

# *From the Start, Consider the Finish*

## End-of-Life Care Cultural Resource Guide



### **MUSICAL CREATED BY**

Voices Theater in collaboration with Milwaukee Public Theatre

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# ABOUT THE RESOURCE GUIDE

This resource guide represents an overview of the literature on the cultural and historic issues regarding end-of-life care. In conjunction with the musical, *From the Start, Consider the Finish* and the post-performance talk-back sessions, we hope this resource guide will provide audience members with starting points for future reflection and support, including a broader practical, historical/cultural perspective on differing beliefs, attitudes and practices around death.

**This section provides an overview of cultural attitudes towards end-of-life care in Wisconsin and references.** Because of the vastness of the subject we are focusing on four cultures that have strong representation in Wisconsin: African American, Hispanic/Latino, Hmong/Southeast Asian and Native American. We also acknowledge that there are many Wisconsinites from other cultures and religions who have different practices/traditions. We encourage readers to contact us regarding their own traditions and we will post them in future versions of this guide.

# CULTURAL ATTITUDES TOWARDS END-OF-LIFE CARE IN WISCONSIN

## ADVANCE DIRECTIVES & LIFE SUPPORT AND COMMUNICATION & DECISION MAKING IN THESE CULTURES:

- AFRICAN AMERICAN
- HISPANIC/LATINO
- HMONG/SOUTHEAST ASIAN
- NATIVE AMERICAN

## CONCLUSIONS

## ADDITIONAL RESOURCES

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# Cultural Attitudes Towards End-of-Life Care in Wisconsin

*National Institutes of Health  
State-of-the-Science Conference Statement  
December 6–8, 2004*

“Anticipatory decision making about end-of-life care is predominantly a North American concept.” (Thomas, Wilson, Justice, Birch, and Sheps, 2008). A majority of individuals undergoing treatment in the United States embrace some portion of the Western philosophy of medicine. This philosophy holds that a patient should have: 1) a clear understanding of illness and treatment options; 2) freedom of choice; 3) a practical attitude toward the future; and 4) a willingness to engage in difficult discussions. However, not all cultures living in the United States embrace these principles of the Western philosophy of medicine (Klessig, J, 1992).



The United States is a nation increasingly composed of people with diverse racial or ethnic and cultural backgrounds. The rapid increase in the number and proportion of minority elders (U.S. Census Bureau, 2002) suggests the importance of recognizing and understanding the role of race or ethnicity and culture on end-of-life decision making. Individuals from racial or ethnic minority backgrounds may be especially likely to turn to their traditional norms and practices at the end of life because religious and cultural beliefs, norms and practices can provide them with meaning for their illnesses and guide them in making decisions regarding treatment and care options (See Ersek, et.al in Kwak and Haley, 2005).

When faced with difficult, complex, and multiple choices for health care treatment, patients and families draw on their inner resources, which may include cultural expectations of treatment, familial support, and spiritual or religious beliefs. The behaviors surrounding death can be highly resistant to change for any cultural group. As a result, patients may temporarily return to older cultural and religious traditions, in times of crisis, regardless of their socioeconomic status (Klessig, J, 1992). “The language of our childhood remains the language used during times of intimacy and stress” (Haffner, 1992).

Not surprisingly then, there are many ways to view end-of-life care. We know “substantial differences exist among cultural groups in the percentages with living wills/advance directives, and they are less frequent for those with family-centered decision making or with less trust in the healthcare system” (Thomas, Wilson, Justice, Birch, and Sheps, 2008). In fact, recent studies show that while many ethnic minority patients receive fewer medical services and spend less on health care throughout most of their lives than white patients, they have, on average, higher costs in their last 6 months of life. Why is this? In order to increase awareness and understanding of different communication preferences, we need to take a closer look at how minorities in Wisconsin (African American, Hispanic/Latino, Hmong/Southeast Asian and Native American) engage with the end-of-life care topics of advance directives and life support.

