

Direct Engagement With Communities and Interprofessional Learning to Factor Culture Into End-of-Life Health Care Delivery

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Aging patients with advanced or terminal illnesses or at the end of their lives become highly vulnerable when their cultural needs—in terms of ethnic habits, religious beliefs, and language—are unmet. Cultural diversity should be taken into account during palliative care delivery (i.e., noncurative, supportive care during advanced illness or at the end of life). Providers and systems deliver disparate palliative care to diverse patients. I present 2 strategies to improve how culturally diverse populations are served during advanced illness: (1) health service provider assessment of local populations to understand service populations' cultural needs and guide services and policy; and (2) interprofessional education to improve multicultural understanding among the health care workforce. (*Am J Public Health*. Published online ahead of print March 17, 2016; e1–e6. doi:10.2105/AJPH.2016.303073)

Those receiving health care at the end of life in the context of terminal illness or nonpursuit of curative treatment are necessarily vulnerable. The cognitive or physical decline that can result from advanced age can increase patients' vulnerability in a complex care delivery system. Cultural differences can create vulnerabilities as a result of a health care provider's or system's response to a person's cultural needs. The dying process combined with the effects of aging can be further complicated by unmet cultural needs, creating one of the most at-risk patient populations in health care delivery today. We can help individuals and populations experiencing the combined effects of aging, terminal illness, and cultural diversity through community engagement and collaborative learning about end-of-life issues and advanced illness. End-of-life care is not solely a health care issue. How this type of care is utilized has broad implications for the public's health, public policy, and health care spending.¹

The Centers for Medicare and Medicaid Services (CMS) details the end-of-life care standard as

patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the

continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.²

Optimal delivery of standard end-of-life care and care in advanced illness in the United States relies on health care providers' and systems' responses to our growing cultural diversity. It is important to integrate culture-based preferences for palliative care modalities. These include symptom management (e.g., pain, shortness of breath, anxiety, and nausea), social and spiritual support for both the patient and the family, and a team-based approach to care delivery that includes realistic goals of care for a particular prognosis.³

Currently, there is no standard way of taking into account patients' cultures in end-of-life care delivery. I describe the approach to end-of-life care and how culture has been negotiated within it, along with what this care

can be following systems changes. I describe a realistic strategy for health systems to achieve cultural understanding of service populations and a workable strategy to achieve improved multicultural understanding among the health care workforce using interprofessional education (IPE).

END-OF-LIFE CARE AND CULTURE

The World Health Organization (WHO) and the CMS (in its population health-oriented model) define palliative care similarly as a program of care that “integrates the psychological and spiritual aspects of patient care” through a team-based effort to improve the quality of life remaining while not hastening death.⁴ However, the CMS and WHO models are not explicit enough about broader cultural integration. Broader cultural integration is a growing challenge in the United States: current and projected census data note the continued growth of certain populations, particularly Hispanics and Asians.⁵

Additionally, the WHO definition is cancer diagnosis oriented. The expansion of palliative approaches to care beyond cancer diagnoses is an important effort in the United States and, therefore, may limit the WHO model's application.⁶ Improvements in end-of-life care in the United States have been a challenge owing to advanced technology and training focused on cure even when

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chances for survival are poor.⁷ Palliative care delivery systems need to be culturally integrative and multidisciplinary because of the broad range of patients with serious illnesses who can benefit from supportive, noncurative approaches.

Culture can be defined by, but not limited to, language, religion, and social contexts.⁸ Although many definitions of culture exist, a 1963 definition captures the idea in a manageable format: “the learned and shared behavior of a community of interacting human beings.”^{9(p169)} Individuals’ cultural lens can determine their views on death and dying.¹⁰

Not providing culturally responsive care can result in minority patients receiving poorer quality of care.¹¹ A systematic review of 25 studies of end-of-life care delivered to Whites, African Americans, Asians, and Hispanics indicated underuse of end-of-life care and advance directives, care misaligned with patient preferences, and inadequate knowledge of care options among the minority patients compared with Whites.¹² Studies have reported that racial/ethnic minorities who are seriously ill are more likely to experience pain than are Whites and to report health care staff providing poorer pain management.¹³ Patients’ underutilization of hospice and palliative care services has been attributed to language barriers (e.g., lack of interpreter services) and perceptions that religious needs will not be met—reflecting 2 areas of cultural diversity.^{14,15}

