. Sauaia, and J. S. Kutner. (2007). "Patient navigation: A culturally competent strategy to address disparities in palliative care." *Journal of Palliative Medicine* 10: 1023-1028.
- Fishman, J., P. O'Dwyer, H. L. Lu, H. R. Henderson, D. A. Asch, and D. J. Casarett. (2009). "Race, treatment preferences, and hospice enrollment: Eligibility criteria may exclude patients with the greatest needs for care." *Cancer* 115(3): 689-697.
- Flores, G., M. Abreu, C. P. Barone, R. Bachur, and H. Lin. (2010). "Errors of medical interpretation and their potential clinical consequences: A comparison of professional versus ad hoc versus no interpreters." *Annals of Emergency Medicine* 60(5): 545-553.
- Gamble, V. N. (1997). "Under the shadow of Tuskegee: African Americans and health care." *American Journal of Public Health* 87: 1773-1778.
- Gordon, H. S., R. L. Street, Jr., B. F. Sharf, P. A. Kelly, and J. Soucek. (2006). "Racial differences in trust and lung cancer patients' perceptions of physician communication." *Journal of Clinical Oncology* 24(6): 904-909.
- Gordon, H. S., R. L. Street, Jr., B. F. Sharf, and J. Soucek. (2006). "Racial differences in doctors' information-giving and patients' participation." *Cancer* 107(6): 1313-1320.
- Hanchate, A., A. C. Kronman, Y. Young-Xu, A. S. Ash, and E. Emanuel. (2009). "Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites?" *Archives of Internal Medicine* 169(5): 493-501.
- Hanson, L. C., T. D. Armstrong, M. A. Green, et al. (2013). "Circles of care: Development and initial evaluation of a peer support model for African Americans with advanced cancer." *Health Education & Behavior* 40: 536-543.
- Hofmann, J. C., N. S. Wenger, R. B. Davis, et al. (1997). "Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment." *Annals of Internal Medicine* 127(1): 1-12.
- Holley, A. P. H., R. Gorawara-Bhat, W. Dale, J. Hemmerich, and D. Cox-Hayley. (2009). "Palliative access through care at home: Experiences with an urban, geriatric home palliative care program." *Journal of the American Geriatrics Society* 57: 1925-1931.
- Johnson, K. S., K. I. Elbert-Avila, and J. A. Tulsky. (2005). "The influence of spiritual beliefs and practices on the treatment preferences of African Americans: A review of the literature." *Journal of the American Geriatrics Society* 53(4): 711-719.
- Johnson, K. S., M. Kuchibhatla, and J. A. Tulsky. (2008). "What explains racial differences in the use of advance directives and attitudes towards hospice care?" *Journal of the American Geriatrics Society* 56(10): 1953-1958.
- Johnson, K. S., M. Kuchibhatla, and J. A. Tulsky. (2009). "Racial differences in self-reported exposure to information about hospice care." *Journal of Palliative Medicine* 12(10): 921-927.
- Johnson, K. S., M. Kuchibhatla, and J. A. Tulsky. (2011). "Racial differences in location before hospice enrollment and association with hospice length of stay." *Journal of the American Geriatrics Society* 59(4): 732-737.
- Johnson, K. S., M. Kuchibhatla, D. Tanis, and A. Tulsky. (2008). "Racial differences in hospice revocation to pursue aggressive care." *Archives of Internal Medicine* 168(2): 218-224.

- Kagawa-Singer, M., and L. J. Blackhall. (2001). "Negotiating cross-cultural issues at the end of life: 'You got to go where he lives.'" *JAMA* 286(23): 2993-3001.
- Kapo, J., H. MacMoran, and D. Casarett. (2005). "'Lost to follow-up': Ethnic disparities in continuity of hospice care at the end of life." *Journal of Palliative Medicine* 8(3): 603-608.
- Kelley, A. S., N. S. Wenger, and C. A. Sarkisian. (2010). "Opiniones: End-of-life care preferences and planning of older Latinos." *Journal of the American Geriatrics Society* 58: 1109-1116.
