

Cultural Sensitivity in End-of-Life Discussions

by David A. Fleming, MD

Attitudes regarding death and dying vary between countries and even between different cultures within the same country



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Abstract

Cultural origins influence the way patients and health care providers think about care and treatment at the end-of-life. With increasing ethnic diversity there is greater chance that clinical encounters will occur between individuals of different backgrounds, therefore there is greater risk of misunderstanding. Health care providers should be mindful of cultural differences when informing patients, discussing advance care planning, responding to requests for assistance in dying, and responding to requests for limiting treatment.

Introduction

Encounters between physicians and patients of different cultures are increasingly common. The need for cultural awareness by health care providers is therefore becoming more important. This is especially true in end-of-life discussions where cultural beliefs and traditions may strongly influence decisions made by patients and families.

Attitudes regarding death and dying may vary considerably between countries and even between different

cultures within the same country.¹ Questions pertaining to disclosure of information, advance directives, assisting death, and the withholding or withdrawing of treatment are some of the major ethical challenges confronted during terminal illness that are influenced by cultural background.

Healthcare professionals experienced in palliative care tend to have similar attitudes when caring for dying patients regardless of their socio-cultural context.² This suggests that certain attitudes about death and dying are shared universally by health care professionals in spite of the wide variation of beliefs and the typically strong influence of religion and cultural background.

In Missouri, ethnic diversity is becoming more evident. The task of this article is to review the cultural perspectives that influence decisions at the end-of-life and to encourage clinicians to be sensitive to these influences. The risk of misunderstanding can be minimized with knowledge and awareness that cultural influences exist and by responding to these differences respectfully and by taking into account the values and beliefs of each individual patient. Cultural stereotyping can be as disruptive as ignoring cultural beliefs, re-emphasizing the importance of

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being patient-centered and maintaining good communication when dealing with end-of-life issues.

Missouri Demographics

According to the U.S. Census Bureau, Missouri's population increased from 5,117,073 in 1990 to 5,595,211 in 2000.³ Overall Missouri's population grew 9.34 percent, but in central Missouri it grew 14.57 percent. The African-American population grew 14.1 percent overall, compared to 33.46 percent in central Missouri. Missouri's Hispanic population has nearly doubled, increasing by 168 percent in the central corridor. Though Hispanics comprise only 2.1 percent of Missouri's population, the trend in growth indicates a need for greater awareness and sensitivity to the cultural needs of this and other ethnic minorities, especially in geographic areas where expansion has been greatest. In Saline County, for instance, 4.4 percent of the population is Hispanic. Asians and Native Americans comprise 1.4 percent and 1.1 percent of Missouri's population respectively, but there are some areas where the Asian population is more concentrated. In Boone County, Asians comprise 3 percent of the population. These numbers

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Historical Context of Death

The ideal of “dying well” in the context of relieving pain and suffering have occupied the core of medical moral discourse for over 2,000 years.⁴ Death in most societies has been an accepted part of life, and often welcomed as a means of escape from suffering. But the expectancy of life leading to death has been blurred by the modern advancement of medical science. The ability to postpone death through repeated medical interventions has created unreasonable expectations of longevity, regardless of the disease, severity of illness, or prognosis. An ethical paradox has resulted. The societal emphasis on cure rather than care, and the medical emphasis on continued intervention and treatment, has led to fear by many patients that they will suffer needlessly at the end-of-life.⁵ Today people live longer and 70 percent of Americans die in hospitals or other institutions, rather than at home.⁶ Many spend their last days on life support and in critical care settings despite health care directives to the contrary.⁵

Death, once an inevitable and accepted partner of life has become the enemy and only “reluctantly admitted into the realm of medicine” as the major barrier to achieving a longer and improved quality of life.⁷ Responding to the fear of medical entrapment patients are now asking for more information and demanding greater control over health care decisions while they are still able to speak for themselves.

In some ethnic groups discussions about limiting treatment and assisted suicide tend to be avoided for reasons that are not always clear. For instance, African American patients are more likely to desire life-sustaining treatments and less likely to complete a health care directive or pursue palliative care options than white patients. This tendency is not necessarily related to lack of trust or fear of inadequate medical treatment.⁸

Discussions about end-of-life care such as limiting treatment, health care directives and other forms of substituted judgment are now expected. Patients and families across all cultures are concerned and more aware of other options for terminally-ill patients, such as palliative care and hospice. Physicians should be sensitive to the influences of cultural background when these issues arise, and recognize that verbal and written health care directives reflect core values of patients as tempered by their cultural heritage. Physicians should also be sensitive to the influence that their own cultural background has on decision making and the advice that they give to patients during terminal illness.