# AFRICAN AMERICAN

## Advance Directives & Life Support

Active end-of-life care planning is not an unfamiliar concept to most African American elders. Providers who have these discussions, however, should remember that elders might be reluctant to participate due to an understandable mistrust in the health care system based on past history of segregation and discrimination toward African Americans. Several studies suggest that African Americans are less likely to complete advance directives such as do-not-resuscitate (DNR) orders or living wills (Caralis, Davis, Wright, & Marcial, 1993; Eleazar, Hornung, & Egbert et al., 1996; Hopp & Duffy, 2000; Mouton, 2000). Elders may feel that if they decided to opt for “Do Not Resuscitate,” that would give the system the license to provide sub-standard care or give up on them “too soon”. Religious beliefs may also play a role, in that many older African Americans believe that God is ultimately in control, and is the only one who can determine the timing of death.

Among both African American patients and physicians, more have been found to favor aggressive life-prolonging treatment in the case of terminal illness than among comparison White groups (Caralis, 1993; Hopp & Duffy, 2000; Mebane, Oman, Kroonen, & Goldstein, 1999; Mouton, 2000). Mouton (2000) points out that life support may be equated with life, and that any effort at withholding life-sustaining therapies might be seen as another attempt of genocide by predominantly Caucasian institutions, recalling the history of unethical experiments on African Americans, such as the Tuskegee Syphilis Study. Some will request tube feeding even in the face of terminal illness. Providers, then, should be very sensitive to issues regarding refusal or withdrawal of tube feedings.

## Communication & Decision Making

Particularly because of the experience of many African American elders who grew up with segregated health care and social service systems in which they faced continual discrimination, it is extremely important to show respect to them in clinical settings in order to put them at ease and establish rapport. This includes, at the very least, using respectful titles (e.g., Mr., Mrs.) unless they give the clinician and staff permission to do otherwise.

The knowledge of the 40-year Tuskegee Experiment, which recruited African American men with syphilis to be a part of a research project in which they were promised but never given treatment, is widely known in the African American community. This memory, in addition to the widespread discrimination most have faced in their lifetimes, are likely to provide reasons for African American elders to be more than a little suspicious of health care providers, especially those who suggest any type of experimental treatment or research. Clavon (1986) and others have emphasized the importance of recognizing and respecting patients’ cultural habits, listening attentively, and encouraging conversation.

Some African-American families may request that certain diagnoses or disease prognoses be withheld from the patient to shelter them from disturbing information. Other patients and families favor forthright discussion of all medical issues and treatment plans. Some patients may prefer that their loved ones be the conduits for information. So direct provider-patient communication may be limited by patients’ desire not to know the full implications of their illness.

The loved ones may be a patient’s family members or “fictive kin”. “Fictive kin” are people that are considered “family”, as the result of longstanding relationships, but may not be linked directly by blood ties. These individuals may be serving as the primary care giver or even as the surrogate decision makers and may sometimes be more involved than the directly related family members.



Extreme tact and sensitivity are called for when having discussions about advance care planning and end-of-life issues. Since trust is so critical in adequate end-of-life care with African American elders and their families, it is very important for the provider to have built a trusting relationship with the patient and family in the past. Ensure that you have adequate time and that the patient’s family is present. In all cases it may be helpful to ask the patient or family about their understanding of the illness and treatment options, and use this as the basis for further discussion. Since many of the elders may have strong religious beliefs, having a trusted spiritual counselor as part of the team may be helpful for patients.

## HISPANIC/LATINO

### Advance Directives & Life Support

The act of dying and death has been a more naturally accepted process culturally in the Hispanic/Latino communities than other communities (Talamantes, Gomez, Braun, 2000). Religion, faith and spirituality hold an important role in the acceptance of death (Villa, 1991). El Dia de Los Muertos (Day of the Dead) is a holiday celebrated throughout Mexico and in Hispanic/Latino communities in the United States. During El Dia de Los Muertos, families go to the gravesites of deceased family members and take food and other symbols in order to honor the lives and to celebrate the unity of the family. Additionally, decorated altars depicting pictures of the deceased and symbols representing death and dying and important mementos for the family members can be displayed in numerous places during this holiday. In discussing dying and death, Hispanic/Latino elders often incorporate “dichos” or sayings about God and their faith (Talamantes, Gomez, & Braun, 2000).



