

Improving Access to Hospice Care for Hispanic and African-American Patients



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End-of-Life Care Dilemma

Ethnic and racial minorities suffer disproportionately from certain cancers and serious chronic illnesses.

The percentage of minorities that utilize hospice services and palliative care is also disproportionately low.

- 9% African Americans
- 5% Hispanics
- 1.3% Asians
- 0.3% American Indians

Minorities receive end-of-life care inconsistent with their stated wishes.

Flawed Health Care System

- ❖ Inadequate resources.
- ❖ African Americans and Hispanics who lived in census tracts with greater percentages of minorities were less likely to use hospice services.
- ❖ Inadequate access to care.
- ❖ Inability of the system to provide insurance for the uninsured.
 - ❖ 15 million Hispanics uninsured in 2006.
 - ❖ Possible change – PPACA, 2014.

Flawed Health Care Policy Choices

- ❖ Clash with payer policies.
 - ❖ Forgoing curative treatment before accessing hospice services.
 - ❖ False dichotomy between curative and palliative care.
- ❖ Necessity that an attending physician certify terminal condition
 - ❖ Members of minority groups more likely to lack regular access to physicians.
- ❖ Differences among states in Medicaid hospice coverage.
 - ❖ Conflict with Medicaid waiver policies.

Institutional and Academic Realities

- ❖ Need for an in-home primary caregiver.
 - African-American and Hispanic patients generally have lower incomes and may be unable or less able to provide full-time caregiving at home.
- ❖ Lack of adequate number of health care professionals from the same or similar cultural background.
 - Minority physicians from all racial and ethnic groups comprise 9% of the country's physicians.
- ❖ Failure to appreciate cultural influences among majority health care professionals.
 - Lack of cultural competence.
 - Limited academic programs on cultural competence and palliative care.
 - Most existing courses less than twelve hours on average.

Factors Impacting Access to Hospice Care



Cultural Influences

- Contribute to development and expression of beliefs, attitudes, opinions and behaviors.
- Affect how people perceive the symptoms of illness.
- Provide explanations for the causes of disease.
- Shape attitudes toward treatment and the use of medication and technology.
- Influence perceptions of the role of health care professionals.
- Determine patient/physician styles of communication.
- Influence concepts and expression of pain and suffering.
- Affect views of death, dying and care at the end of life.

Hispanics

While cultural variations exist among Hispanics from different countries, influenced also by levels of acculturation, studies have found that the following factors influenced decisions:

- Belief that life should be in God's hands.
- Emphasis on hope (patients should not know about their terminal diagnoses).
- Existence of strong family networks negatively impacting completion of advance directives.
- Burden of decision-making placed on family.
- Value of dying at home in the care of family.
- Less likelihood of discussing hospice with physicians.
- "Hospice," in Spanish, means a place for orphaned children.
- Lack of race/language concordance between patient and physician.

African-Americans

- Philosophical and religious differences with prevailing values related to death and dying.
- Existing health disparities.
- History of discrimination and racism.
- Preference for aggressive treatment at the end of life.
- Lack of health care providers' familiarity with African-American metaphors for death and overall cultural practices.

CONCLUSIONS

- All patients bring a complex mix of cultural influences to any discussion of health care decision-making, especially end-of-life care.
- Generally speaking, patients of Hispanic and African-American backgrounds differ in significant ways from Caucasian patients around whose values and beliefs systems Western medicine and law have developed.
- Cultural and religious views among Hispanics and African-Americans seem to have contributed to a much lower rate of hospice usage than among Caucasians.
- Features of the current hospice system, including payer rules and institutional barriers, clash with the cultural influences and socio-political systemic realities of many Hispanics and African-Americans.
- Research should be conducted to investigate whether certain changes in the existing system could help alleviate under-utilization of hospice services among Hispanics and African-American patients.
- Palliative care transition programs deserve further study as does the idea that someone other than an attending physician might certify the patient's terminal illness.
- PPACA demonstration projects hold promise.