Communicating About Death and Advance Directives

The enthronement of autonomy as *the* guiding ethical principle for health care is felt by some to be the most important achievement of the North American

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bioethics movement that began in the early 1970s.⁹ Full disclosure about prognosis and advance directives are direct descendents of the principal of autonomy insofar as these forms of communication theoretically represent discussions about personal values, wishes and expectations regarding decisions at the end-of-life. The United States has vigorously embraced a focus on individual autonomy and the use of both written and verbal advance directives that provide clear and convincing evidence as to the patient's wishes when they are unable to speak for themselves.¹⁰ Legal requirements for the implementation of health care directives were provided by the Supreme Court in 1990 with *Cruzan*, and the U.S. Congress in 1991 with the Patient Self-Determination Act.¹¹ Such aggressive application of autonomy has not been true world wide, however.

Asian, European, and Middle Eastern cultures have been less focused on informing patients about prognosis and encouraging personal choice at the end-of-life. These societies do tend to favor dignified death and have done so through forms of "social discourse" but have not ratified the use of advance directives in statute or regulation.¹¹

In Japan decisions are based on a paternalistic model whereby the physician may direct care by informing the family but not the patient. If it is in the "best interest

of the patient" they are not informed because their culture believes it would further add to the suffering of the dying patient. Asian families will often take a protective role as well in decision-making, though this is still an individual understanding between the patient and family and cannot always be assumed.

The genocide of the 1930s has influenced much of the debate regarding end-of-life issues in Europe. In Germany living wills and substituted judgment have been recognized though their implementation has not been legally ratified. Advance directives tend to be accepted, but are viewed as guidelines that endorse patient choice. The expectation is that the physician will make the ultimate decisions.

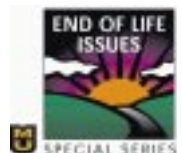
Discussing end-of-life issues and advance directives effectively with patients and families requires sensitivity to their beliefs regarding disclosure and carefully assessing their expectations about life sustaining intervention and what mechanism is going to be used to make that decision. Though rarely used outside of the United States advance directives appear to make a significant difference in decision-making at the end-of-life when they are employed regardless of the cultural milieu. Patients at the end-of-life are more likely to undergo treatment in Asia, Europe, and the Middle East than in the United

States.¹¹ Ironically, physicians from all countries have been willing to forgo these treatments if specific advance directives are in place.

Physicians should also consider their own beliefs if they are strongly different from those of the patient. If ideological differences exist this may disrupt the physician-patient relationship and cause a breakdown in communication, altering the physician's ability to disclose certain information or assist the patients and families in end-of-life planning. Should disruption in the relationship be imminent, referral to a different provider should be considered.

Assisting Death for Suffering Patients

Euthanasia is a merciful act that directly or indirectly causes the death of a suffering person. The intention is to relieve suffering, and the means chosen is as painless as possible. Assisted suicide is the prescribing of medication or otherwise providing a means by which patients can take their own life. Though the Hippocratic Oath proscribes any form of "mercy killing," the moral arguments for direct voluntary euthanasia and physician-assisted suicide (PAS) have become increasingly vigorous worldwide, carried forward by the autonomy movement that began in the United States thirty



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A popular argument defending these practices is that it is a beneficent and compassionate thing to do for suffering patients. Equally compelling is the argument that dying patients have the right to choose when and where they will die. Respecting such a choice also preserves dignity by enabling personal control after the patient becomes incapacitated.

A countervailing argument is that allowing (or requiring) physicians to take life is in violation of professional standards and will undermine trust at a crucial time in the healing relationship. Others fear that social acceptance will diminish the intrinsic value of life and ultimately lead to the slippery slope of involuntary euthanasia for incompetent persons who are “suffering” or otherwise existing in a life not worth living. Choosing death may become too easy when other options for treatment and care remain viable.

