Racial, Cultural, and Ethnic Factors Influencing End-of-Life Care

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ABSTRACT

Past efforts in the palliative and end-of-life care field have been laudably directed at increasing the cultural competence of providers and institutions and improving outreach to multicultural communities. Today, however, we face new challenges with regard to racial, cultural, and ethnic factors at the end of life. We now have documented evidence of disparities in almost every area of health care. In addition, breakthroughs in genomics research, including “race-based therapeutics,” have redefined the meaning of our human differences. These trends, unfolding in an increasingly polarized post-9/11 world, greatly challenge our understanding of concepts of race, culture, and ethnicity.

By definition, when considering these concepts, our focus shifts from the individual to that of group membership. In turn, this suggests using a population-based or epidemiological approach, which at once reveals inequalities and inequities in mortality patterns across diverse groups. Understanding and serving the needs of specific populations requires us to apply a framework of equity and to consider strategies to eliminate disparities. These include identifying sources of bias and discrimination in health care; enhancing the collection of racial, ethnic, and other demographic data; and increasing the representation of a range of diverse population groups in well designed qualitative and quantitative research. Using an epidemiological framework does not suggest, however, that we lose sight of dying individuals and their families. At the end of life, an individualized approach to care with a focus on quality is paramount for any patient, regardless of racial, ethnic, or cultural background.

INTRODUCTION: THE NEED FOR CLARITY IN A CHANGING LANDSCAPE

A decade ago, discussions on racial, cultural, and ethnic factors at the end of life were largely influenced by two trends: (1) the racial and ethnic demographic transformation of the United States, where minority population growth was noted to be increasing more rapidly than the majority white population; and (2) the recognition that patients and families participating in and benefiting from the hospice and palliative care movement did not reflect this shifting diversity. Efforts were directed at increasing the cultural competence of providers and institutions and improving outreach to multicultural communities. Although the need to address these issues is still a critical and laudable goal for end-of-life care, the last 10 years have brought on new challenges. We now have documented evidence of differential quality of end-of-life care for minority patients in nursing homes, cancer centers, emergency departments, and other health care settings.1-10 In addition, breakthroughs in ge-
nomics research have redefined the meaning of our human differences. These trends, unfolding in an increasingly polarized post-9/11 world, greatly challenge our understanding of concepts of race, culture, and ethnicity.

Semantic confusion and inconsistency in use frequently surround these words. In the extreme, differences in meanings and significance are at the core of serious political, legal, scientific, and societal debates. The polemic nature of these concepts is apparent in ballot propositions, legislation, and court cases pertaining to the collection and use of data on race and ethnicity, as well as by the most recent research and media attention paid to race-based therapeutics. Perhaps most controversial of the concepts is that of race itself. President Bill Clinton, in his June 2000 comments on the Human Genome Project, illustrated the paradox of racial differences by observing that “... one of the great truths to emerge from this triumphant expedition inside the human genome is that in genetic terms, all human beings, regardless of race, are more than 99.9 percent the same. What that means is that modern science has confirmed what we first learned from ancient fates: The most important fact of life on this earth is our common humanity” [emphasis mine]. Note that President Clinton did not say, “All human beings are 99.9% the same.” Ironically, qualifying his statement with the phrase, “regardless of race,” highlights confusion about the subject. Although it is generally accepted among anthropologists that race is subjective and that racial categories are used as imprecise surrogate measures of biologic or genetic differences among populations, our society is strongly conditioned to reify visible physical differences and to treat race as a categorical objective fact.12

This is not to say that the idea of race is without social impact. On the contrary, because of the historical and social consequences of racial categorizations, “racialization” exerts an important influence.13,14 Harold Freeman, Director of the National Cancer Institute Center to Eliminate Cancer Health Disparities defines this idea of racialization or racialism as “the ways in which we see, value, and behave toward others according to [some notion of] race.”14 Unfortunately, as evidenced by the range of documented health inequities, beliefs about and attitudes and behaviors toward racially visible persons (e.g., African Americans, Hispanic Americans, Native Americans, Asian Americans) have been generally negative.15 An irony exists in that in order to document the negative impact of racialism, such as patterns of racial profiling and discrimination, it is necessary to continue to collect data on the basis of the very same race categories that may perpetuate essentialist ideas.

