

Cultural Beliefs in End-of-Life Care



by Dr. Michael C. Marschke
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An urban hospice with a diverse patient population, Horizon Hospice takes pride in promoting cultural sensitivity among our staff. In our end-of-life care educational programs, Horizon also encourages healthcare professionals to learn about the impact of cultural belief systems on the provider-patient relationship. In this issue of *On The Horizon*, we interview two guest authors. Dr. Sara Schwarzbaum explores cultural norms in the Hispanic community that may affect end-of-life care, and Dr. Ronald Barrett points out the importance of the physician's role in discussing advance directives with Black patients. This knowledge may help focus the physician's efforts to communicate effectively about end-of-life care issues in diverse communities.

End-of-Life Care for Hispanic Patients

An interview with Dr. Sara Schwarzbaum

Sara Schwarzbaum, Ed.D., is currently an Associate Professor and Coordinator of the Master's Program in Couple and Family Counseling in the Counselor Education department at Northeastern Illinois University. She is the former Coordinator of the Hispanic Family Counseling Program of Lake County, where she provided outpatient psychotherapy services to Hispanic individuals, couples and families.



Q: Isn't it difficult to generalize about Hispanics?

A: Yes. Hispanics in the United States are not a racially homogenous group. Differences among Hispanics exist in all dimensions of life — including social class; religious affiliation; country of origin; language use; first-, second- or third-generation immigrant status; levels of acculturation; and the degree and nature of biomedical, religious or holistic based beliefs. But despite a wide range of intragroup differences and the importance of doing individual assessments, some generalities can be extracted that may be useful when providing care to Hispanic patients with a life-limiting illness.

Q: What are some characteristics that may distinguish Hispanic from non-Hispanic patients at the end of life?

A: Family involvement is critical. The illness of an individual is a family affair, and members of the family are expected to care for one another. In contrast with North

American individuals who may not want to inconvenience family members, lack of privacy and becoming dependent on family may not be problematic for Hispanics. The involvement of large networks of people is common — and the network may include extended family, godfathers and godmothers, and other friends or neighbors.

Not to be present at the time of an illness or death of a family member may be more tragic than the illness or the death itself. In the home, hospital or nursing home setting, family members may take turns coming and going at the bedside to ensure that the patient's emotional and personal needs are met. This constant attention may puzzle healthcare providers, but it reflects a strong sense of family obligation.

Q: What are common end-of-life-care challenges for the Hispanic elderly?

A: Hispanic elderly may be particularly vulnerable. Elderly widowers are at higher risk of death, suicide or substance abuse — especially if they are poor, first-generation

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immigrants with few connections to either their original or the mainstream culture. Hispanic elderly often do not have pensions, Social Security benefits or Medicare. When they fall ill, they become dependent upon a system which they are ill-equipped to navigate.

In a hierarchical society, the elderly often elicit respect and a sense of duty and obligation in the younger kin. Although the young are expected to care for the old, the young are lower in the family hierarchy, which makes it awkward for them to address impending illness or death with their elders. Initiating discussions about matters such as insurance coverage, treatment plans, advance directives or disposition of the body after death may be difficult or impossible for the younger members of a family with a firm hierarchical organization.

Q: What happens if there is a language barrier in communicating with the elderly?

A: Elderly, first-generation Hispanic immigrants who do not speak English may be forced to rely on younger, English-speaking members of the family — which, again, alters the family hierarchy. Also, younger translators who are English-speaking, second-generation Hispanics raised in the U.S. may not speak Spanish very well. Additionally, they may be fluent in English without knowing the words for conditions, symptoms and other medical vocabulary. Even though they have not been trained in simultaneous translation, younger family members often act as translators for their elderly relatives. This is so challenging, it may result in a disservice to the patients — despite good intentions.

Q: What influence does social class have on end-of-life issues among Hispanics?

A: Class issues may be more salient than ethnicity when dealing with Hispanics in the U.S., and yet class differences are often not emphasized. Fears about sudden death are more common in families who belong to a lower socioeconomic

background, whereas people with a higher socioeconomic status may worry about experiencing a long, difficult and painful illness or dying process.

Poverty, more than ethnicity, increases vulnerability and exposure to chronic illnesses, which may precipitate earlier deaths. Poor Hispanics' rate of death in the perinatal period — as well as mortality rates due to homicide, AIDS and alcohol abuse — are higher than for non-Hispanics, especially in first-generation immigrants, who are more likely to be poor. It is not unusual to see Hispanics with end-of-life issues at much younger ages than the non-Hispanic population.

Q: What common Hispanic beliefs about illness and death should healthcare providers consider?

A: Many Hispanics have a fatalistic view of life, death, and illness, which holds that there is little a patient or a family member can do to alter individual destinies. This view is related to a cultural emphasis on knowing how to suffer, as opposed to how to avoid suffering — which is more common in Western cultures where the standard of living is higher and people have more control over their fate.

