Review of the Literature on Cultural Competence and End-of-Life Treatment Decisions: The Role of the Hospitalist

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Objective: To determine whether any associations exist between cultural (racial/ethnic, spiritual/religious) competence and end-of-life treatment decisions in hospitalized patients and the potential impact of those associations on hospitalists' provision of care.

Data Sources and Methods: MEDLINE, PubMed, Embase, PsychInfo, and CINAHL databases were searched using the following search terms: *cultural competence, race, ethnicity, minority, African American, Hispanic, end of life, palliative care, advanced care planning, inpatient, religion, spirituality, faith, hospitalist,* and *hospice.* We identified studies in which spirituality/religion or race/ethnicity was used as a variable to study their potential impact on end-of-life treatment decisions in hospitalized patients.

Results: In only 13 studies was spirituality/religion or race/ethnicity used to study its effect on end-of-life decisions in hospitalized patients. African American patients tended to prefer the use of life-sustaining treatments at the end of life, and race/ethnicity did not appear to affect decisions to withhold or withdraw certain types of life-sustaining technology. Specific spiritual needs were identified both within and outside organized religions when members of those religions were hospitalized at the end of life.

Conclusions: End-of-life care may present unique challenges and opportunities in culturally discordant hospitalist-patient relationships. Culturally competent health care in an increasingly diverse population requires awareness of the importance of culture, particularly spirituality/religion and race/ethnicity, in the care of hospitalized patients at the end of life.

Keywords: race/ethnicity ■ hospital/office administration ■ spirituality

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INTRODUCTION

In Western medicine, a fundamental unit of health care is the patient-physician relationship. In the United States, the new paradigm of inpatient care, in which hospitalists oversee patients' care and treatment, has been accepted by nearly all leading hospitals and is in place or being considered by most other hospitals. In 2005, survey data from the American Hospital Association noted that 40% of the 4936 community hospitals in the United States have hospitalist programs, and the proportion was 70% for hospitals with 200 or more beds.[1]

This system of care typically does not give the patient (or the patient's family) a choice of physicians or the physician the opportunity to consult with the patient before hospital admission. As most Americans die in acute care hospitals,[2,3] hospitalists are asked routinely to provide end-of-life care for patients with whom they have not had previous interaction and who typically are not given a choice of inpatient providers. Thus, the parties are brought together at a most stressful time without the benefit of prior acquaintance or interaction. The increasing diversity and rapidly changing demographics of the US population increase the likelihood that the patient and physician will come from different sociocultural backgrounds.

Culture is not entirely based on a person's race/ethnicity and is determined by such influences as spirituality/religion, economic status, level of education and acculturation, age, gender, sexual orientation, and country of origin and immigration status. Culture plays an important role in how individuals (including physicians) see themselves and others with whom they interact. Individuals' cultural identity fundamentally influences how they understand illness and dying and the decisions they make at the end of life. Sociocultural differences between physicians and patients can lead to communication barriers because physicians today are challenged with caring for patients from many different cultures who speak different languages and have varying levels of acculturation.

Several studies have documented the treatment preferences of certain ethnic groups at the end of life, primarily by using hypothetical survey data collected from out-

patients.[4-7] These reports indicate that African Americans prefer more-aggressive treatment at the end of life than do whites and are less likely to have formalized advance directives.[6,7] There are few objective studies on the preferences of Hispanics, but 1 study did report that the preference of Hispanic patients for aggressive end-of-life care fell between that of African American patients and non-Latino white patients.[8] Although the hypothetical preferences of outpatients have some validity, patients may have a change of heart once hospitalized and faced with end-of-life decisions.[9] For this reason, we conducted this literature review on hospitalized patients to determine an association between race/ethnicity or spirituality/religion and end-of-life treatment decisions.

Firm evidence suggests that cultural discordance between patients and physicians influences clinical decision making,[10-13] but current practices in mainstream medicine have not elevated "culturally competent" health care to an appropriate level of importance. Physicians in hospital medicine cannot afford to make light of its importance in the care of hospitalized patients at the end of life. This paper discusses the complex and dynamic nature of race/ethnicity and religion/spirituality and offers some strategies to address the confusion often encountered in culturally discordant clinical relationships between physicians and hospitalized patients at the end of life.