Less controversial but equally misunderstood are the concepts of culture and ethnicity. Culture refers to patterns of explanatory models, beliefs, values, and customs. These patterns can be expressed materially (as in diet, dress, or ritual practices) or nonmaterially (as in language, social or political order, or kinship systems).16 Ethnicity, on the other hand, refers to a way of socially grouping persons on the basis of historical or territorial identity or by shared cultural patterns. Although they are similar, culture and ethnicity are conceptually distinct. For example, we can think of the culture of Western medicine “with its own specific language, values, and practices that must be translated, interpreted, and negotiated with patients and their families.”17 We do not think of medicine as having ethnicity.

Race and ethnicity have also been conflated with indicators of socioeconomic status (SES), obscuring their utility in outcomes research. Social economic position (including social class, economic status, education attainment, social networks, and occupation), age, gender, religion, country of origin, refugee or immigrant status, acculturation, and other social metrics exert meaningful influence on health outcomes.18 In some instances, variability in SES factors such as income distribution as opposed to race or ethnicity may account for perceived differences across population groups.

Furthermore, there is great heterogeneity among individuals who may be classified otherwise as having a shared “racial” or ethnic identity. In addition, these categories are fluid and mutable: persons may inhabit multiple social, racial, ethnic, and cultural identities that are expressed or perceived differently as need and circumstance change. Yet health data collected in this country fail to reflect this dynamic diversity. Standards for the Classification of Federal Data on Race and Ethnicity issued by the Statistical Policy Directive No. 15 from the Office of Management and Budget (OMB) initially collapsed separate populations representing many distinct ethnic and cultural groups into four single broad categories of race (white, black or African American, American Indian or Alaska Native, and
Asian or Pacific Islander) and one dichotomous category of ethnicity (Hispanic or non-Hispanic). Revised standards have further separated the Asian or Pacific Islander into two categories: Asian and Native Hawaiian or Other Pacific Islander (NHOPI).¹⁹ These changes did not go into effect until 2003, thus data collection reflects a mixture of categories. By comparison, the United Kingdom census and National Health Service data use five different categories that they define as “ethnicity” (versus race), which include: white, mixed, Asian, black, or Chinese.²⁰ These groups are further broken down into different subgroups based on countries of origin (e.g., Indian, Pakistani, Bangladeshi, or other for Asian; Caribbean, African, or other for blacks, etc.) Differences between U.S. and U.K. census categories illustrate two points: (1) that these classifications are socially and politically constructed; and (2) that meaningful comparisons across nations are difficult.

Acknowledging the complexity of the issues discussed above, the objective of this paper is to review the evidence on patient, family, and health care system factors that are associated with improved or worsened outcomes for care at the end of life based on a critical evaluation of race, culture, and ethnicity in the following ways:

- Using an epidemiological framework, the implications of mortality patterns for care at the end of life across various populations are explored.
- The issue of health care disparities particularly salient to end-of-life care is raised, specifically addressing provider-level and health system–level mechanisms that may contribute to these disparities.
- The limits of “race-based therapeutics,” including new knowledge in pharmacogenetics for palliative medicine, are discussed.
- Finally, the gaps in research on ethnocultural factors that may influence end-of-life decision making and preferences for treatment are identified.

A CHANGE OF LENS: FROM INDIVIDUAL TO POPULATION-BASED PALLIATIVE MEDICINE

Most of our thinking about palliative medicine focuses on the clinical care of individual patients and their families. Yet, by definition, when considering racial, cultural, or ethnic factors, we shift our focus away from the individual patient to that of group membership and populations. When making this shift, we first confront differences in patterns of death, or how we die, across populations. For example, the age-adjusted overall death rate in the US for 2001 was 845.5 per 100,000 persons. This figure was lower for whites and higher for blacks—in fact, 1.3 times higher, highlighting the black–white disparity in mortality.

