Multicultural End-of-Life-Care
Working with Multi-Cultural Populations in Hospice:

A. Introduction:
   1. Challenges we face to improve Hospice care
   2. Appropriate practices for multi-cultural hospice patients and their families.
   3. Danger in stereotyping.

B. Points of Cultural Diversity in Health Care for African Americans, Hispanic Americans, Native Americans, and Asian Americans:
   1. Definition of Family
   2. Common views of gender-roles, care of older adults
   3. Communication patterns, views of marriage and relationships
   4. Common religious and spiritual belief systems
   5. Cultural attitudes toward pain and suffering, death and afterlife

C. Death and Dying Customs of various cultures:
   1. African Americans
   2. Muslims
   3. Traditional Judaic Customs
   4. Japanese
   5. Asian Indian
   6. Chinese Buddhist
   7. Mexican Americans

D. How to Become More Culturally Competent:
   1. Build trust, respect and deliver individualized care.
   2. Learn about patient’s religious beliefs and how these religious beliefs come into play in the process of dying and death.
   3. Allow the patient to define her/his culture and community.
   4. Include culturally specific issues in medical documentation and add cultural questions to assessments.
   5. Increase the number of multi-cultural staff and volunteers.

E. Conclusion:
   1. For Hospice to continue to grow and meet needs of our community, we need to educate ourselves and develop a more culturally competent staff.
   2. Building good rapport with our patients and family members is the first step in showing respect and in developing trust.
   3. Ask questions, keep an open mind, and be aware of our own biases.
Introduction

There are many challenges we face in the effort to improve Hospice care. Hospice has typically in U.S. been used extensively by white, often middle-class population. When providers do not have a common cultural background with patients, the ability to support, nurture, and promote maximum independence can be threatened. Hospice service delivery must be tailored and targeted in ways that are considered appropriate and acceptable practices for multi-cultural hospice patients and their families. It is Essential to avoid stereotyping in our efforts to become culturally competent.

U.S. Census Bureau: Rutherford County, NC People Quick Facts:

<table>
<thead>
<tr>
<th>Category</th>
<th>2005 Population</th>
<th>2004 Percentage</th>
<th>2004 Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>63,771</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White persons, percent</td>
<td>87.4%</td>
<td>55,574</td>
<td></td>
</tr>
<tr>
<td>Black persons, percent</td>
<td>11.2%</td>
<td>7,122</td>
<td></td>
</tr>
<tr>
<td>American Indian and Alaska Native persons, percent</td>
<td>0.4%</td>
<td>229</td>
<td></td>
</tr>
<tr>
<td>Native Hawaiian and other Pacific Islander, percent</td>
<td>0.0%</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Persons reporting two or more races, percent</td>
<td>0.6%</td>
<td>381</td>
<td></td>
</tr>
<tr>
<td>Persons of Hispanic or Latino origin, percent</td>
<td>2.0%</td>
<td>1,285</td>
<td></td>
</tr>
<tr>
<td>Asian persons, percent</td>
<td>0.4%</td>
<td>245</td>
<td></td>
</tr>
<tr>
<td>White persons, not Hispanic, percent</td>
<td>85.6%</td>
<td>54,407</td>
<td></td>
</tr>
<tr>
<td>Language other than English spoken at home in 2000</td>
<td>3.3%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
African Americans:

**Beliefs in regard to Healthcare and Advance Directives:** Cultural mistrust is a prominent barrier to African American involvement in hospice. Some African Americans may mistrust the health care system as it is mostly made up of Caucasian health providers. There continues to be prejudice against African Americans and this continues to cause this lack of trust, fear, hopelessness, lack of knowledge and an inability to identify with mostly white health providers. Throughout history African Americans have been treated as second class citizens, and have received unequal treatment and inadequate medical care. This has created a tradition and culture of distrust. It is critical not to violate African American patient’s developing trust. Many African Americans do not recognize or understand Hospice. Very few caregivers or volunteers are African Americans. Research documents show a tendency of Blacks to be less inclined to complete advance directives in end of life situations. Blacks are more likely to prefer aggressive life-saving interventions and insist on aggressive life-saving efforts- even when such efforts appear futile. One theory for this is that Blacks may suspect that completing an advance directive will limit or compromise the quality of care they receive. Researchers feel this may be due to the history of discrimination, betrayal and victimization of Blacks within predominately White healthcare institutions this may have fostered feelings of alienation and cultural mistrust of these institutions. Blacks may suspect that a White Doctor may readily “pull the plug” on them and not give them the same quality of care as White patients. Black patients are more likely to complete an advance directive after some discussion and communication with their physicians.