*Offrenda by Nicole Acosta, Milwaukee Mijas. Used by permission.*

In response to survey questions regarding life-prolonging treatments, Hispanic/Latino elders were more likely than non-Hispanic whites to approve the use of cardiopulmonary resuscitation (CPR), hospitalization, the use of antibiotics, intubation, and intravenous nutrition (Caralis et al., 1993). Research has shown that Mexican Americans both favored and desired the use of life support, although sometimes it was because of their perception that a doctor would suggest or use life support only if there was hope that the patient would survive (Thomas, Wilson, Justice, Birch, and Sheps, 2008).

In contrast, although death appears to be more readily accepted by Latino elders, the use of hospice services tends to be significantly lower for this elder group (Talamantes, Lawler, Espino, 1995). Reasons for not utilizing hospice services included lack of knowledge about Hospice programs; a belief that the use of hospice services would denote “giving up hope and faith” in the life of the dying patient; lack of insurance; and distrust in the provider or health care system (Talamantes, Gomez, & Braun, 2000).

In focus groups with Latinos, the National Hospice and Palliative Care Organization (NHPCO) found that most participants were not familiar with the idea of advance health care planning. There were also misunderstandings about terms such as “caregiver,” which in the Latino community implies a professional role rather than one undertaken at home by family members. Some Latinos have also not heard of hospice and may equate it with nursing homes, which have a negative connotation because they go against the traditional cultural belief that it is the family's responsibility to care for their sick and elderly relatives. (Marquand, 2008)

Questionable immigration status may also make families skittish about taking the legal steps necessary to enroll loved ones in hospice programs. “There is the fear factor,” said Carlos Gomez of Capital Hospice. “Some of them are loath to sign lots of pieces of paper. There is the trust issue.” (Stein, 2007)

## Communication & Decision Making

For medical staff, early attention to building rapport will go a long way to facilitate communication. In many cultures, such as in Mexico, rapport begins through exchange of pleasantries or chit-chat before beginning the business of medical history-taking and physical examination (Gallagher-Thompson, Talamantes, Ramirez, Valverde, 1996; Elliott, 1996). “Personalismo”, a display of mutual respect, is an essential quality for providers to have when caring for this population. Older Hispanic/Latino Americans often expect health care personnel to be warm and personal and they express a strong need to be treated with dignity (Villa et al., 1993).

Suggestions for respectful communications between medical staff and elders from Hispanic/Latino backgrounds include: as a sign of respect, older persons should be addressed by their last name; take care to evaluate whether questions or instructions have been understood, because some persons will nod “yes” but not really comprehend; outright questioning of authority, such as a physician, is taboo in some cultures, so encourage the patient to ask questions. Due to the heterogeneity of the Hispanic/Latino caregivers and their use of formal and informal resources, it is critical for health providers to assess the social and family networks to determine the extent of support that is being provided to the primary caregiver.



It is evident in the literature that Hispanic/Latino elders do not make end-of-life decisions autonomously, rather, decisions are made in a familial context usually with reliance on the physician for guidance (Talamantes & Gomez, 1996; Blackhall, et al., 1995). Talamantes and Gomez (1996) found that 46% of Mexican American elderly would rely on their physicians to make health care decisions for them, 24% preferred to make their own decisions, and 18% would rely on their families to make their health care decisions for them. When asked who could make decisions about life support measures if they were unable to make these decisions, 28% selected their daughters, 14% selected spouse, and 12% selected their physicians.