The leading causes of death for all Americans are heart disease, cancer, cerebrovascular disease (strokes), chronic lower respiratory disease, accidents, diabetes mellitus, influenza and pneumonia, Alzheimer’s disease, kidney disease, and septicemia. When stratified by race, each population bears unique, additional burdens from diseases that are not among the top 10 causes of death for others.²¹ (Table 1). For example, for whites, Alzheimer’s disease ranked #8, accounting for more than 50,000 deaths in 2001. Yet it ranked #14 for blacks and #15 for both American Indians and Asians/Pacific Islanders in that same year. For the former, the #6 cause of death was chronic liver disease and cirrhosis, which did not rank above #12 for any other group. An even more complex picture of differences emerges when racial or ethnic comparisons are further stratified by age, sex, access to health care, and other social factors.

An epidemiological perspective reveals that we are not all equal in the presence of death. Figure 1 illustrates a rough estimate of excess deaths in 2001 for blacks caused by assault (6885 deaths) and human immunodeficiency virus (HIV) disease (6902 deaths), which ranked #6 and 7, respectively, for blacks. By comparison, these same diseases ranked #19 and 22 for whites.

These figures were calculated by multiplying the 2001 age-adjusted death rates for whites for these diseases by the U.S. Census mid-year 2001 population estimates for blacks and subtracting these “expected” deaths from the observed numbers. The concept of excess deaths presumes that all persons die equally: in other words, if blacks and whites died in equal proportions, there might have been 6902 less black deaths from HIV disease. To put these 2001 figures into perspective: this number is nearly 2.3 times the number of persons who died from all September 11, 2001–related events in that same year. This disparity is even more troubling when considering documented evidence of differential care for blacks.
and Hispanics with HIV or acquired immunodeficiency syndrome (AIDS) as compared to whites. Studies have shown that minorities are less likely to receive beneficial drug therapies and that the wait time to receive these therapies is longer than for whites.22–24

Furthermore, although heart disease, cancer, cerebrovascular disease, chronic lower respiratory diseases, accidents, diabetes mellitus, and kidney diseases—seven of the 10 leading causes of death—are shared by the four defined “racial” groups (using pre-2003 National Center for Health Statistics categories of race), these population groups do not bear these burdens to an equal extent.21 The 2002 Institute of Medicine (IOM) Report titled Unequal Treatment provided compelling evidence of race- and ethnic-based inequities associated with these conditions even after accounting for access (health insurance), income, clinical appropriateness, or patient preferences. Both the IOM and the 2003 U.S. Department of Health and Human Services National Healthcare Disparities Report (NHDR) identified the prevalence and extent of differential and, in many cases, less optimal medical care for minority as well as the poor and elderly populations.10,15 For example, although heart disease and cancer account for a larger number of deaths for all persons, blacks and Hispanics who present with cardiac symptoms or acute myocardial infarction, or blacks presenting with potentially curable early stage lung cancer are less likely to receive optimal care compared to whites.10,15,25–28

What is the significance of these data for palliative care? For one, it forces a reconsideration of some of the fundamental assumptions held

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>All persons</th>
<th>White</th>
<th>Black</th>
<th>Native American</th>
<th>Asian or Pacific Islander</th>
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<tr>
<td></td>
<td>Rank (%) of total deaths</td>
<td>Rank (%) of total deaths</td>
<td>Rank (%) of total deaths</td>
<td>Rank (%) of total deaths</td>
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<tr>
<td>Heart diseases</td>
<td>1 (29.0)</td>
<td>1 (29.4)</td>
<td>1 (27.0)</td>
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<td>2 (25.4)</td>
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<tr>
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<td>2 (23.1)</td>
<td>2 (21.6)</td>
<td>2 (18.0)</td>
<td>1 (26.4)</td>
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<tr>
<td>Cerebrovascular disease</td>
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<td>3 (6.8)</td>
<td>3 (6.6)</td>
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<td>3 (9.4)</td>
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<tr>
<td>Chronic lower respiratory disease</td>
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<td>4 (5.5)</td>
<td>8 (2.6)</td>
<td>7 (3.6)</td>
<td>6 (3.2)</td>
</tr>
<tr>
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<td>5 (4.1)</td>
<td>4 (4.3)</td>
<td>3 (11.4)</td>
<td>4 (4.7)</td>
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<tr>
<td>Diabetes mellitus</td>
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<td>6 (2.7)</td>
<td>5 (4.3)</td>
<td>4 (5.4)</td>
<td>5 (3.4)</td>
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<tr>
<td>Influenza and pneumonia</td>
<td>7 (2.6)</td>
<td>7 (2.6)</td>
<td>11 (2.0)</td>
<td>9 (2.7)</td>
<td>7 (3.2)</td>
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<td>15 (0.8)</td>
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<td>10 (2.0)</td>
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<tr>
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<td>—</td>
<td>10 (1.3)</td>
<td>16 (0.7)</td>
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<td>Septicemia</td>
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<td>11 (1.2)</td>
<td>10 (2.0)</td>
<td>12 (1.3)</td>
<td>11 (1.1)</td>
</tr>
<tr>
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<td>—</td>
<td>12 (1.1)</td>
<td>15 (1.0)</td>
<td>6 (4.5)</td>
</tr>
<tr>
<td>Assault (homicide)</td>
<td>—</td>
<td>—</td>
<td>19 (0.5)</td>
<td>6 (2.9)</td>
<td>11 (1.8)</td>
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<tr>
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<td>—</td>
<td>22 (0.3)</td>
<td>7 (2.7)</td>
<td>16 (0.6)</td>
</tr>
</tbody>
</table>