Patients, health care providers, and health administrators make decisions that lead to gaps in care among minority populations. Gaps can be related to language differences, misalignment with societal norms, assumptions about goals of care, and the degree to which information is shared between patient and provider.¹⁶ A recent report from the Agency for Healthcare Research and Quality indicates worsening quality in end-of-life care for Hispanics, American Indians, and Alaska Natives.¹⁷ Health care delivery inefficiencies can arise from culturally inappropriate care. One study queried 37 leaders from managed care, government, and academe and revealed that culturally responsive care enhances service quality and uses resources more intelligently.¹¹ Deficiencies in culturally responsive care delivery are incongruent with the tenets of the Affordable Care Act,

including sections 4302 (culturally reflective health data collection) and 10334 (improving delivery infrastructure to reduce disparities)¹⁸ as well as new palliative care recommendations.¹⁹

A review of 33 empirical studies concluded that African Americans preferred life-supporting interventions more than did Whites, who utilized advance care planning more and life-support intervention less.²⁰ The same study found that Hispanics and Asians preferred family-level decision-making over the autonomous mode of decision-making most commonly encouraged in US health care institutions. African American and Hispanic patients are twice as likely as are Whites to pursue aggressive end-of-life care aimed at curing disease rather than accepting the expected terminal trajectory.²¹

In 2012, Whites accounted for the majority (81.5%) of US hospice users, one setting for end-of-life care delivery, whereas Blacks/African Americans (8.6%), Hispanics (6.9%), and Asians/Hawaiians/other Pacific Islanders (2.8%) appeared to underutilize the service.²² A combination of mistrust on the basis of historical injustices (e.g., the Tuskegee Syphilis Study)²³ and inadequate health information provided to minority patients¹² may account for the more aggressive care choices and lower use of palliative services among racial/ethnic minorities. Health care providers and systems can focus on educating patients and families and acknowledge different modes of decision-making for health care decisions on the basis of previous research.

End-of-life and palliative care are complex because of their many patient, provider, and community stakeholders. Health care providers must be educated and supported in their efforts to deliver care to a diversifying population. End-of-life care education has been scattered in health professions’ training programs. The nursing and medical professions have developed end-of-life-related curricula that have been delivered to learners in the workforce as well as trainees.^{24,25} Both curricular designs demonstrate increased end-of-life care knowledge among participants. However, the designs are discipline specific (i.e., physician or nurse) and do not emphasize interprofessional collaboration to improve care.

The nursing curriculum discussed by Ferrell et al.²⁴ emphasizes cultural

considerations in the evolving international components of the course, but it is not clear that US cultural diversity is held in as high regard. The curriculum for physicians discussed by Gisondi et al.²⁵ has been adapted in the past for African Americans and Roman Catholics,²⁶ but it is not clear to what extent it is currently employed. Patients with advanced illnesses do not always get the culturally competent care they need from providers. The revision and expansion of these programs could fill this gap. Incorporating innovations in Web-based education focused on both palliative care and cultural diversity, for example, may also assist this process.²⁷ Expanded health professions education that discusses cultural needs in the setting of palliative care is needed. An interprofessional learning approach to this education would strengthen learners’ experience because of the innate complexity of these topics requiring multidisciplinary perspectives.

Payers (e.g., insurance plans) have a substantial stake in efficient and effective service provision. Palliative care can save the health care system money and benefit patients when it is accessed early; however, this requires proactive effort on the part of health care providers, who can educate patients and link them to services.²⁸ Insurance reimbursement improvements would spur providers to advocate palliative care for appropriate patients.²⁹ Culturally competent palliative care can make good business sense³⁰ and, because this competence affects quality, is attractive to administrators concerned with health care payment and delivery.¹¹ Both payers and hospital systems have the ability to effect changes in palliative care access through policies and payments that encourage its use.³¹

WHAT CULTURALLY RESPONSIVE END-OF-LIFE CARE CAN BE

Issues surrounding death and dying are often less medical or scientific and more related to social, ethical, legal, and spiritual concerns, which creates a complex situation in which societal, familial, and individual perspectives play a role.³² There are recent indications of improvements in the cultural responsiveness of end-of-life care at certain

medical centers or in particular regions of the United States.³³ Culturally responsive care can be universal. It can be available to all US patients, everywhere. Providers and systems must first learn about their patient populations and then strive, collaborating with other professionals, to engage these populations on their cultural terms. National organizations, clinicians, and government organizations alike have highlighted the importance of considering and respecting cultural difference in end-of-life and advanced illness care in an effort to achieve health care system reform in these important areas.^{3,34,35}

The 2014 Institute of Medicine report “Dying in America” cautioned against making assumptions about patients’ care preferences; encouraged incorporating cultural, spiritual, and religious needs aimed at patient-centered care; and supported family involvement in the decision-making process.¹⁹ This well-circumstantiated report noted that because the cadre of palliative care specialists is relatively small, it is important that health care providers and other professionals operating in settings of advanced illness be familiar with palliative concepts. A key recommendation from the Institute of Medicine is for health systems and municipalities to engage the public, especially underserved populations, on end-of-life issues to determine their values and to educate them about available end-of-life options. Minority populations are expected to account for 28% of older Americans by 2030³⁶; this should motivate a shift in the way we view inclusion of cultural difference in advanced illness care.