Both earlier and current research emphasize the importance of the family (nuclear and extended) and community (friends and neighbors) as the most important social and supportive entities for Cuban, Puerto Rican and Mexican Americans (Gallagher-Thompson, Talamantes, Ramirez, & Valverde, 1996). Some studies have reported that elderly Hispanics/Latinos expect their children to provide support (Cox & Monk, 1990; Markides, Boldt, and Ray, 1986). So it is not unusual to see multiple family members visiting the elderly when institutionalized, or scheduled for appointments or tests, in order to provide support to the individual, to consult with each other and reach consensus regarding what is best for the elderly, and to assist with decision making as necessary. In situations in which there is a strong family system, Hispanics/Latinos may opt for not having a health care proxy. This may be considered irrelevant in the setting of an involved family unit or may be considered potentially harmful as it may isolate one family member as the primary decision maker.

For Hispanics/Latinos, acculturation level may also play an important role. A study by Sabogal and colleagues (1987) found that family obligations and the perception of the family changed with level of acculturation in that the higher the level of acculturation, the lower the perception of family obligations and the family as a referent. However, there were no ethnic differences found among the Mexican American, Cuban American and Puerto Ricans in relationship to their cultural values regarding the family even though there was heterogeneity among groups regarding accessibility to family (Sabogal et al., 1987).

## HMONG/SOUTHEAST ASIAN

### Advance Directives & Life Support

The belief and practices of Buddhism are widespread in Southeast Asia. Many Buddhists believe that human suffering and hardships provide the catalysts for change and development (Young-Eisendrath, 1998). During difficult periods of life, people will become enlightened and focus on how their suffering and hardships are brought about by their own attitudes and intentions, actions and relationships. Buddhism teaches believers that suffering is necessary to develop personal



responsibility for subjective lives and awaken thoughtful compassion about human limitations. Illness as suffering has value as a catalyst for change and development. Therefore, the illness and disability journey, through pain and suffering, can provide valuable lessons in life (Miles, 1995). Delays in obtaining relief from illness may be a Buddhist stoic response to religious awakening.

Braun, Pietsch & Blanchette (2000) argued that culture influences a wide variety of death and dying attitudes and medical decisions. Southeast Asian families have been influenced by their religious and cultural philosophies, such as Buddhist beliefs surrounding karma and reincarnation with concern for ancestral spirits. These beliefs may lead to an avoidance of hospitals where souls of people who died may not have a place to rest and can create havoc for the living. Delayed medical attention may be the result of this avoidance of hospitals where lost souls may gather.

For many Asian American elders, traditional healers' offices serve as meeting places to socialize with other elders (Yeo, 2001). The socialization function of traditional healing parallels the traditional Chinese medical view that illness should be addressed not only through medicine, but also through social and psychological aspects of life. End-of-life decisions about care may be characterized by: family vs. individual decision making—even if the elder is competent to make decisions, family members might feel that it is their filial duty to take the decision-making role; non-disclosure of terminal illness to protect the elder; and placement of the dying person or the body—wanting to "go home to die" and the practice of not disturbing the body, reflecting reluctance of organ donation or autopsy (Yeo, 2001). Therefore it is quite typical for Southeast Asians to view the withdrawal of life supports as causing or speeding the demise of their family elder. Palliative care, with its comforting, peaceful, and family supportive dimensions, may be more acceptable for Buddhists and other Southeast Asians.

### Communication & Decision Making

The Hmong are a very traditional people without a written language prior to coming to the United States. The Hmong formed nomadic clans who wandered in the remote and sparsely populated mountains of Laos, used shamans, and were animistic in their folk healing beliefs. The Hmong combine Chinese medicine and Protestant Christian beliefs, but spirit illness and soul loss beliefs still persist in this country (Fadiman, 1997). As such, it is very important to provide cultural and linguistic competence in aging services because more Southeast Asian elders are non-English or limited English speaking in comparison to younger Southeast Asians.