*Adapted from the National Vital Statistics Report, Vol. 52, No. 9, November 7, 2003. Italicized shows within top 10 causes of death that is unique only for that group. Assaults (homicide) were ranked in top 10 for two groups (black and Asian/Pacific Islander).
in the field. For example, how do we define a “dignified” death for an African American patient—say, because of AIDS—if that death was premature because quality, state-of-the-art, evidence-based treatments and interventions were denied to that patient? Or, in formulating and implementing hospital futility policies, to what extent does the assessment of ethical obligations include the duty to address the societal injustices that may have contributed, in whole or in part, to a potentially preventable death? Granted that such policies differ across institutions and are themselves subject to controversy, most adopt some form of the American Medical Association statement on futility such that physicians or institutions are not ethically obligated to offer or to continue medical interventions for which there is no reasonable chance of patient benefit. In light of racial inequities, these standards may need to be reconsidered, as they are relevant not only at the policy level but also at the bedside. When confronting conflicts involving futility, providers should engage in a process of “reflective equilibrium” by first making every effort to learn about and to understand the life circumstances of their patients—not only those related to impending death, but also those that are significant in terms of the patient’s entire life narrative and that may have resulted from an unjust basic structure of society. Then, this information should be incorporated into deliberations among conflicting moral principles such as beneficence, distributive justice, and justice as fairness. Finally, the resultant palliative and other treatment decisions should reflect coherence among these considered judgments.

DISPARITIES IN PALLIATIVE AND END-OF-LIFE QUALITY CARE:
PROVIDER/HEALTH SYSTEM FACTORS

In addition to the mortality differences described above, disparities have been noted in a range of healthcare outcomes. Studies of relevance to palliative care have shown race- and ethnicity-based inequities in the treatment of pain and compromised quality in long-term care for minority patients. Differential use of hospice services across populations has also been reported.

Pain and symptom management

Although inadequate pain management is a problem for all Americans, blacks and Hispanics in pain have been found to receive inadequate analgesia compared to non-Hispanic whites, even in those environments such as emergency departments and cancer centers where sensitivity to pain should be a priority. Once appropriate pain medication is prescribed, minority patients cannot rely on their community pharmacies to keep adequate stocks of drugs such as opioids, resulting in delays in relief of pain and suffering.

Quality of long-term care

Although there is evidence of a lack of benefit and potential harm in the use of tube-feeding intervention among cognitively impaired individuals, several studies have shown persistent disparities in the increased use of feeding tubes among minority patients, particularly African American dementia patients in nursing homes. In addition, data from the Centers for Medicare and Medicaid Services Nursing Home Resident Profiles showed two other troubling trends suggesting that minority patients receive compromised care in nursing homes. First, it was noted that blacks and Hispanics were more likely than whites to have bedsores, a problem that was shown to worsen across increasing age of residents. Second, the data showed that Hispanic and Asian/Pacific Island nursing home residents were placed in physical restraints more often than whites, a problem that also worsened for older residents. In fact, among older residents, all minority patients (blacks included) were more likely to be placed in restraints than were whites.

