



CULTURAL INFLUENCES ON END-OF LIFE DECISION MAKING

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The growth of sophisticated life-sustaining medical technology has resulted in greater attention to medical care at the end of life (EOL). These issues are particularly relevant for a growing number of adults in the United States and their family members who are faced with increasingly complex choices related to initiating, withholding, and terminating medical treatment (Diamond, Jernigan, Moseley, Mesina & McKeown, 1989; Heynor, 1998; Zweibel & Cassel, 1989). Many of these individuals and families will be people of color, as it is projected that by the third decade of the twenty-first century, people of color will outnumber European Americans 51% to 49% (Fitzgerald, 1992). These individuals will receive advice on EOL decisions from a work force that may be largely made up of European Americans. How this advice is given and received will be largely influenced by the culture of the recipient of care, the culture of the provider of care, and the culture of the institution where the care is being received.

For providers and institutions, EOL decisions have a financial reality that must be addressed. However, quality of life is also an issue as both institutions and families wrestle with EOL decisions. Being aware of the cultural implications for

EOL decisions can reduce the potential for conflict, misunderstanding and the use of inappropriate resources.

It is not surprising that hospice care providers have investigated the influence of culture on EOL medical care preferences. These investigations are, in part, motivated by the fact that two of the largest ethnic groups (African Americans and Latino/Hispanics) under-utilize hospice service (Gaffin, Hall, & Penso, 1996; Lister, 1997; Gordon, 1996; Infeld, Crum & Kostuta, 1990; Noggle, 1995; Talmantes, Lawler, Espino, 1995). The reasons why hospice services are under-utilized are not entirely clear, but the literature speaks of lack of access to hospice care and preferences toward alternative EOL modes of treatment.

The purpose of this study was to identify barriers to hospice care for African-Americans who primarily utilize the Henry Ford Health System as their primary care provider. Subjects were recruited to attend one of three focus group discussions on African-Americans and EOL decision making. A small monetary incentive was used to induce individuals to participate. The three focus groups were comprised of 21 African Americans who ranged in age from 26–82. There were 5 males and 16 females. Most subjects identified a religious preference although several indicated they were nondenominational.

The questions used during the focus group discussions were developed by the researchers and analyzed for content validity by experienced hospice nurses. Further analysis occurred as a result of a small pilot study that helped to refine and focus the questions. All of the focus group sessions were audiotaped, the tapes transcribed, and the texts analyzed using modified grounded theory approach as described by Strauss (1989), Miles and Huberman (1994). The software, QRS Nud-Ist (1997) was used to assist with data management and analysis. Text units were open coded until core conceptual categories emerged and then axial and selective coding was done to identify clusters/themes. The investigators performed independent coding of the focus group statements

then compared and discussed areas of disagreement to enhance credibility. Face validity was also confirmed by both hospice staff and additional members of the African American community.

Preliminary analysis revealed the following key concepts about EOL medical care preferences and decision-making of African Americans:

- 1 Not wanting to be a burden
- 2 Death as an avoided issue
- 3 Need for hope and faith
- 4 Being independent
- 5 Lack of communication with physicians
- 6 Fear of pain and suffering
- 7 Fear and distrust of the health care system
- 8 Wanting to stay at home
- 9 Need for resources
 - a. information
 - b. finances
 - c. access to care
 - d. family and community support

One major area addressed was to ascertain under what conditions African Americans would utilize hospice services. Some participants indicated they would be reluctant to use hospice services because this would mean giving up hope. Statements such as, “Black people don’t believe in giving up” and “I would not want to give up treatment, but the rest sounds nice” are certainly culturally influenced.

Since the beginning of the hospice movement in this country, a foundation of hospice care has been the belief that most people want to die at home. However, this concept was hotly debated among the study participants. Some participants did express a wish to die at home, but they also, along with others, voiced concerns about being a burden and whether there would be sufficient resources and support for their families. Several focus group participants stated that they

would not be able to sleep in the bed where their loved one had died. If indeed this is an issue for African Americans, then this ethnic group may not view death at home as preferable to dying in an institution.