- Kiely, D. K., S. L. Mitchell, A. Marlow, K. M. Murphy, and J. N. Morris. (2001). "Racial and state differences in the designation of advance directives in nursing home residents." *Journal of the American Geriatrics Society* 49: 1346-1352.
- Krakauer, E. L., C. Crenner, and K. Fox. (2002). "Barriers to optimum end-of-life care for minority patients." *Journal of the American Geriatrics Society* 50(1): 182-190.
- Kwak, J., and W. E. Haley. (2005). "Current research findings on end-of-life decision making among racially or ethnically diverse groups." *The Gerontologist* 45: 634-641.
- Lauderdale, D. S., M. Wen, E. A. Jacobs, and N. R. Kandula. (2003). "Immigrant perceptions of discrimination in health care: The California Health Interview Survey 2003." *Medical Care* 44(10): 914-920.
- LaVeist, T. A., K. J. Nickerson, and J. V. Bowie. (2000). "Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients." *Medical Care Research and Review* 57 (Suppl. 1): 146-161.
- Lillie-Blanton, M., M. Brodie, D. Rowland, D. Altman, and M. McIntosh. (2000). "Race, ethnicity, and the health care system: Public perceptions and experiences." *Medical Care Research and Review* 57 (Suppl. 1): 218-235.
- Loggers, E. T., P. K. Macjewecki, E. Paulk, et al. (2009). "Racial differences in predictors of intensive end-of-life care in patients with advanced cancer." *Journal of Clinical Oncology* 27(33): 5559-5564.
- Ludke, R. L., and D. R. Smucker. (2007). "Racial differences in willingness to use hospice services." *Journal of Palliative Medicine* 10(6): 1329-1337.
- Lyke, J., and M. Colon. (2004). "Practical recommendations for ethnically and racially sensitive hospice services." *American Journal of Hospice & Palliative Care* 21: 131-133.
- Mack, J. W., M. E. Paulk, K. Viswanath, and H. G. Prigerson. (2010). "Racial disparities in the outcomes of communication on medical care received near death." *Archives of Internal Medicine* 170(17): 1533-1540.
- Mebane, E. W., R. F. Oman, L. T. Kroonen, and M. K. Goldstein. (1999). "The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision making." *Journal of the American Geriatrics Society* 47(5): 579-591.
- Medicare Payment Advisory Commission. (2013). "Report to the Congress: Medicare payment policy." Washington, DC: MedPAC. Accessed May 22, 2015, <http://www.medpac.gov/documents/-reports>.
- Morrison, R. S., and D. E. Meier. (2004). "High rates of advance care planning in New York City's elderly population." *Archives of Internal Medicine* 164: 2421-2426.
- Morrison, R. S., L. H. Zayas, M. Mulvihill, S. A. Baskin, and D. E. Meier. (1998). "Barriers to completion of health care proxies: An examination of ethnic differences." *Archives of Internal Medicine* 158: 2493-2497.
- Murphy, S. T., J. M. Palmer, S. Azen, G. Frank, V. Michel, and L. J. Blackhall. (1996). "Ethnicity and advance care directives." *Journal of Law, Medicine & Ethics* 24: 108-117.

- National Center for Education Statistics. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy*. Washington, DC: US Department of Education.
- National Center for Health Statistics. (2012). *Health People 2010 final review*. Hyattsville, MD: National Center for Health Statistics.
- National Hospice and Palliative Care Organization. (2013). "NHPCO's Facts and Figures: Hospice Care in America." Alexandria, VA: National Hospice and Palliative Care Organization. Accessed April 22, 2014, http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf.
- National Research Council. (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care (with CD)*. Washington, DC: National Academies Press.
- Ngo-Metzger, Q., D. H. Sorkin, R. S. Phillips, et al. (2007). "Providing high-quality care for limited English proficient patients: The importance of language concordance and interpreter use." *Journal of General Internal Medicine* 22(Suppl. 2): 324-330.
- Ortman, J. M., and G. E. Guarneri. (2009). "United States population projections: 2000 to 2050." Accessed April 22, 2014, www.census.gov/population/projections/files/analytical-document09.pdf.