**Family:** Faith and family are very important. African Americans who are very traditional are likely to have a profoundly spiritual approach to dying. When someone dies, they might choose to hold wakes or have a “home going service” meaning the deceased is “going home” to the spirit world. There is a strong belief in the afterlife and many believe in times of crisis or times of joy loved ones are with them. 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. Typically, African Americans feel very strong sense of obligation to gather at the time of death. They often believe death to be a part of life. An old very commonly held belief is that when someone dies, a baby is born. In comparison to Whites, Blacks are less likely to be knowledgeable about legal documents and the language of living wills and more likely to rely on their physicians and family in making such important decisions. Educational efforts and communication should include family and significant others who might support the patient in end-of-life decision making.

“Cultural Diversity at the End of Life; Issues and Guidelines for Family Physicians.”
“Death and Dying in the Black Experiences: An Interview with Ronald K. Barrett, PhD.”
Innovations in End-Of-Life Care, September-October 2001, Vol.3, No.5
Hispanic Americans:

Beliefs about illness and healthcare: Subgroups which are classified under “Hispanic” include Mexican Americans, Puerto Ricans, Cubans, and Central and South Americans. Each of these ethnic groups has a distinctive socio-historical background, unique cultural norms and patterns of interaction. There is a very large population of Hispanic Elders and many do not speak English. Many have little economic resources. Language barriers, lack of awareness of existing services and lack of trust of formal services often keep Hispanic population from utilizing hospice services. Hispanic elderly tend to live in their Hispanic communities and are less likely to utilize long term care institutions. Many older Hispanics have a high incidence of depression as well as do their caregivers. Hispanics are less likely to complete advance directives due to lack of knowledge of terminology and may need further explanation and discussion before completing. Hispanic Americans are very concerned with dying with dignity and do not wish to be dependent on others for care. Most would like to avoid nursing homes and want control of their place of death.

Family: The research no longer supports belief that family roles are rigid with Hispanic male being dominant in the marital relationship. What has been found is that children are very close to their parents and siblings. Families tend to only accept support from kin. Families often provide high levels of support to Hispanic elders in time of need. Children are taught to care for their elders. Studies have found that Hispanic Men want little intervention at end of life while Hispanic women tend to favor extensive medical intervention. Many Hispanic elders do not have private insurance and this often causes limited access to medical care and many receive too little care too late. Hispanic families can become very emotional as they are very passionate about their family members. Family is number one priority, including extended family, cousins and neighbors. Family members will often take care of the patient and want to “handle it all”. The family may not want the patient to know he/she is terminal. They want to relieve the burdens of the sick patient. Religion is very important to these families. The Hispanic population has diverse beliefs about death and healing. Some believe that the deceased are watching over them in times of difficulty. Some believe in spiritual healers. Some believe death is a natural part of life and if Catholic may offer masses in honor or anniversary of a family member’s death.

Beliefs in regard to death and afterlife: Some of the beliefs of Native Americans in regard to death and afterlife include the belief that upon death people pass-over into the spirit world, where they are met by the creator and their ancestors who have passed on before them. This world is a world of love and beauty, not to be feared. Native Americans believe that all religions, all things and all living creatures fit into “the Indian Hoop of Life” it is all part of the Native Americans giving respect to everything. Many Native Americans believe their spirits live on and the outer shell deteriorates, and that their spirits choose this outer covering or vessel while they were on their life journey. Native people have been instructed not to hold onto materialistic things; to do so is known to them as greed. Native Americans believe they should be thankful for what they receive from their elders but they must not hold onto them. They feel to hold on is disturbing to both parties and frustration will be felt on both sides, the one preparing to pass-over and the individual or families which remain. They feel dying should be a time of peace and understanding, a time to communicate, if at all possible, settle differences, to make peace with themselves and others. Then they are prepared to take the next step through the “Big Open Door” into the spirit world to greet the Creator and all of their ancestors.

