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Ethical Issues: Disparities in End of Life Care

Today 80 million African American, Hispanics, and Asians comprise more than one-quarter of our population and by 2050 it is estimated that non-Anglos will comprise over 47% of the population. These figures are given in a recent *Time* article arguing that for American business to remain competitive in today's market it must design strategies to reach the "new mainstream" of American society, which is defined by the vast multicultural diversity of its ethnic minorities.ⁱ This new mainstream is transforming how America will work, play, learn, and spend in the coming decades, and any company or institution failing to respond to this economic force will be left behind. Unfortunately, however, market strategies tend to work as a negative force when it comes to ensuring adequate health care for the underserved in our society. When it comes to health care, and in particular end of life care, color still divides.

Black men and women continue to experience a higher incidence of and higher death rates from cancer compared to whites. American Cancer Society statistics reveal that from 1989 – 1996 five-year relative survival for patients with cancer was 62% for whites compared to 49% for blacks.ⁱⁱ Compounding this discrepancy the National Hospice and Palliative Care Organization found that in 2002 of the 885,000 patients admitted to hospice programs, 82% were white, less than 10% were black, and less than 5% were Hispanic or Latino.ⁱⁱⁱ

So, why a persistent ethnic divide in a society posing civil rights as a core value and with entitlement programs, such as Medicare and Medicaid, designed to assist underserved and physically disadvantaged populations in obtaining health care and end of life services? Ensuring reimbursement addresses only part of the problem. Researchers have found that literacy, language, cultural, and spiritual barriers tend to prevent patients and families in minority groups from seeking appropriate services, including palliative care and hospice, even when Medicare or other programs cover the expenses. Ineffective communication is a common theme that influences those providing as well as those getting information about end of life services, which may not be provided effectively or appropriately, if at all. There is also a trust issue. Black patients tend to have fewer DNR orders written, will receive more CPR, and have fewer advance directives than white patients because they often believe that they will be treated differently, cared for less, or otherwise marginalized if their providers put such limitations into place.^{iv}

Contrary to contemporary thinking influenced by anecdotal experience, however, recent evidence indicates that Latinos and African Americans are receptive to receiving end of life services when culturally sensitive needs are met. A recent study in Kansas City explored end of life preferences and barriers among low income urban African

Americans and Latinos found that both groups preferred having families provide care for loved ones at the end of life, but emphasized a desire to have services available to reduce caregiver burden.^v Spirituality was identified as a primary means of coping and promoting holistic well being in both patients and families. Low hospice utilization was due to lack of awareness of hospice services in addition to the cost, which was prohibitive for many. Latinos were more likely to report language barriers, while African Americans were more likely to report mistrust of the system. Both ethnic groups in this study were highly receptive to end of life care that would provide relief for both patients and caregivers, emphasize spirituality, and seek family consensus.

There is little doubt that increasing awareness of and offering end of life services will improve and enhance utilization. But such information must be placed in a context of understanding and sensitivity as to the unique barriers that exist for some groups. In general all patients and families are receptive to end of life services when information is offered with compassion and empathy and framed in a style and form appropriate to their culture and language, and through means appropriate to the patient's level of understanding. Spirituality, family consensus, concern for the caregiver, and special efforts to engender trust are central to excellence in end of life care, but may be of particular importance for some patients.

ⁱ *Time*. Selling Ethnicity Inc. Why American Business Needs to Design Strategies to Reach the New Mainstream. Sep 20, 2004

ⁱⁱ Greenlee RT, et al. Cancer Statistics, 2001. *CA Cancer J Clin* 2001; 51:15-36

ⁱⁱⁱ Keller J. End of Life Care Lags for Blacks, Latinos. *Science & Technology News*. 2004. www.stnews.org/news_end_0904.html

^{iv} Born W, et al. Knowledge, Attitudes, and Beliefs about End-of-Life Care Among Inner-city African Americans and Latinos. *J Pal Med*. 2004. 7:247-255

^v Ibid