METHODS

Data Sources

A detailed search of the English-language literature was used to identify potential journal articles indexed in the following databases: MEDLINE (1950-2007), PubMed (1966-2007), Embase (1988-2007), PsychInfo (1967-2007), and CINAHL (1982-2007). The strategy applied the following search terms: *cultural competence*, *race*, *ethnicity*, *minority*, *African American*, and *Hispanic*, which were linked with *end of life*, *palliative care*, *advanced care planning*, *inpatient*, *religion*, *spirituality*, *faith*, *hospitalist*, and *hospice*. The search terms *African American* and *Hispanic* were chosen because they represent the 2 largest ethnic minority groups in the United States. The reference lists of the articles identified during the search were also reviewed.

Eligibility Criteria

A narrative review approach was used because of the limited amount of available data. It allowed for the evaluation and inclusion of studies that used different methods to address the same problem. Articles were included if (1) study participants were recruited from inpatient medical settings (hospitals) and (2) culture (race/ethnicity or spirituality/religion) was examined as a possible predictor of provider or patient decisions at the end of life.

Study Selection

After articles were identified, the abstracts were reviewed by 2 reviewers (not the authors) blinded to journal and article authorship. Each independently analyzed the studies for inclusion on the basis of the 2 eligibility criteria. After abstract evaluation, the full text of the article was analyzed for inclusion by the same 2 reviewers. All studies (except case reports) conducted in the United States were included without regard for the research method used in an attempt to capture the widest range of data.[14]

RESULTS

Of the 91 articles identified for evaluation, we reviewed the full text of 36 articles and found 13 studies that met our inclusion criteria: addressing race/ethnicity or spirituality/religion and the possible effect on treatment decisions at the end of life in hospitalized patients.

Race/Ethnicity

Wenger et al[15] used a nationally representative sample of 9932 Medicare patients who were hospitalized with 4 conditions (pneumonia, congestive heart failure, acute myocardial infarction, and cerebrovascular accident) at 297 acute care hospitals. The hospitals were further defined as rural, urban teaching, and urban nonteaching in 30 areas in 5 states. They conducted a retrospective chart review and noted that black patients were less likely than nonblack patients to receive do-not-resuscitate (DNR) orders, even after adjustment for insurance and socioeconomic status.

Elpern and colleagues[16] also noted a greater preference for life-supportive care among blacks admitted to a large tertiary academic medical center. This greater preference for aggressive care over comfort measures at the end of life was also observed by Bardach et al[17] and Phillips et al,[10] but after adjustment for these preferences, they noted no differences in treatment decisions or outcomes.

Shepardson et al[18] reviewed 90821 consecutive admissions to 30 hospitals in a large metropolitan region and also noted a lower rate of DNR orders in blacks than in whites (9% vs 18%). They also noted that blacks were more likely to have DNR orders written after the first hospital day. In a multisite, retrospective study of clinical outcomes in 1376 patients with pneumocystis pneumonia, Tulsky et al[9] noted no difference between ethnicity and the presence of DNR orders, but they also found that blacks were more likely to have DNR orders written later in the hospitalization.

Fischer et al[19] reviewed the medical records of 217 seriously ill hospitalized veterans and found that black patients were more likely to have DNR orders and advance directive discussions than white patients. Thompson et al[20] also retrospectively reviewed the records of 288 hospitalized patients who died and also found that nonwhites were more likely to have DNR

orders, but the timing of the orders did not differ significantly by race.

One in 5 Americans dies using intensive care unit (ICU) services.[21] Barnato et al[22] evaluated the terminal hospitalization of 192 705 nonfederal patients from 4 states in 1999 to determine if racial variations existed in ICU use. They found that terminal ICU use was highest among blacks and Hispanics but noted the observed difference was attributable to their use of hospitals with higher ICU use rather than to racial differences in ICU use within the same hospital.