Family: Family is broadly defined to include the immediate family as well as extended family members “Family” is a matter of blood and spirit. Other members of the family’s tribe may also be included as part of the family. Extended family relationships are important, especially during illness and death. Any illness concerns the entire family. Decision-making varies with kinship structure. Generally, individuals speak for themselves, but family members may speak on behalf of the person who is ill. Family spokesperson varies with kinship structure and culture. Spokesperson may not be decision maker.

Asian Americans:

**Beliefs in regard to illness:** Asian Americans include Japanese, Chinese, Filipinos, Koreans and Hawaiians residing in the US. Asian Americans may believe that suffering is due to karma, law of cause and effect, which is inevitable. Some prefer to die at home, and hold rituals and practices specific to their cultural beliefs. Meditation and transcendence are learning method. They respond best to quiet, respectful approach and interactions. Asian Americans are more likely to complete Advance Directives and some older Korean Americans support advance planning and wish to forego life support. However they worry that Advance Directives could cause conflict with family centered values and religious beliefs. They are concerned about conflict between generations and worry that their adult children may not honor their wishes to forego life support. Cultural beliefs of Karma or God’s plan may conflict with Advance Directives.

**Family:** In the traditional Asian family ancestors and elders are viewed with great reverence and respect. The father is traditionally the head of the household, and his authority is unquestioned. The primary duty of the son is to be a good son, and his obligations to be a good husband or father come secondary to his duty as a son. Role of the females is that of subservience to males and performers of domestic duties. Women were expected to marry, become obedient helpers of their mother-in-law and bear children, especially male ones. Family members roles are often rigid defined. Much effort is expended to avoid offending others, and if family members have feelings that might disrupt family harmony, they are expected to restrain them. The welfare and integrity of the family is of great importance. In Asian culture, health care decision making is clearly proscribed to be undertaken by a specific individual. Even if an elderly patient is competent to make decisions, the responsibility of making the decisions usually falls on the elder male family member. A hospice team member’s focusing on the patient’s preferences and wishes rather than this family member’s decision may antagonize the rest of the family. Asian cultures are often concerned about how medical decisions may affect the extended family. Asian families are often concerned about the impact of the elderly person’s death on the family.

“End-Of-Life Challenges, Honoring Autonomy”. Valente PhD, RNCS, FAAN, Sharon M., Cancer Nurs 27-(4), 2004 Lippincott Williams, and Wilkins.
Religious beliefs throughout history have been central in helping families accept, understand, adjust, and give meaning to death and dying. Even though a family may not formally adopt a religion, they will be influenced by cultural traditions, beliefs, and practices related to death and dying that have evolved in their particular culture under the influence of one or a combination of religions.

**Buddhism**

The focus is on taking up a path allowing one to deal with the inevitability of suffering. Change cannot be stopped. Suffering, although inevitable, is not desirable. One’s Karma or destiny cannot be altered. The only part of the process that can be influenced by the individual is dealing with the desire that creates the suffering. To eliminate the desires is to eliminate the suffering. Such philosophy places the responsibility for the suffering squarely on the sufferer. Modification of desire is recommended as an eight-fold path of right living through which the preferred outcome of neither happiness or pain, but rather a passive acceptance of life, is achieved. One gives no pain, and one feels no pain. Not being caught up in emotions allows the individual to concentrate on the pursuit of wisdom and the knowledge of reality. Although an apparent emotional passivity is encouraged, a whole series of rituals are performed to allow the family members to express feelings symbolically. Many believe that illness and suffering, and bad luck are thought to come from a variety of spirits when they are offended. The Buddhist understanding of good health is a balanced interaction between mind and body, as well as between life and its environment. When such interactions are out of balance, illness tends to arise. Buddhist theory and practice are then aimed to restore and strengthen balance. In the treatment of illness, Buddhism does not reject modern medicine and its powerful array of diagnostic and therapeutic tools. Rather, it states that these can be put to most effective use in combating illness when based on compassionate action of others. Buddhism asserts that they make it possible for an individual not only to create value from severe adversity, including sickness, but to also forge an opportunity for personal growth from this adversity.