What accounts for these patterns of disparities? The IOM report suggests that they may be caused by patient-level, provider-level, and/or health system-level variables, alone or in combination. Among this array of variables, patient-level factors (which include patient preferences and treatment refusal) were thought to contribute the least to disparities. On the other hand, provider stereotyping and bias was shown to be a likely influence on health outcomes for minority patients.
Stereotyping relates to beliefs; prejudice refers to feelings; and discrimination points to behaviors or actions—all directed toward persons on the basis of their group membership. Provider treatment recommendations, referral patterns, communication styles, information sharing, and expectations of patients may be shaped by negatively held attitudes and behaviors aimed at diverse racial and ethnic patients. Such acts of commission or omission have been linked to poor health outcomes across a range of medical conditions and health care services. Most members of society are presumed to abhor consciously such biased attitudes and behaviors. However, as the IOM report and other research suggests, it is not conscious attitudes but, rather, it may be those that are unconscious or implicit and that surface under duress (e.g., stressful, crises-oriented, resource-limited situations) that may drive agents to act in ways that are knowingly or unknowingly discriminatory.

Structural bias or institutional racism may be a factor. Segregation of services and facilities can create barriers to quality care. How health care is organized and financed can certainly influence access to hospice and other palliative care services. For example, the structure of Medicare benefits may result in financial disincentives for some persons, particularly those who may not have an available full-time caregiver in the home or for whom other requirements are not well understood. Lack of access to care is a critical element, yet it does not wholly account for observed differences. Most observed disparities were found to exist even after accounting for socioeconomic factors.

Inclusion in research

We do not know the extent to which disparities effect care at the end of life because of the dearth of studies in this area. In the comprehensive systematic review conducted by investigators for the Agency for Healthcare Research and Quality, few studies were found that reported results on symptom control at the end of life separately by racial or ethnic groups. Clearly the collection of race or ethnicity data may not be irrelevant for certain research objectives; however, looking at palliative care outcomes without the benefit of identifying racial or ethnic patterns seems to be a prevailing pattern. Identifying and eliminating disparities that effect end-of-life care should be an important objective for all persons in this field. We can achieve this only through greater inclusion of diverse populations in research, collection of more uniform racial and ethnic information, and more analysis of outcomes data by race/ethnicity. This can help to identify specific provider or institutional behaviors or practices that may lead to stereotyping and bias, and can help point to potential strategies or courses of action that can eliminate all forms of discrimination.

“RACE-BASED THERAPEUTICS” AND PALLIATIVE MEDICINE

Concepts of race and ethnicity clearly play a prominent role in the new genetics as evidenced by the latest scientific and media attention paid to racially targeted drug therapies. At the heart of this matter is the ongoing debate on the use of race and ethnicity as a marker for genetic identity. It is beyond the scope of this paper to elucidate in detail, let alone attempt to resolve, the arguments from either side of the race and genetics debate. Suffice it to say that there are at least two basic tenets with which all parties agree. First, as illustrated in the previously mentioned quote by President Clinton, it is established that most of our species variation occurs between individuals and not between groups. Individual variability notwithstanding, it is also agreed that shared geographic ancestry does confer some degree of genetic similarity. From here, parties differ on how to apply these ideas. Clinicians or researchers rarely have the genetic profiles of individuals from which to base medical decisions or findings. In the absence of more detailed ancestry information, the question remains: can race and ethnicity be used as default labels for genetic information? Are there significant enough correlations between racial self-identification and geographic ancestry or between racially visible markers (as in skin color) and genetic heritability to make clinical assumptions based on race or ethnicity? Finally, if the correlations were such that we could use race as a proxy, then what racial classifications would adequately describe the distributions of genetic variation?

The immediate relevance of this debate to palliative care is seen in studies of interethnic differences in the metabolism and pharmacodynamics of drugs used in palliative medicine.
We know that differences in how an individual metabolizes a drug will depend on the presence of genetic polymorphisms for various enzymes and proteins. However, metabolic differences will occur as a result of a range of other intrinsic variables such as age, gender, and body size. They will also be influenced by a host of extrinsic factors; these include dietary habits, drug interactions, and other social or economic or cultural factors that affect drug availability.

