Broadcast to many sites nationwide, the 2009 Hospice Foundation of America National Bereavement Teleconference “Diversity and End-of-Life Care” featured a distinguished panel of EOL experts, including Duke ICEOL’s director, Richard Payne, MD. While it is impossible to do justice to the 3-hour teleconference and the numerous speakers, we offer a few nuggets from the speakers and some additional resources available to our volunteers who may be working with patients and families who aren’t just like them.

Nuggets:

- Go beyond what you see. Make no assumptions about the disease, the family, their acceptance or denial of hospice, their race, religion, ethnicity, sexual orientation. There’s more diversity in diversity than we are addressing.

- Understand your own culture. What are your biases? How does your background affect what you see, what you believe, what you feel?

- Hispanic Concerns/Barriers to Appropriate Hospice Care: Lack of medical knowledge, lack of understanding of the “hospice” concept (in Spanish “hospicia” may imply an orphanage or a place of refuge for the abandoned; thus, to work with hospice might imply abandoning the sick person); point of entry into the medical system is often through the ER; don’t assume that Hispanics speak Spanish. Be very aware of body language when it conflicts with spoken language. (I’m fine; I’m painfree.) Rather than asking if the patient is in pain, ask if she is comfortable.

- Chinese Concerns/Barriers to Appropriate Hospice Care: Lack of Western medical knowledge, goal of treatment is most often extending life at the expense of its quality, mentioning death is bad luck. Because of this latter issue, Chinese media have been very resistant to spreading information about hospice or EOL care. In this environment, pre-crisis education is critical. Chinese people often rely on traditional Chinese medicines and may be resistant toward / non-compliant in using Western pharmaceuticals, particularly morphine for pain. They often use traditional herbs that the Western doctor may know nothing about.

- African-American Concerns/Barriers to Appropriate Hospice Care: Many African Americans assume they’ll receive inferior care and are afraid of the “system”; a strong feeling in the African American community is that “we take care of our own.” The final word on whether a person lives or dies at any given time comes from God, not the doctor, not the hospice.

- Muslim Concerns/Barriers to Appropriate Hospice Care: Modesty is the #1 concern. How much of the body is exposed, for what purpose, and to whom? It is very important to have family or another Muslim in attendance at the time of death so that the appropriate prayers are said with or for the patient.
• Concerns about *American Veterans* on Hospice: Some hospices link their patients who are veterans with active duty servicemen and women, someone to share his story with, someone who can validate his history, patriotism, and brotherhood.

• News that needs to be communicated to all:
  
  o Hospice isn’t just about death, but about living most fully.
  o Medicine is not just curative, but also palliative.
  o Many hospices (including Duke) will serve hospice-appropriate patients without regard to the patients’ ability to pay, without regard to their legal (immigration) status, or their language.

• Hospice is not a place but a concept of care.

• How can families help their doctors who may be hesitant to say the patient is dying? Say to the doctor, “Will you please tell us when it’s appropriate to bring in hospice?”

• Re: language barriers: Don’t use family members as interpreters. Family members will frequently filter information they don’t understand, don’t agree with, don’t think the patient should know. If you must use an interpreter, have a conversation with him/her first to make sure the interpreter is willing/able to transmit information as it is given.

**Thoughts on Bereavement in diverse communities**

*Buddhists* – Do not touch the dead body for 8 hours. The spirit is still in the body and should not be disturbed as it is leaving. This can raise a significant problem if the patient dies in a hospital where rooms must be cleared and reoccupied quickly.

*Muslims* – Burial the day of death in a shroud only. This death is the will of God—be patient, have hope.

*African-Americans* – Funerals are likely to have a “call & response” quality to them and be quite emotional. It is taboo to discuss anger toward the deceased.

*Chinese* – Don’t talk about the dead, even among the family. This unwillingness to talk means that bereavement can be very complicated.
Useful Ways for Getting Out the Good News about Hospice

Better: Senior Centers, Volunteer Service Organizations, Clinics

Not So Good (but keep trying): Churches. Some hospices have tried a 1-day EOL Care education blitz for local clergy.

Also, take a look at the art and materials that accompany your work. Do they reflect the clientele you want to serve?

And one of the best ways for becoming more informed about the diverse people you MIGHT serve is to get to know the people you work with who are not like you.

A companion book to this teleconference has been published by the Hospice Foundation of America: *Living with Grief: Diversity and End of Life Care*, forward by Richard Payne, MD. A copy of this book is in the Resource Room at Duke HomeCare & Hospice. Ask Carolyn for the book if you would like to read it. Contents include:

Section I: Understanding and Responding to Cultural Diversity
   1. Cultural Influences on Death, Dying, and Bereavement: An Overview
   2. The Culturally Competent Practitioner
   3. Ethical Aspects of Cultural Diversity
   4. Diversity and Access to Hospice Care
   5. Cultural Diversity: Implications for Funeral Traditions

Section II: Ethnicity and Race as Sources of Diversity
   6. Sociocultural Considerations: African Americans, Grief, and Loss
   8. Death, Dying, and End of Life in American-Indian Communities
   9. Hispanic Cultural Issues in End-of-Life Care

Section III: Diverse Spiritualities
   10. Jewish Perspectives on Loss, Grief, and End-of-Life Care
   11. Dying and Grief in the Islamic Community
   12. Buddhist Perspectives on Death, Grief, and Loss
   13. Christian Evangelicals: The Challenge for Hospice and Palliative Care

Section IV: Other Sources of Diversity
   15. Death and Loss in Deaf Culture
   16. Assessment & Mgmt. of Posttraumatic Stress Disorder in Palliative Care Patients
   17. Aspects of Death, Grief, & Loss in Lesbian, Gay, Bisexual, & Transgender Communities

Continuing Education essays on EOL diversity can be found on the Duke HomeCare & Hospice website:

- *A Perspective on African-Americans and End of Life*, Michael & CeCe Dublin, April 2005
- *Islamic Funeral Rites: Care for the dying, funeral prayers, burial & mourning*, September 2005
- *Hispanic EOL Care*, October 2005
- *Hindu EOL*, February 2007
- *Jewish Visiting the Sick and EOL*, April 2007
- *Age Specific Competencies*, May 2008