Spirituality/Religion

Wall et al[23] surveyed the family members of patients who died during ICU stays or within 24 hours of discharge and found a strong association with spiritual care and satisfaction with the total ICU experience. They also noted that family members were more satisfied with spiritual care if a pastor or spiritual adviser was involved in the last 24 hours of the patient's life.

Several other studies also confirmed the importance of spirituality at the end of life in hospitalized patients. In a cohort of 90 hospitalized human immunodeficiency virus–infected patients, Kaldjian et al[24] noted a tendency for spiritual beliefs and religious practices to play a role in end-of-life decisions. Their study, as well as that of Duke et al,[25] found that those who prayed daily or possessed a "sense of spirituality" were more likely to have advance directives.

An intervention program designed by Miller et al[26] to address the psychosocial and spiritual needs of inpatients with life-threatening illnesses observed fewer death-related feelings of hopelessness and significantly better spiritual well-being in the study group compared with the control group.

DISCUSSION

Race/Ethnicity

The vast majority of the published data on hospitalized ethnic minority patients at the end of life confirms that blacks were less likely to receive DNR orders and had a greater preference for aggressive care. It is unclear why blacks tend to request more life-sustaining treatment at the end of life. The finding that black physicians' preferences for their own end-of-life care follow the same pattern by race[27] makes it less likely that socioeconomic status or unfamiliarity with the medical system accounts for the difference.

There are many historical and contemporary reasons for blacks and other ethnic minorities to believe they will not receive optimal health care, particularly at the end of life. While the Tuskegee syphilis study[28] is the most well known, there are many well-documented examples of racism in American medicine.[29-32] Even though more recent studies tend to discount interpersonal discrimination as a mediator of well-documented disparities in health care,[33,34] a vast repository of research into social categorization and stereotyping suggests all humans share this adaptive strategy.

Indeed, Hamilton et al[35,36] describe how categorizing and generalizing techniques simplify massive amounts of information and stimuli and help make the social world more manageable. This automatic stereotyping is believed to occur unconsciously, is effortless and uncontrollable, and occurs very quickly.[37] So, when Groopman,[38] in his book *How Doctors Think*, asks the question, "Do a doctor's emotions—his like or dislike of a particular patient, his attitudes about the social and psychological makeup of his patient's life—color his thinking?" it is almost as if he knows the answer to his question. Indeed, the sheer complexity and very nature of physicians' work make it more likely that social stereotypes are used. When individuals are stressed for time and then required to make complicated judgments with insufficient information, the use of stereotyping increases.[39-41] Since this adaptive strategy is believed to be common to all humans and cultures, it is idealistic to think that physicians are immune and that these perceptions do not influence their interactions with patients. In fact, multiple studies have shown that patients' sociodemographic status influences both physician behavior during clinical encounters[42,43] and the diagnosis and treatment patients receive.[44-46] Even though most of these studies were case studies or retrospective reviews of outpatients or patients being treated in emergency departments, it is unlikely that physicians' behavior and diagnosis and treatment biases would be different treating hospitalized patients at the end of life.

In light of these findings, it is no wonder that multiple studies have confirmed trust as a vital component of the patient-physician relationship and that trust is strongly related to continuity and adherence to patients' preferences and needs.[47-49] Results of a community tracking survey that was thought to be representative of a national sample indicated a strong correlation between race/ethnicity and lack of trust.[50] The diminished trust was reinforced by lack of continuity on repeat visits, and both lack of trust and lack of continuity were particularly pronounced for black patients.

Spirituality/Religion

Definitions of *religion* and *spirituality* differ, although some use the words interchangeably. The most widely accepted understanding of these concepts appears to be that expressed by Kearney and Mount,[51] who distinguish spirituality from religion, describing the spirit as a "dimension of personhood…a part of our being. Religion, on the other hand, is a construct of human making that, for some, enables conceptualization and expression of spirituality." Even though spirituality, as a social construct, would appear to be broader than religion,[52] little

empirical evidence is available to characterize how dying patients define either.