- Park, N. S., I. V. Carrion, B. S. Lee, D. Dobbs, H. J. Shin, and M. A. Becker. (2012). "The role of race and ethnicity in predicting length of hospice care among older adults." *Journal of Palliative Medicine* 15(2): 149-153.
- Pew Hispanic Center. (2007a). "Changing faiths: Latinos and the transformation of American religion." Accessed April 22, 2014, <http://pewhispanic.org/reports/report.php?ReportID=75>.
- Pew Hispanic Center. (2007b). "English usage among Hispanics in the United States." Accessed April 22, 2014, www.pewhispanic.org/2007/11/29/english-usage-among-hispanics-in-the-united-states/.
- Pew Hispanic Center. (2011). "Statistical portrait of Hispanics in the United States, 2011." Accessed April 22, 2014, www.pewhispanic.org/files/2013/02/Statistical-Portrait-of-Hispanics-in-the-United-States-2011_FINAL.pdf.
- Pham, K., J. D. Thornton, R. A. Engelberg, J. C. Jackson, and J. R. Curtis. (2008). "Alterations during medical interpretation of ICU family conferences that interfere with or enhance communication." *Chest* 134(1): 109-116.
- Phelps, A. C., P. K. Maciejewski, M. Nilsson et al. (2009). "Religious coping and use of intensive prolonging care near death in patients with advanced cancer." *JAMA* 301(11): 1140-1147.
- Phipps, E. J., G. True, and G. F. Murray. (2003). "Community perspectives on advance care planning: Report from the Community Ethics Program." *Journal of Cultural Diversity* 10: 118-123.
- Phipps, E., G. True, D. Harris, et al. (2003). "Approaching the end of life: Attitudes, preferences, and behaviors of African-American and white patients and their family caregivers." *Journal of Clinical Oncology* 32(3): 549-554.
- Reese, D. J., R. E. Ahern, S. Nair, J. D. O'Faire, and C. Warren. (1999). "Hospice access and use by African Americans: Addressing cultural and institutional barriers through participatory action research." *Social Work* 44(6): 549-559.
- Reese, D. J., E. Melton, and K. Ciaravino. (2003). "Programmatic barriers to providing culturally competent end-of-life care." *American Journal of Hospice & Palliative Care* 21: 357-364.
- Rhodes, R. L., K. Batchelor, S. C. Lee, and E. A. Halm. (2015). "Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development." *American Journal of Hospice & Palliative Care* 32(3): 137-143.

- Rhodes, R. L., Teno, J. M., and S. R. Connor. (2007). "African American bereaved family members' perceptions of the quality of hospice care: Lessened disparities, but opportunities to improve remain." *Journal of Pain and Symptom Management* 34(5): 472-479.
- Rhodes, R. L., J. M. Teno, and L. C. Welch. (2006). "Access to hospice for African Americans: Are they informed about the option of hospice?" *Journal of Palliative Medicine* 9(2): 268-272.
- Rhodes, R. L., L. Xuan, and E. A. Halm. (2012). "African American bereaved family members' perceptions of hospice quality: Do hospices with high proportions of African Americans do better?" *Journal of Palliative Medicine* 15(10): 1137-1141.
- Rose, A., N. Peters, and J. A. Shea, and K. Armstrong. (2004). "Development and testing of the health care system distrust scale." *Annals of Internal Medicine* 19(1): 57-63.
- Rosenfeld, P., J. Dennis, S. Hanen, et al. (2007). "Are there racial differences in attitudes toward hospice care? A study of hospice-eligible patients at the Visiting Nurse Service of New York." *American Journal of Hospice & Palliative Care* 24(5): 408-416.
- Sahgal, N., and G. Smith. (2009). "A religious portrait of African-Americans." Washington, DC: Pew Research Center. Accessed April 22, 2014, www.pewforum.org/2009/01/30/a-religious-portrait-of-african-americans/#overview.
- Scott, T. L., J. A. Gazmararian, M. V. Williams, and D. W. Baker. (2002). "Health literacy and preventive health care use among Medicare enrollees in a managed care organization." *Medical Care* 40(5): 395-404.