In the United States public and professional sentiments lean in favor of legalization. Recently 60 percent of physicians and nearly 70 percent of the public surveyed favored legalization of PAS.¹²⁻¹³ Though a majority of terminally-ill patients surveyed support legalization only about 11 percent would seriously consider it for themselves

and about half of these later changed their mind, suggesting

considerable ambivalence.¹⁴ With increasing public pressure, five U.S. states have introduced public referenda that would allow physician-assisted suicide under specific conditions. Thus far only Oregon has been successful in passing such a law. The “Death with Dignity Act” was passed in 1994 and became the first law anywhere in the world to legalize physician-assisted suicide.¹⁵ In the first six years following legalization 42 terminally-ill patients died as a result of assisted suicide in Oregon.¹⁶ The primary reasons given for requesting assistance was not fear of pain or physical suffering but fear of losing control of bodily functions and their sense of autonomy.

Other societies have decriminalized these activities. On November 28, 2000, the Lower House of the Dutch Parliament, by a vote of 104-40 approved a bill to legalize euthanasia and physician assisted suicide.¹⁷ Though technically illegal, euthanasia and physician-assisted suicide had been tolerated and practiced openly in the Netherlands for over 20 years to the extent that in 1987 the Royal Dutch Association of Pharmacy issued guidelines on the use and preparation of drugs for euthanasia.¹⁸ By 1999 there were over 2,000 deaths annually reported in the Netherlands resulting from euthanasia and PAS, though some believe that many more such deaths have occurred but have gone unreported.¹⁹

Asian societies are less inclined to promote patient choice, honoring the established authority of the physician, which is in marked contrast to Western views.¹¹ Japanese view death as “incorporation with nature and return to nature,” allowing death to occur at “Nature’s hand.”²⁰ Though suicide may be accepted as a personal choice, assisting or otherwise hastening death for someone with terminal illness is not consistent with the Asian belief that death comes naturally and in its own time.

Other Western societies have allowed such practices. In May 1995 the Northern Territory of Australia legalized euthanasia but this law was overridden within a year by the national parliament.²¹ Withholding or withdrawing treatment for terminally-ill patients is allowed in European countries; however, active euthanasia or assisted suicide is discouraged or forbidden in most. Switzerland is unique in that assisted suicide is only forbidden when the assisting person stands to gain personally.²²

It is estimated that voluntary euthanasia occurs in 12 out of the 49 countries affiliated with the International Association for Suicide Prevention (IASP), although these acts are illegal in all.²³ Concern for these findings prompted the IASP to investigate, discovering that over 20 percent of patients admitted to hospice care in Ireland have a positive attitude toward euthanasia. Not surprisingly



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the majority of these patients (16 of 22) were found to be clinically depressed or anxious, stressing the relevance of psychological factors that influence end-of-life decisions.²³

The debate about assisting death for terminally-ill patients may be irreconcilable because the public demand for euthanasia services is in conflict with professional standards and is confronted by political resistance to legalization in most countries. Though culturally diverse, people tend to share a common avoidance of suffering and loss of control that is often greater than their fear of death. Awareness and sensitivity to the psychological factors that tend to encourage these requests will prepare the physician to respond when requests for euthanasia or assisted suicide are made.

Limiting Treatment

With noted exception, the active and intentional ending of life is legally prohibited across Asia, the Middle East, Europe, and North America. Where legally permitted, however, actively assisting death is common. As many as 45 percent of Dutch physicians report that they sometimes allow or actively assist infants to die with parental consent when further treatment is felt to be futile.²⁴ Up to 25 percent of Dutch physicians admitted to euthanising incompetent adult patients without their consent when treatment was clearly no longer indicated or effective.²⁵

In contrast, when considering limiting futile treatment there is

general cross-cultural consensus that overly aggressive treatment should be discouraged.²⁶ Patients and families of Asian descent will tend to desire more aggressive treatment if preferences are not clear. When death is eminent, however, aggressive palliative care is encouraged. In Japan patients tend to expect physicians to intervene paternalistically to prolong life beyond what physicians in North America and Europe might do, but Japanese physicians will also act aggressively to optimize comfort measures when it is clear that death is eminent.²³

In general there tends to be cross-cultural agreement about decisions not to force oral or intravenous fluid on dying patients, to restrict unnecessary diagnostic procedures, to emphasize hospice care, and to use advance directives.³ However, the treatment of incompetent elderly patients varies widely and warrants comment. One study examined medical treatment of incompetent elderly patients with life-threatening, but not necessarily “terminal” illness in seven countries and found considerable variability. Up to 40 percent of physicians chose a level of care different from what had been requested by the patient and 10 percent would have tried cardiopulmonary resuscitation despite a “Do Not Resuscitate” request.²⁷ South American and United States physicians were found to be most aggressive with treatment decisions while Australian physicians tended to be more conservative, respecting

patient requests to limit treatment. These findings support other studies that report conflicting attitudes in the care of critically-ill elderly patients with dementia.