The Institute of Medicine[53] lists spiritual well-being as 1 of 6 domains of quality supportive care of the dying. Although the literature is robust on the importance of spirituality at the end of life, most studies are either testimonials or interviews conducted with hospice patients with terminal cancer or AIDS.[54]

Many cultures rely on their faith at the end of life to a greater degree than is typically recognized in the US health care system. Davidson and colleagues[55] analyzed the gap between current services and staff knowledge vs perceived cultural and religious needs in hospitalized patients during birth and death. They used interviews and surveys of religious leaders as well as lay people to document specific needs of many ethnic groups, particularly at the time of death. Also, several outlines help support the importance of spirituality at the end of life: The Framework for a Good Death[56] and The Conceptual Framework for End of Life Care.[57] Both were constructed to help clinicians consider the entire spectrum of the dying process and develop a systematic approach to treating dying patients and their families. Although both tools emphasize the importance of spirituality, they also recognize the interdependence of physical, functional, and psychosocial care in helping patients achieve a good death. Surveys of US practitioners found that the vast majority felt that a patient's spirituality could directly affect clinical outcomes, and most agreed with the importance of physicians' understanding the religious and spiritual beliefs of their patients.[58]

Although objective quantitative studies of hospitalized patients are limited, many sociocultural variables have increased relevance at the end of life. In addition to spirituality/religion, hospice use and advance directives are especially important. Most studies[25,59,60] have consistently shown that black and Hispanic/Latino ethnicities are associated with low rates of written advance directives and hospice use. In addition to different cultural perspectives on death and dying, the awareness of health care disparities and lack of trust in the heath care system may be especially problematic for some ethnic minorities.[31]

Advance Directives

Even though race/ethnicity may play a role in an individual's personal thoughts toward life support, feelings toward withholding or withdrawing treatment may follow seemingly contradictory patterns.[61] The lack of acceptance of advance directives among blacks is especially complex. The issue of trust was raised by Caralis et al,[8] when their study found that blacks were more likely to feel they would receive less care if they had a living will. The authors interpreted their results as a manifestation of lack of trust by black patients in living wills and the health care system in particular and of societal maladjustment in general. Black patients are about one-half

as likely to accept DNR status and are more likely than whites to later change DNR orders to more-aggressive levels of care.[9] The same group of researchers also noted that black patients were more likely to sign DNR orders later in their hospitalization. They suggested that since DNR orders are eventually written for most patients who die in the hospital, "the timing of the DNR order may be a surrogate marker to distinguish those patients who choose to receive aggressive care."[9]

Hospice Use

In the United States, hospice has historically served only a small number of dying Americans. In 1995 the Urban Institute of Analysis used the Medicare Current Beneficiary Survey Cost and Use files to show that 11% of minority decedents used hospice compared with 17% of non-Hispanic whites. A recent review of the literature[62] showed that hospice utilization by blacks continues to be markedly less than use by whites but also noted most studies were insufficiently powered to show significant differences between Latinos and whites. Appearing to mimic the diversity in growth of the US population, the percentage of minority patients using hospice continues to increase (19% in 2006 compared with 17.8% in 2005).[63]

Although the use of hospice tends to parallel the creation of written advance directives among ethnic minorities, there does appear to be some regional variation. A review of Surveillance, Epidemiology, and End Result study data collected from Medicare databases (1991-1998) from New Mexico and California shows no difference in hospice use between Hispanic and non-Hispanic white cancer patients.[64] This trend of improved hospice acceptance and use in areas with large minority populations appears to reflect better outreach and attempts to deliver culturally appropriate services to these communities.[65] Many obstacles to greater hospice acceptance remain and vary by ethnicity and locale (urban vs rural). Hospice organizations caring for inner-city ethnic minorities have noted problems with the length of time and residency requirements for Medicaid qualification.[66] Proportionately more dying Hispanics than African Americans are covered by Medicaid.[67] One of the biggest obstacles, the presumption of a full-time caregiver, which is needed for in-home hospice care, appears to have been addressed by the creation of inpatient hospice units. Indeed, Johnson et al[68] noted that when evaluating the place of death in all hospice patients enrolled by a national hospice provider, Hispanics and blacks were more likely to die in inpatient hospice settings. Once inpatient units become more widespread, their impact on end-of-life care in minority communities will have to be measured.