- Selsky, C., B. Kreling, G. Luta, et al. (2012). "Hospice knowledge and intentions among Latinos using safety-net clinics." *Journal of Palliative Medicine* 15(9): 984-989.
- Smith, A. K., R. B. Davis, and E. L. Krakauer. (2007). "Differences in the quality of the patient-physician relationship among terminally ill African-American and white patients: Impact on advance care planning and treatment preferences." *Journal of General Internal Medicine* 22(11): 1579-1582.
- Smith, A. K., R. L. Sudore, and E. J. Perez-Stable. (2009). "Palliative care for Latino patients and their families: Whenever we prayed, she wept." *JAMA* 301(10): 1047-1057.
- Teno, J. M., B. R. Clarridge, V. Casey, et al. (2004). "Family perspectives on end of life care at the last place of care." *JAMA* 291(1): 88-93.
- Thornton, J. D., K. Pham, R. A. Engelberg, J. C. Jackson, and J. R. Curtis. (2009). "Families with limited English proficiency receive less information and support in interpreted intensive care unit family conferences." *Critical Care Medicine* 37(1): 89-95.
- Torke, A., N. S. Garas, W. Sexson, and M. T. Branch. (2005). "Medical care at the end of life: Views of African American patients in an urban hospital." *Journal of Palliative Medicine* 8(3): 593-602.
- US Census Bureau. (2012). "State and county quick facts 2012." Accessed April 22, 2014, <http://quickfacts.census.gov/qfd/index.html#>.
- US Department of Health and Human Services, Administration on Aging Administration for Community Living. (2013a). "A profile of older Americans: 2012." Accessed April 22, 2014, www.aoa.gov/Aging_Statistics/Profile/2012/docs/2012profile.pdf.
- US Department of Health and Human Services, Agency for Healthcare Research and Quality. (2013b). "National healthcare disparities report 2012." Accessed April 22, 2014, www.ahrq.gov/research/findings/nhqrdr/nhdr12/2012nhdr.pdf.
- US Department of Health and Human Services, Office of Minority Health. (2001). "National standards for culturally and linguistically appropriate services in healthcare." Accessed April 23, 2014, <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15>.

- US Department of Health and Human Services, Office of Minority Health. (2014a). "Minority populations: African American profile." Accessed April 23, 2014, <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=3&lvlid=23>.
- US Department of Health and Human Services, Office of Minority Health. (2014b). "Minority populations: Hispanic/Latino profile." Accessed April 23, 2014, <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=3&lvlid=31>.
- US Department of Health and Human Services, Office of Minority Health. "What is cultural competency?" (2014c). Accessed April 23, 2014, <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=11>.
- Volandes, A. E., M. Ariza, E. D. Abbo, and M. Paasche-Orlow. (2008a). "Overcoming educational barriers for advance care planning in Latinos with video images." *Journal of Palliative Medicine* 11: 700-706.
- Volandes, A. E., M. Paasche-Orlow, M. R. Gillick, et al. (2008b). "Health literacy not race predicts end-of-life preferences." *Journal of Palliative Medicine* 11(5): 754-762.
- Waters, C. M. (2001). "Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making." *Qualitative Health Research* 11(3): 385-398.
- Welch, L. C., T. M. Teno, and V. Mor. (2005). "End-of-life care in black and white: Race matters for medical care of dying patients and their families." *Journal of American Geriatric Society* 53(7): 1145-1153.
- Wicher, C. P., and M. A. Meeker. (2012). "What influences African American end-of-life preferences?" *Journal of Health Care for the Poor and Underserved* 23: 28-58.
- Williams, M. V., D. W. Baker, R. M. Parker, and J. R. Nurss. (1998). "Relationship of functional health literacy to patient' knowledge of their chronic disease. A study of patients with hypertension and diabetes." *Archives of Internal Medicine* 158(2): 166-172.
- Zaide, G. B., R. Pekmezaris, C. N. Nouryan, et al. (2012). "Ethnicity, race, and advance directives in an inpatient palliative care consultation service." *Palliative and Support Care* 6: 1-7.