HOW WE GET THERE

The multifaceted nature of end-of-life issues demands system-wide alteration. We can arrive at this by focusing some efforts beyond the bedside, acknowledging that complex issues of death and dying in our society necessitate stronger collaborations between community members and fellow professionals in nonclinical spheres. There are 2 ways to approach this: health system engagement with the surrounding populations and IPE on end-of-life issues.

Health System Engagement With Populations

Health care quality improvement is on the agenda of health care organizations and the US government; it concerns health care systems’ response to patient needs, cost of care, and appropriate access and delivery of services.³⁷ The quality of services provided at the end of life—previously evaluated using the independently administered Family Evaluation of Hospice Care survey of surviving families of hospice patients—has recently been shifted more closely to governmental concern and oversight at the CMS.³⁸ Portions of this survey consider a health care organization’s delivery of services that respond to patients’ and families’ spiritual and social needs. Aspects of health care quality, which include perceptions of patients and their families (e.g., the CMS surveys), meeting quality goals mandated by insurers, and professional peer review and opinion,³⁹ can drive improvements in culturally responsive end-of-life care delivery.

To address the values and perspectives of the community adjacent to the medical center itself, we should discuss their cultural needs with community members before illness or hospital admission so that we may be more preemptive and less reactionary. Determining the cultural composition of a neighborhood served by a medical center and gauging opinions on care regarding future advanced illness can allow the institution to tailor services to those most likely to come through their door.

Assessing and monitoring population health, rather than focusing only on individuals, have moved to the forefront of health care delivery on a national scale. This is supported by the Institute for Healthcare Improvement’s Triple Aim, which prioritizes population health along with patients’ experience of care and per capita cost of care.⁴⁰ Engaging the community through focus groups and skill-building workshops revealed frustrations with health systems’ lack of cultural competence. Problems included inadequate translation services, poor patient or family understanding of medical advice, unreliable access to services, and poor coordination of care.⁴¹ Another study indicated deficits in care coordination, the need for patient and family involvement in care

planning, and the need for earlier access to services.⁴²

The ABCDE cultural assessment model,⁴³ which I modified for health care organizations rather than individual providers (see the box on this page), could be used by a health system to engage its surrounding community on the topics of end of life and advanced illness. Establishing a community’s preferences for health care delivered near the end of life, as

MODIFIED ABCDE MODEL FOR HEALTH SYSTEM ENGAGEMENT WITH POPULATIONS

Attitudes of Community Members and Their Families

What is the general attitude toward discussing death and dying?

How aggressively should a cure be pursued when there is little chance for recovery?

To what extent should family be involved in health decisions?

What is the view on advance care planning?

Beliefs

How does religion or spirituality influence ideas about death and dying?

Where does one find strength and support during times of stress?

How can the medical center support needs and practices?

Context

What is the immigration status, socioeconomic status, experience of discrimination, degree of cultural and US integration, and preferred language?

Decision-making style

How do individuals and families make decisions in that culture?

Who is the head of the family?

To whom should health providers speak about individuals’ health conditions?

Environment

What supports and resources are available to patients and families during illness?

What community resources are available to providers to help navigate represented cultures?

Source: Kagawa-Singer and Blackhall.⁴³

viewed through their cultural lens, will lay the foundation for the health care system's next step—integration of community preferences into end-of-life health service delivery. Policy and staffing will need to change in response to this shift in the relationship between community and health care organization. This shift can be achieved in part through health care workforce knowledge enhancements via colearning with community members and present and future colleagues.