The variation of cultural nuances within any racial or ethnic minority group can be quite large. Indeed, even as statements have been made in this paper about a particular group, they were made with the understanding that

the reader is aware that these are generalizations, and within-group differences are likely to be as large as between-group differences. As knowledge of the patient's cultural beliefs, values, religion, and spiritual practices is obtained, the physician must then determine the degree to which the patient or the patient's family adheres to specific beliefs. All patients are individuals, and all members of any group do not necessarily conform to the same cultural practices.

Our systematic review of the literature confirms that little objective data address end-of-life treatment decisions in hospitalized minority patients. The majority of the available literature suggests that blacks are more likely than white patients to make treatment decisions at the end of life to use all available resources to prolong life.

The limited empirical data found reinforce that research is needed to clarify the socioeconomic, demographic, psychosocial, and medical factors that interact and influence the decisions at the end of life for racial/ethnic minorities. The possible role of sociocultural and educational discordance between patients and physicians in miscommunications about patients' preferences and expectations at the end of life should be further elucidated. Studies should also be designed to examine how race/ethnicity and personal or historical experiences influence an individual's concept of trust in the health care system and evaluate the extent to which discrimination, stereotyping, and bias exist. Because the end of life for most Americans occurs in a hospital, many of these studies should focus on inpatients and the multiple disciplines involved in caring for them (physicians, nurses, clergy, etc).

The available literature cited reinforces the importance of spirituality in hospitalized patients but, like the majority of research conducted in this realm, it remains qualitative in nature. It has the presumed advantage of being more substantive and relevant as death in this population is considered much more possible or imminent. The spiritual/religious beliefs of the patient and family should be assessed and respected. Hospitalists should recognize the multidimensional approach required to facilitate a good death and the need for adequate treatment of psychosocial problems as well as pain, dyspnea, and anxiety. If there are particular customs or ceremonial practices relevant to end-of-life care, these should be openly discussed and negotiated before death is imminent and emotions are soaring. Established and expressed beliefs about the handling of the decedent's body should be respected and carried out if possible.

The limitations of this literature search were that the search terms were not broad enough to capture all the available literature on the topic, or the manner and format of the search was deficient. Also, the databases queried may not have included all the available literature because of inherent deficiencies in their indexing systems. Review of the abstracts may have been biased by process, even though the reviewers were blinded to arti-

cle author and journal. However, we believe the terms used and the databases queried allowed us to capture the available published literature on the topic. Because of the limited amount of available literature on the topic, we believe the narrative review was logical.

The studies identified were predominantly conducted on elderly Medicare patients with cancer or younger patients with AIDS. It is not known whether the findings are applicable to younger patients, those uninsured, or with diagnoses other than cancer or AIDS. Most of the studies had no controls, or when utilized, the controls were not consistent to allow for quantitative comparison. Most could not account for the effects of confounding variables such as patients' insurance status and level of education or physician demographics. Most studies were statically underpowered to detect significant differences in Hispanic populations.

CONCLUSIONS

In the new paradigm of inpatient care, where hospitalists care for many patients after admission, these physicians typically do not have the opportunity to meet or establish a rapport with patients or their family members before hospitalization. During what can be an especially stressful and frightening time for patients, the present reality of practicing medicine does not allow most physicians adequate time to address all the cultural nuances that may affect a patient's care at the end of life. Physicians must evaluate the culturally relevant aspects of a patient's history and focus on the factors that may affect the clinical relationship.

By being aware of and sensitive to the cultural influences that may be especially relevant to the care of hospitalized patients, physicians can lead the way in assuring that culturally competent health care is the goal of the entire inpatient team. As they educate themselves and acknowledge the role of history, culture, and even current events, their ability to respectfully provide optimal care to hospitalized patients should improve. Hospitalists have an opportunity to set an example among inpatient staff members for an objective and studied response to a complicated issue.

As the new model of inpatient care gains more acceptance in the United States, physicians should acknowledge how increased cultural diversity among patients and health care professionals may lead to varied clinical decisions based on cultural values. They must learn to communicate openly with patients and colleagues from other cultures, respect their values and beliefs, and identify and resolve cultural dissimilarities that affect patient care.

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