Hispanic patients who attribute the causes for illness or death to fate or divine will may refuse life support, thinking that if it is not God's will to extend a person's life, it should not be attempted artificially. Others may refuse pain management, accepting the fate that a great deal of suffering must be endured near the end of life. Hispanic patients might find it hard to discuss advance directives or hear the truth about their diagnosis or prognosis. Their apparent passivity might reflect this non-Western orientation.

Q: Does folk medicine play a role in healthcare for Hispanics?

A: Hispanics who subscribe to a superstitious or magical belief system may attribute illness and death to strong emotional states related to either rage or anger, another person's envy or fear, or severe family conflicts or breakups. These beliefs may exist simultaneously with the acceptance of Western style scientific explanations. A terminally ill patient's family may seek medical care and the care of a religious or traditional healer simultaneously. Fear of ridicule or criticism of the healthcare team might make it harder to disclose that fact.

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Q: What about gender roles in the Hispanic family?

A: Male dominance is common in many patriarchal cultural groups and the Hispanic is no exception. The father or husband may be viewed as the head of the family and the primary decision-maker. The input of the wife can be influential in private, but not necessarily obvious in public. Many women might help a husband “save face” in public so that he appears to be in charge even if he is not.

Q: What do Hispanics typically think about the possibility of life after death?

A: Many Hispanics believe in the afterlife and maintain that the spirit of the deceased needs reassurance from the living before it can find peace in the afterlife. Ongoing communication with the deceased may be perceived as possible. Spiritual visitations of the dead to re-work relationships are quite common among the bereaved. This may be healing and need not be viewed as pathological. Many Hispanics may be opposed to the cremation of the body, thinking it may hinder communication in the afterlife.

Q: What practical recommendations can you make for physicians?

A: To avoid stereotyping, make an individual assessment of each patient’s beliefs, practices and family circumstances. Inquire with a curious, respectful tone to increase disclosure. **Ask about:** whether a **translator** is required, and, if so, use a professionally trained, non-family member if possible; how the patient and family view the **cause of the illness**, whether the patient uses **alternative healing practices** and what **form of medication** is preferable.

Q: What other questions should the physician ask?

A: It’s useful to know:

- How does the patient view the role of the doctor?
- How much information does the patient want?
- What are the patient’s views on advance directives, life support, hospice, cremation?
- Who will be involved in caregiving? If there are no family members available, are there other support networks present in the neighborhood or the faith community?
- Who is the decision maker in the family? And who should be included in discussions about decisions? ■

The Physician’s Pivotal Role with Advance Directives and Blacks*

An interview with
Dr. Ronald Keith Barrett



Ronald K. Barrett, Ph.D., is a professor of psychology at Loyola Marymount University in Los Angeles, where he teaches a course he created on the Psychology of Death & Dying. He is an internationally recognized specialist on the study of cross-cultural differences in death, dying and funeral rites and has published widely on African American funeral practices and multicultural perspectives. During his sabbatical in 2001, Dr. Barrett began to study funeral and aftercare practices among West African Akan in Ghana and Blacks in the Caribbean. He is the founder of the Caribbean African International Bereavement Association.

** Dr. Barrett uses the term “Black” to represent all persons of African descent as members of a subculture, which includes — but is not limited to — African-Americans.*

Q: You recently completed an exhaustive review of the literature on Blacks and advance directives. What did you find?

A: The research documents a tendency of Blacks to be less inclined to complete advance directives in end-of-life situations. This is ironic given that Blacks more often die prematurely — in other words, at a faster rate — and with a greater frequency from most major causes of death than Whites. But while the tendency for Blacks not to utilize health directives is well-documented, it is not fully understood or examined.

Q: Isn’t the use of advance directives relatively low among all racial and ethnic groups?

A: The percentage of Americans completing advance directives is estimated to be between 5 percent and 15 percent of patients in the United States. In comparison to other ethnic

groups, Blacks are less likely to complete a written advance directive than Hispanics or Whites. This is consistent with the common observation that Blacks are more likely to prefer aggressive life-saving interventions. Again, the phenomenon is documented, but not understood. I have applied a psychocultural analysis of these racial and ethnic patterns in an effort to explain these observations.**

Q: What factors influence the cultural pattern of Blacks not completing advance directives?

A: One contributory factor is that some Blacks may suspect that completing an advance directive will limit or compromise the quality of care they receive. A number of researchers argue that a history of discrimination, betrayal and victimization of Blacks within predominantly White healthcare institutions has fostered feelings of alienation and cultural mistrust of these institutions. It is reasonable for Blacks to suspect that White doctors may more readily “pull the plug” on them and not give them the same quality of care as White patients. So it logically follows that Blacks often prefer and insist on aggressive life-saving efforts — even when such efforts appear futile.

Q: What have you learned about communication between physicians and Blacks?

A: Researchers report less communication between physicians and Blacks and Latinos than between physicians and Whites in similar end-of-life caregiving situations. The absence of quality rapport and effective communication seem to play a major role in the completion of advance directives at end-of-life. A number of researchers and practitioners have observed that patients are more likely to complete an advance directive after some discussion and communication with their physicians. Additional findings suggest Blacks as a cultural group may prefer or have a greater need for open communication with their physicians in crisis caregiving situations.