Interprofessional Education on End-of-Life Issues

The Interprofessional Education Collaborative, which represents 6 major health-related professional organizations, has detailed “embracing the cultural diversity and individual differences that characterize patients, populations, and the health care team” as a competency.⁴⁴ Health care organizations and health professions training programs alike are recognizing the value of collaboration between disciplines that care for patients, including those receiving end-of-life care.⁴⁵

WHO's recognition of the value of multidisciplinary collaboration to improve care underscores the value of IPE.⁴⁶ Advanced and terminal illnesses can be complex. No single professional, no matter how highly trained and experienced, can respond to every patient need. Acceptance of this fact can motivate us to establish new frontiers in colearning and collaborative care delivery focused on improving care at the end of life and during advanced illness. IPE has been shown to increase teamwork⁴⁵ and decrease burnout among professionals working with dying patients.⁴⁷

A stronger multidisciplinary team approach would increase the coverage of patients' needs at the end of life or during periods of advanced illness. For providers to be effective in the delivery of end-of-life care, they need to know patients' and families' perspectives on death and dying, health, palliative services, Western-style practices, spirituality and religion, problem solving, and modes of communicating.⁴⁸ It is not possible for individual care team members to obtain all this information readily, so they must share information among the team and know with whom it should be shared. Role familiarity, teamwork skills, and collaborative communication strategies are critical in this regard and are

identified domains of IPE.⁴⁴ Health providers would benefit from interprofessional learning when the aggregated experience of the group offers practice strategies for engaging patients on this challenging and sometimes uncomfortable topic.⁴⁹

We can borrow from an intersectional framework, described and enhanced by Powell Sears,⁵⁰ which sees the interdependence of a person's various “social locations” (e.g., family, race/ethnicity, job, neighborhood, economic status) as helping to shape minorities' health views, needs, and experiences. We can enhance IPE for both trainees and the professional workforce using this framework. There is growing evidence of the effectiveness of health professions IPE to improve learners' cross-cultural communication skills,⁵¹ awareness of cultural factors affecting population health,⁵² and understanding of cultural influences on processes and outcomes of care.⁵³ Furthermore, an organization's commitment to culturally attuned end-of-life and palliative care could be realized with an organized approach to dissemination and implementation, a framework that necessarily employs interprofessional collaboration.⁵⁴

The box on this page details how these efforts might be manifest through community-based interactions, discussions about cultural and social issues, and deliberate engagement at the intersection of culture and end-of-life preferences. The model could improve collaborations for end-of-life care delivery by increasing professionals' role familiarity, comfort with end-of-life discussions, and awareness of culturally responsive care in advanced illness. For example, planned interactions (e.g., interviews, home visits) with community members on the topic of death and dying could increase trainee and workforce comfort with the topic as participants deliberately elicit others' opinions and express their own. This approach could help make end-of-life care and decision-making a normative component of population health management and part of the array of beneficial services provided in a community.

CONCLUSIONS

In the United States, there is an opportunity to affect health care delivery and the

INTERPROFESSIONAL EDUCATION ON END-OF-LIFE ISSUES AND CULTURE

Trainees

Exposure to identified cultural populations surrounding a training program

- Meet with key informants in the community
- Interview local community leaders
- Interact with panel of “health care consumers”
- Interview community members and admitted patients, focusing on social concerns

Colearning with other professional trainees

- Share didactic coursework
- Participate on Web-based discussion boards
- Share clinical experiences (e.g., multidisciplinary home visits, health fairs)
- Interact with multidisciplinary panel (e.g., perspectives intersecting end of life and culture)

Professional workforce

Colearning with other professionals

- Interact with multidisciplinary panel (e.g., perspectives intersecting end of life and culture)
- Participate on Web-based discussion boards collaborating for current patients
- Deliver end-of-life education in teams to communities (e.g., at senior and community centers)
- Participate in team meetings about patients' end-of-life care with administrators, quality professionals, and community service providers (e.g., aging services administrator, community social worker, cultural center leaders)

Health care organization-led activities

- Sharing and acting on findings from community engagement activities related to end of life
- Multidisciplinary formulation of policies guiding end-of-life care and planning for diverse patients
- Community members' participation on organizational committees dealing with end-of-life issues

Note. Opportunities for self-reflection via journaling or blogging are applicable throughout.

public's health near the end of life in ways not encountered in routine health care delivery. As a public health priority, and as a relevant task for health promotion efforts, culturally

responsive end-of-life care should be pursued. Cultural differences must be considered if end-of-life care is to be delivered in an accessible, interdisciplinary fashion across health settings to relieve distress among vulnerable and diverse populations. As US health care reform evolves, it stipulates that we wed cost and quality concerns to cultural concerns in the delivery of equitable care.³⁴ Health care organizations' direct engagement with their communities combined with interprofessional learning about and collaboration on end-of-life issues could help improve care in advanced illness for our diversifying nation. **AJPH**

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No protocol approval was necessary because no human participants were involved in this study.

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