Inconsistent attitudes about end-of-life care may exist between ethnic groups within society as well. African-American patients tend to place a higher value on longevity and tend to request more life sustaining treatments than white patients. African-American physician attitudes follow the same pattern making it unlikely that low socioeconomic status, lack of familiarity with the treatment, or lack of trust account for the difference.²⁸ The reason for this difference in attitude is unclear, though lack of trust may still be an important factor as well as the tendency for strong religious preferences in the African-American population.

The differences in opinion about treating patients with critical or terminal illness underscore the difficulty that pluralistic societies have in defining futility and quality of life. The moral algorithm of Pellegrino is useful in defining futility and when the limitation or withdrawal of treatment is being considered. When there is a disproportionate relationship between the burden of further treatment and the relative sum of therapeutic effectiveness and the presumed benefits to



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derived, life support may and perhaps should be withdrawn.²⁹ Though the clinician determines the clinical effectiveness of treatment, only the patient can ultimately determine the benefits and burdens of continuing treatment relevant to their personal life plan, values, and beliefs. Decisions about futility and limiting treatment are unique to each clinical encounter and must be individualized, taking into account the moral beliefs and cultural background of each patient.

Evaluating Cultural Influence

It is equally important for physicians to avoid cultural stereotyping when assessing the potential influence that cultural background has on patients and their families during end-of-life discussions. Though core values and beliefs may be influenced by cultural origin, how those core beliefs are developed individually must be acknowledged in order to build trust and enable open communication. Physicians can use knowledge about particular cultural beliefs, values, and practices to respectfully recognize a person's identity and to assess the degree to which an individual patient or family might adhere to their cultural background. One tool suggested to

enable this dialogue is to evaluate patients' and families' attitudes, beliefs, context,

decision-making, and environment (ABCDE).³⁰ The purpose of this mnemonic is to help the physician avoid the dual pitfalls of cultural stereotyping and cultural ignorance. This assessment can also serve to identify potential areas of conflict and opportunities for negotiation should conflict occur.³¹ This assessment tool has been adapted from Koenig and Gates-Williams.

Conclusion

Cultural origins of belief shape individual meanings of illness, suffering, and death. This holds true for physicians as well as patients. As ethnic and cultural diversity become more prominent there will be greater risk for cross-cultural misunderstanding and communication break down when engaging in end-of-life discussions. It is therefore increasingly important that health care providers be able to assess the influence that cultural beliefs have on patient attitudes, and that they communicate effectively about these issues. Assessing cultural influence will help to minimize the risk of cultural stereotyping as well as cultural ignorance, and may prevent miscommunication about unwanted and potentially harmful treatment at the end-of-life.

Though modern medical advancements have blurred the traditional acceptance of death as being a natural part of life, for the past thirty years physicians and health care systems in all cultures have

identified the importance of respecting the wishes of the patient and tend to promote palliative care and limiting unnecessary services at the end-of-life. Asian, Hispanic, Middle Eastern, and African American patients often expect more aggressive treatment at the end-of-life but they frequently share in the belief that palliative care and limiting treatment is desirable when the patient's wishes are clearly known and when death is clearly imminent.

References

1. Caralis P, et al. The Influence of Ethnicity and Race on Attitudes toward Advance Directives, Life-Prolonging Treatments, and Euthanasia. *The Journal of Clinical Ethics*, 1993; 4(2): 155-165.
2. Voltz R, Akabayashi A, Reese AC, et al. Attitudes of Healthcare Professionals Toward Clinical Decisions in Palliative Care: a Cross-Cultural Comparison. *The Journal of Clinical Ethics*, 1999; 10 (4): 309-315.
3. U.S. Census Bureau, Census 2000.
4. Etzioni M. *The Physician's Creed. An Anthology of Medical Prayers, Oaths and Codes of Ethics Written and Recited by Medical Practitioners Through the Ages*, 1973; Charles C. Thomas: Springfield, IL.
5. The SUPPORT Principle Investigators. A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT). *Journal of the American Medical Association*, 1995; 274(20): 1591-1598.
6. Lyons J. Boomers Begin Looking Beyond the Good Life to the "Good Death". *Wall Street Journal*, February 25, 2000.
7. Callahan D. Pursuing a Peaceful