Q: Can you make any generalizations about the role of the family in healthcare decision making for Blacks?

A: For many Blacks, important decision making in healthcare crisis situations is traditionally approached via a “family centered” approach where immediate family members

and significant others are often part of the decision making process. In comparison to Whites, Blacks and Hispanics are less likely to be knowledgeable about living wills and more likely to rely on their physicians and family in making such important decisions. This suggests that educational efforts and the communication process should include family and significant others who might support the patient in end-of-life decision making dilemmas.

Q: What conclusions did you draw from your study?

A: The literature suggests that the relationship between the physician and the patient is crucial to having end-of-life discussions. Numerous cultural and historical factors contribute to the cultural mistrust many Blacks feel toward traditional healthcare institutions and their care providers, who are more likely to be White. Blacks as a group appear to have less knowledge and sophistication about legal documents and the language of living wills. They may have a particular need for physicians to educate and assist them in their end-of-life decision making, which is best accomplished through a family centered approach.

Q: What recommendations would you make to physicians on how to improve communication about advance directives with Black patients and their families?

A. Most importantly, learn to **practice culturally sensitive styles of communicating and listening** when working with Black patients and families. Become knowledgeable and seek more information about Blacks as a cultural group for personal and professional growth. An evolving literature on end-of-life care for multicultural patients suggests cultural sensitivity in caregivers can significantly improve quality of life for the terminally ill.

Most Black patients and their families might also appreciate an approach that is sensitive to the cultural tradition of **collaborative family decision making** regarding critical end-of-life decisions. The patient’s rights for confidentiality should be honored at all times. But remember that when a patient delays and appears to resist taking action on critical decisions, it may be because the patient needs more information and/or an opportunity to share such matters with their families and/or significant others.

You may also need to **accept a leadership role** and actively assist patients with the process of completing

The Physician's Pivotal Role

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advance directives. Effective rapport and open communication will facilitate the dialogue for information sharing, patient education, clarification of rules, roles, and possible cultural misunderstandings, as well as suspicions and fears about advance directives.

Q: Isn't there a danger in making assumptions based on generalizations or stereotypes?

A: Absolutely. It's critical to do individual assessments and resist the temptation to communicate with patients stereotypically. While stereotypes and generalizations can be useful guides, they can also be misleading. Get to know each patient as an individual. Also, if you take risks in allowing the patient to get to know you as well, your ability to achieve more meaningful levels of rapport and more effective levels of communication will likely increase.

Q: If you're not sure what to say, is it better not to say anything?

A. No. Silence is NOT golden — especially when caring for terminally ill Black patients. Physicians are often overworked and overwhelmed and struggling with many factors that challenge their ability to achieve optimal rapport with each patient. Nonetheless, choosing to risk little and say little out of the fear of saying the “wrong thing” simply perpetuates the silence. A good relationship with one's doctor is invaluable, and research demonstrates that the elderly believe physicians should initiate discussions about advance directives with their patients while they are well. So establishing a good rapport with patients prior to a crisis will avoid awkward attempts to do so in late-life caregiving, when it may seem disingenuous.

Q: Are there specific barriers to communication with Black patients?

A. One potential communication barrier is that Black patients in predominantly White institutions may communicate with White physicians with a minimal amount of communication or engagement. This censored style, or “muted speech,” is typical among underserved Black elderly patients. Such patients may be silent and non-assertive

because they may not understand their role or rights, they may lack the capacity to make their needs known, and they may not know how the healthcare system works. The physician who is unaware of these cultural realities may misinterpret the patient's lack of self-expression.

Q: Any final thoughts on the physician's role?

A: It's useful to remember that the physician enjoys unparalleled power and authority in most clinical settings. Consequently, the physician must accept responsibility for leading the way out of the cloak of silence to improve the quality of care for Blacks in end-of-life caregiving situations. In doing so, they provide valuable assistance to Blacks in learning about advance directives and making meaningful choices.

*** Complete results of Dr. Barrett's investigation and analysis can be found in this publication: Barrett, R.K. (In Press) “Advance Directives, DNRs, and End-of-Life Care for African Americans,” In Doka (Ed.) OMEGA. Washington, D.C.: Taylor and Francis, Inc.*



Horizon Hospice's Palliative Care Program

- **What is the goal of Palliative Care?**

To achieve the best possible quality of life for seriously ill patients by relieving their pain and providing supportive comfort care when a cure is unlikely.

- **When is Palliative Care helpful?**

When patients have advanced incurable illnesses, such as metastatic cancer, heart disease, advanced emphysema or dementia, or liver or kidney failure. Palliative care patients can continue to receive chemotherapy, radiation therapy or other aggressive, curative treatments for their disease. They may have longer than six months to live.

- **Who provides Palliative Care?**

The core Palliative Care Team consists of physicians and advanced practice nurses who specialize in palliative care, as well as licensed clinical social workers. Care is delivered in the patient's home or residential facility and visits are billed to insurance on a fee-per-visit basis.

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