Judaism

There are three denominations of Judaism; Orthodox, Conservative and Reform. Orthodox Jews follow the teachings in the Old Testament very literally, keep strict Dietary rules, this is called keeping kosher, many do no work on Sabbath (Friday at sundown to Saturday at sundown), and attend evening Sabbath service on Friday nights and most of the day Saturday. Men and women are separated in the synagogue when they pray. Men are the authority in the family and women take care of children and may work outside of the home but must dress modestly and cover their heads at all times. There are strict rituals surrounding death, burial and the mourning period. Conservative and Reform denominations are less strict, some do keep kosher and keep the Sabbath but others have changed to adjust to “modern times” and do not follow the strict dietary laws and rules of keeping the Sabbath. According to people who interpret Jewish Law, each person has a duty to keep themselves in good health. This encompasses physical and mental well-being, as well as early treatment for illness and prevention. Judaism is very supportive of Hospice philosophy. Jewish people are taught that all individuals are considered to have value regardless of their condition. This includes individuals with developmental disabilities, AIDS or other illnesses. Judaism opposes discrimination against all persons.

**Hinduism:**

Hindu healthcare customs and beliefs often contribute to the decisions for medical care and choice of healthcare services. The actions of supernatural forces and certain human excesses may be considered important in illness causation among Hindus, regardless of educational level. For example, some believe that excessive consumption of sweets causes round worms and too much sexual activity and worry are associated with tuberculosis. However, do not take for granted that all Hindu have the same belief systems or the same degree of intensity. Deep-rooted beliefs about illnesses can inhibit the acceptance of scientific causes for disease, resulting in treatment challenges. Hindus believe in reincarnation and view death as the soul moving from one body to the next on its path to reach Nirvana, heaven. Death is a sad occasion, but Hindu priests emphasize the route ahead for the departed soul and a funeral is as much a celebration as a remembrance service.

Hindus cremate their dead, believing that the burning of a dead body signifies the release of the spirit and that the flames represent Brahma, the creator. Family members will pray around the body as soon as possible after death. People will try to avoid touching the corpse as it is considered polluting. The corpse is usually bathed and dressed in white, traditional Indian clothes. If a wife dies before her husband she is dressed in red bridal clothes. If a woman is a widow she will be dressed in white or pale colors.

The funeral procession may pass places of significance to the deceased, such as a building or street. Prayers are said here and at the entrance to the crematorium. The body is decorated with sandalwood, flowers and garlands. Scriptures are read from the Vedas or Bhagavad Gita. The chief mourner, usually the eldest son or male, will light some kindling and circle the body, praying for the wellbeing of the departing soul.

After the cremation, the family may have a meal and offer prayers in their home. Mourners wash and change completely before entering the house after the funeral. A priest will visit and purify the house with spices and incense. This is the beginning of the 13-day mourning period when friends will visit and offer their condolences. Often, a garland of dried or fake flowers is placed around a photograph of the deceased to show respect for their memory.

'Shradh' is practiced one year after the death of the person. This can either be an annual event or a large one-off event. This is the Hindu practice of giving food to the poor in memory of the deceased. A priest will say prayers for the deceased and during this time, usually lasting one month, and the family will not buy any new clothes or attend any parties. Sons are responsible for carrying out Shradh.

How to Become More Culturally Competent

*Improve Cross-cultural communication through building a trusting relationship based on, honesty and mutual respect. Show respect for a patient’s dignity and self determination by respecting their cultural differences.
*Treat every patient as an individual and recognize that the perception of events is filtered through the lens of person’s culture.
*Learn about the religious beliefs of the patient and how these religious beliefs come into play in the process of dying and death.
*Allow the patient to define her/his culture and community; ask the patient about the community’s response to death and dying, health and healing.
*Include the identification of culturally specific issues in addition to regular medical documentation and add cultural questions to assessments.
*Increase the number of multi-cultural staff and volunteers.

Conclusion:

When providers do not have a common cultural background with patients, the ability to support, nurture, and promote maximum independence can be threatened. Always make individual assessments, resist temptation to communicate with patients stereotypically. Stereotypes can be misleading. Establish good rapport and be willing to take a risk and learn about patient’s culture and belief system. Inquire with a curious, respectful tone to increase disclosure.

We must learn to become sensitive to our own biases, learn to empower our patients and their families, and develop trusting and therapeutic relationships.