Overall, the concept of discussing death was an issue for all focus groups. Even when subjects were being recruited, some individuals who initially made contact to express interest in attending the group, changed their minds when the subject was fully explained, “No, I don’t think I want to come to that.” “Death is so depressing,” was a statement made by one caller that mirrors statements made by others. Even those who attended the focus groups expressed dismay over the topic. “Black people spend so much energy trying to live, they can’t take time worrying about dying.” Overall, several individuals in the group expressed the thought that Black people don’t prepare for death. “We don’t do wills, pre-pay for our funerals, make plans to die.” If discussing the subject of death is an avoided issue for African Americans, this has tremendous implications for physicians and other health care providers faced with the task of discussing termination of life support and withholding extraordinary measures to sustain life with families of terminally ill patients.

Overall, there was general agreement that hospice would be an option that most African Americans would choose, if they did not have to give up treatment. However, stopping aggressive treatment of the disease is one of the foundational concepts of hospice care. This could be a major barrier for African Americans who might consider hospice as an EOL alternative. This would also limit the care alternatives that physicians, nurses, social workers and others recommend for patient and family consideration when a terminal illness has been diagnosed and the prognosis for life is less than 6 months.

Focus group participants also related “horror” stories related to poor communications with physicians. This reflected general distrust of health care systems and indeed, formal institutions in general. Clearly, the individuals involved in these

discussions believed they would not receive the same level of care as European Americans because of their race. Again, these attitudes have implications for health care providers as they attempt to establish trust between themselves and their patients and patient/family unit. This is particularly sensitive if the topic is withholding extraordinary medical interventions or stopping aggressive treatment.

The findings of this preliminary study support the premise that there are cultural/ethnic issues for African Americans related to EOL medical care preferences and decision-making. However, several questions remain unanswered. Which of these concepts/issues are unique to African Americans? How do these concepts compare to other cultural/ethnic groups? Are there concepts/issues not identified in this study that are important to other cultural/ethnic groups? What is the influence of gender and age on EOL preferences and decision-making? We stand at the dawn of the 21st century and the graying of the baby boomers. While this is not an area of concern solely reserved for the elderly, EOL decision making is a primary concern of older adults. Now, more than ever, we need to know and understand how culture influences these decisions.

REFERENCES

- Diamond, E.L., Jennigan, J.A., Moseley, R.A., Mesina, V. & McKeown, R.A. (1989). Decision-making ability and advance directive preferences in nursing home patients and proxies. *Gerontologist*, 29(5), 622–6.
- Fitzgerald, M. (1992). Multicultural clinical interactions. *Journal of Rehabilitation*, 58(2), 38–42.
- Gaffin, J., Hill, D. & Penso, D. (1996). Opening doors: Improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities. Commentary of palliative care. *British Journal of Cancer—Supplement*, 29, s51–53.

- Gordon, A.K. (1996). Hospice and minorities: A national study of organizational access and practice. *The Hospice Journal*, 11(1), 49–70.
- Heynor, P. (1988). Meeting the challenge of advance directives. *American Journal of Nursing*, 98(3), 26–33.
- Infeld, D.L., Crum, G.E., & Koshuta, M.A. (1990). Characteristics of patients in a long-term hospice setting. *The Hospice Journal*, 6(4), 81–104.
- Lister, A.N. (1997). Multi-faith hospices. *International Journal of Palliative Nursing*, 3(1), 23–25.
- Miles, M.B., & Huberman, A.M. (1994). *Qualitative Data Analysis* (2nd ed.). Thousand Oaks, CA: Sage.
- Noggle, B.J. (1995). Identifying and meeting need of ethnic minority patients. *The Hospice Journal*, 10(2), 85–93.
- Q.S.R. NUD-IST [Computer Software]. (1997). Victoria, Australia: Qualitative solutions and research (revision 4). Newbury Park, CA: Scolaris/Sage.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.
- Talamantes, M.A., Lawler, W.R. & Espino, D,V, (1995). Hispanic American elders: Caregiving norms surrounding dying and the use of hospice services. *The Hospice Journal*, 10(2), 35–49.
- Zweibel, N.R. & Cassel, C.K. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. *Gerontologist*, 29(5), 615–21.