Should we factor race and ethnicity into treatment decisions regarding the choice of and dosage schedule for analgesics such as opioids or other drugs used to control symptoms? The evidence is inconsistent. Even when differences in drug metabolism are found, it is not clear how much of these effects are attributable to interethnic versus interindividual variation. Furthermore, most studies are limited by problems of generalizability: sample populations are small or are from healthy, nonsymptomatic subjects, making it difficult to extrapolate findings to dying patients. As with most studies on race and ethnicity, researchers have not used uniform or clear racial or ethnic definitions of the populations being investigated. Future technological advances will no doubt yield molecularly based therapies targeted to specific individuals or populations on the basis of more precise genetic information. Until that time, however, clinical trials and studies on drug metabolism would benefit from inclusion of the greater range of well-defined population groups.

The question of using racial categories to make treatment decisions is complicated. Given the disparity data on inadequate treatment for minorities, race and ethnicity already seem to be factored somehow into treatment choices, but generally not in ways that benefit patients. In summary, what is needed for quality palliative care is individualized pain or symptom management programs. Providers should factor in each person’s unique attributes as they identify the specific, ongoing needs of all patients.

PATIENT AND FAMILY FACTORS: ETHNOCULTURAL VALUES AND PERSPECTIVES

Although the idea of culture can broadly encompass patterns of beliefs, values, and customs that exist for any group (for example, groups defined on the basis of religion, political beliefs, or sexual orientation), the discussion for this paper focuses on those that are associated with ethnic identity. Central to this focus is the acknowledgment that ethnically diverse patient populations require a health care workforce that can provide culturally and linguistically appropriate services (CLAS). The U.S. Department of Health and Human Services Office of Minority Health has identified “a set of mandates, guidelines, and recommendations . . . intended to inform, guide, and facilitate required and recommended practices related to culturally and linguistically appropriate health services.” These standards were designed to ensure the following: the cultural and linguistic competence of staff, of management practices and of clinical and administrative services; the collection of accurate demographic, cultural, epidemiological, and clinical outcome data for populations served; and quality assurance mechanisms in place to integrate CLAS standards into performance improvement programs. The Joint Commission on Accreditation of Healthcare Organizations is currently collecting data from approximately 60 hospitals to assess their capacity to meet the CLAS standards. Several hospice and palliative care organizations have explored ways of implementing these standards into care for dying patients and have made self-assessment tools available for organizations.

Culture shapes the explanatory framework that patients and providers use to understand health, illness, death, dying, and grief and bereavement. Culture can be dynamic and multidirectional. As in the case of acculturation, persons born or raised in one culture migrate to areas where another cultural pattern dominates and begin a process of cultural change over time or over generations. Language use is an important feature of acculturation and is a key element in health care interactions. Patient and family beliefs, values, customs, languages, and immigration status may influence end-of-life decision making, preferences for treatment (including alternative and complementary medicine), communication with providers, trust, and satisfaction with care.

Numerous qualitative studies and commentaries have described a range of end-of-life values and perspectives held by individuals and families from major American ethnic groups and by immigrants and refugees. For example, Morioka-Douglas and colleagues conducted fo-
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cus groups with leaders from an Afghan American community in California and reported on the importance for dying Muslims to have same-sex providers who are knowledgeable and respectful of Muslim faith practices.86 Kagawa-Singer and Blackhall8 reported the narratives of two patients, an African American man from the South dying of lung cancer and a Chinese American daughter who was the caretaker of her mother and father dying of lung cancer and complications from Parkinson’s disease, respectively. These case stories give the reader insights into the values important to these patients and may shed light on findings of ethnic differences from survey data.