- Death. *Hastings Center Report*, July-August 1993: 33-38.
8. Mckinley E, Garrett J, Evans A, Danis M. Differences in End-of-Life Decision Making Among Black and White Ambulatory Cancer Patients. *Journal of General Internal Medicine*. 1996; 11:651-656.
 9. M.A. Sanchez-Gonzalez. Advance Directives Outside the USA: Are They The Best Solution Everywhere? *Theoretical Medicine*, 1997; 18: 283-301.
 10. Lynn J, Teno J, Dresser R, et al. Dementia and Advance-Care Planning: Perspectives from three Countries on Ethics and Epidemiology. *The Journal of Clinical Ethics*, 1999; 10(4): 271-285.
 11. Cruzan v Director Department of Health, 110 S. Ct. 284 (1990); Omnibus Reconciliation Act of 1990 (OBRA-90), Pub. L. 101-508, sec. 4206 and 4751 (Medicare and Medicaid, respectfully).
 12. Bachman J, et al. Attitudes of Michigan Physicians and the Public Toward Legalizing Physician-Assisted Suicide and Voluntary Euthanasia. *New England Journal of Medicine*, 1996; 334(5): 303-309.
 13. Blendon R. Should Physicians Aid Their Patients in Dying? The Public Perspective. *Journal of the American Medical Association*, 1992; 267(19): 2658-2662.
 14. Emanuel E, Fairclough D, Emanuel L. Attitudes and Desires Related to Euthanasia and Physician-Assisted Suicide Among Terminally-ill Patients and Their Caregivers. *Journal of the American Medical Association*, 2000; 284(19): 2460-2468.
 15. The Oregon Death with Dignity Act. Ballot Measure #16. Revised Statute 127.8000-127.897. November 8, 1994.
 16. Ganzini L, et al. Physicians' Experiences with the Oregon Death with Dignity Act. *New England Journal of Medicine*, 2000; 342(8): 557-563.
 17. Associated Press. Dutch Parliament Legalizes Euthanasia. *The New York Times*, November 28, 2000.
 18. Groenewoud J, et al. Clinical Problems with the Performance of Euthanasia and Physician Assisted Suicide in the Netherlands. *The New England of Medicine*, 2000; 342(8): 551-556
 22. Richburg K. Netherlands Move to Legalize Assisted Suicide. *Washington Post*, November 28, 2000.
 20. Ishiwata R, Sakai A. The Physician-Patient Relationship and Medical Ethics in Japan. *Cambridge Quarterly of Healthcare Ethics*, 1994; 3:60-66.
 21. Phillips P. Views of Assisted Suicide From Several Nations. *Journal of the American Medical Association*, 1997; 278(12): 969-970.
 22. Kelleher M, et al. IASP Task Force on Euthanasia and Assisted Suicide. *Crisis*, 1995; 16(3): 111-115, 120.
 23. Kelleher M, et al. Euthanasia and the Terminally-ill: Can the Civil Killing of Others Be Eroded? *Crisis*, 1998; 9(3): 116-118.
 24. van der Heide A, et al., Medical End-of-life Decisions Made for Neonates and Infants in the Netherlands. *Lancet*, 1997; 350: 251-255.
 25. Hendin H et al. Physician-Assisted Suicide and Euthanasia in the Netherlands. Lessons From the Dutch. *Journal of the American Medical Association*, 1997; 277(21): 1720-1722.
 26. McHaffe H, et al. Withholding/withdrawing Treatment from Neonates: Legislation and Official Guidelines Across Europe. *Journal of Medical Ethics*, 1999; 25:440-446.
 27. Alemayehu E, et al. Variability in Physician's Decisions on Caring for Chronically Ill Elderly Patients: an International Study. *Canadian Medical Association Journal*, 1991; 144(9): 1133-1138.
 28. Mebane E, Oman R, Kroonen L, Goldstein M. 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*. 1999; 47:579-591.
 29. Pellegrino E. Decisions to Withdraw Life-Sustaining Treatment. A Moral Algorithm. *Journal of the American Medical Association*, 2000; 283(8): 1065-1067.
 30. Kagawa-Singer M, Blackhall L. Negotiating Cross-Cultural Issues at the End of Life: "You Got to Go Where He Lives". *Journal Of the American Medical Association*, 2001; 286(23): 2993-3001.
 31. Koenig B, Gates-Williams J. Understanding Cultural Differences in Caring for Dying Patients. *Western Medical Journal*. 1995; 163:244-249. **IVIV**
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