Several quantitative observational studies have focused primarily on patterns and associations among advance planning/do not resuscitate (DNR) processes and patient ethnicity. Although many studies have consistently shown that African American and Hispanic/Latino ethnicity is predictive of not having written advance directives,91–96 the meaning of these findings is complex. For example, patterns among African Americans regarding preferences for the use of resource-intensive care differed when studies asked about hypothetical situations96 (which includes studies asking about advance directives) versus those that looked at actual decisions in clinical settings.97,98 In addition, cultural factors, such as whether a patient spoke English fluently or the degree to which the family was involved in care and treatment decisions, may have accounted for these patterns.91,98

Other studies have compared palliative care/hospice use patterns among different racial or ethnic groups. Overall, hospice use has been shown to be highest among non-Hispanic whites compared to non-whites.59–101 However, these patterns show regional variation. Analysis of 1991–1998 linked Surveillance, Epidemiology, and End Results (SEER)–Medicare data from California and New Mexico (states with large Hispanic populations) showed no differences in hospice use rates between Hispanic and non-Hispanic white cancer patients.102 Similarly, a survey of all hospices in California showed that hospices located in multicultural zip code communities were more likely to provide culturally appropriate services and outreach to those communities.103 In addition to rural/urban variation, differences in use across ethnic groups may also be explained by interaction effects with payment methods, marital status, living situations, immigration status, and referral sources.99,100,102

Although both the qualitative and quantitative empirical literature on ethnocultural perspectives, preferences, and patterns have provided insights into these issues for end-of-life care, few randomized controlled intervention or quasi-experimental studies have been reported.59 The field of hospice and palliative care would benefit from such studies to understand better the causal relationships among end-of-life outcomes and the range of racial, ethnic, cultural, and social factors that make a difference at the end of life.

RECOMMENDATIONS TO THE FIELD

The palliative and end-of-life care movement has taken a leadership role in addressing the health care needs of patients and families facing the inevitability of death. In bringing recognition to the fact that we all die and need a health care system that does not deny this fact, its pioneering efforts toward health care reform and clinical improvements aim to benefit all dying persons, regardless of racial, ethnic, or cultural backgrounds. Laudably, the movement has questioned the wisdom of channeling our limited health care resources into an acute care delivery model that fails to meet the ongoing, long-term needs of an aging population whose serious health problems are chronic and eventually fatal. But what about needs of individuals and communities whose mortality patterns suggest that many deaths are premature and potentially preventable? To serve better a racial and ethnically diverse America, those who are dedicated to improving care for the dying must consider the public health implications of death and dying in the U.S.104 What we need are providers, institutions, and organizations that are not only knowledgeable about the end-of-life care needs of individual patients but that also understand the morbidity and mortality patterns and the disparity implications for the populations they serve and are willing to act responsibly to eliminate inequities in health care.

The palliative care field should follow the lead of federal and state agencies, as well as private foundations and organizations that have prioritized identifying and eliminating health disparities. There are a range of strategies to use, some of which are already being addressed by local hospices or end-of-life care organizations, such as incorporating CLAS guidelines, ensuring the cultural sensitivity and competency of the palliative medicine
workforce, and increasing community-based partnerships. These activities should be a mandatory part of all guidelines developed for the field.

Identifying sources of bias and discrimination will be a challenge to most individuals and organizations. It will take courage to face these issues to create a health care system that serves all persons with integrity and dignity. Resources that help uncover implicit or unconscious bias may be both effective and useful. A recommended resource is Project Implicit, a collaborative effort among Harvard University, the University of Washington, and the University of Virginia that provides a series of well-designed virtual activities in which visitors can explore their underlying preferences and prejudices in a safe, secure, and private environment.105

To delineate structural or institutional discrimination, we need to enhance collection of racial, ethnic, and other demographic data. Although conformity to OMB Directive 15 would allow uniformity in data and enhance the ability to make comparisons across studies, we can set the standards higher to include greater detail regarding geographic ancestry, immigrant and acculturation status, language use, and relevant data on social and economic position. Such data would also enrich our understanding of variations in treatment outcomes and (potentially) genetic patterns associated with drug metabolism.

Race, ethnicity, and culture are complex factors. When considering their influence in health outcomes at the end of life, we must to hold two “lenses” simultaneously. Understanding and serving the needs of specific populations requires us to apply a framework of equity and to consider the recommendations to eliminate disparities delineated above.106 At the same time, however, we must not lose sight of the individuals and families before us, whose needs and concerns may not conform to preconceived or stereotyped patterns. At the end of life, an individualized approach to care with a focus on quality is paramount for any patient, regardless of racial, ethnic, or cultural background.

REFERENCES


RACIAL, CULTURAL, AND ETHNIC FACTORS


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