Trust needs to be built with the physician. Coming from an economically and technologically deprived culture, it can take awhile to understand how the health care options being discussed can help them. Think of how challenging it would be to understand that cutting humans open can save a life when all that was known before was that cutting open an animal killed its life.

There are cultural differences in death and dying truth telling (Crow, Matheson & Steed, 2000; Muller & Desmond, 1992). Many Southeast Asian families do not want or allow the physician to inform dying family members of their terminal prognosis because it would cause them to lose hope. Some do not want to upset the loved one, others don't want to because this may bring death sooner, or truth telling about dying may show a lack of respect for the soon-to-be ancestor.

It is important for health care providers to recognize additional factors. The family often bears responsibility to make decisions, thus, it is important to recognize and respect the role of family when communicating with patients and families—one way to be sensitive to diversity within each group—

doctors can ask patients whom should be included in decision making, and how much information the patient wants to know, and how much information is to be shared with family representative. The role of community leaders such as clan leaders is very important among Hmongs – they mediate conflicts in decision-making and also help families plan for the funeral.

## NATIVE AMERICAN

### Advance Directives & Life Support

Many older Native Americans may be less likely to have written advance directives, due to historical misuse of signed documents, distrust of the dominant system, and belief that families will take care of decision making. However, many Native Americans know what their preferences are. A survey of 50 Native Americans over the age of 55 in a community clinic in a large urban area of California revealed that only one respondent had written an advance directive, “because he wanted to make sure a certain member of his family had no say” (Hendrix, 2000).

End-of-life care varies from tribe to tribe with cultural tradition and individual acculturation. There is a general preference for naturalness, and home care is preferred unless there is a cultural taboo regarding death. Many Native American tribes/nations have specific rituals and ceremonies concerning care of the body after death in order to ensure that the spirit crosses over safely to the other side, and is not held here by inappropriate behavior or thoughts by the deceased person’s family. Most Native American traditions teach that there will be a joining with the ancestors and those that have gone before, and that death is a natural part of the life cycle.



Therefore, Native Americans typically do not desire organ donation or autopsy (Kramer, 1996). And it is not unusual for Native American patients to request any removed body tissues be returned to them after surgery. This includes hair, nail clippings, tonsils, organs surgically removed and often, amputated limbs or digits (Alvord, 1999), anything to facilitate the body being whole in order to “cross over” into the next world (Levy, Neutra, & Parker, 1987).

Many traditional Native Americans were taught to withstand pain as a skill for survival. Overt expression of pain (verbal or non-verbal) is unacceptable in many Native American cultures today. Older Native Americans may be less likely to ask for pain medication and more likely to use internal resources to manage pain (Hendrix, 2001b). Native Americans are also generally undertreated for chronic and acute pain. A request for assistance may not be repeated, or may be told to a family member who will relay the request (Kramer, 1996).

## Communication & Decision Making

Culturally appropriate interventions depend upon the elder's individual tribal affiliation, level of traditional beliefs, and acculturation to Western biomedical health care system. Most Native Americans have had some exposure to allopathic medicine through Indian Health Service units, or care in urban clinics or military settings. Many older Native Americans exhibit a basic distrust of the Western health care system based on historical abuses and belief that this system is based on "greed" rather than care for the individual (Hendrix, 1999).

Whether or not interpreters are needed, literacy level should be assessed, as well as English language skills. Many Native American languages do not have equivalent words or concepts for many English words, especially medical language. The cultural nuance of language (e.g., voice inflection and accent) can influence the meaning of words and phrases.

Some Native American cultures do not speak of death, dying, or of negative outcomes to medical procedures, as thought and speech can cause the negative outcome to occur (Hendrix, 1998). Speaking the name of a deceased person may hold that person's spirit in limbo, and delay their journey to the next world. The heterogeneity of Native American tribal beliefs affects the provider's ability to speak directly about negative outcomes in some situations. One way to work within this framework is to discuss with the family or spokesperson situations requiring decisions that have happened to others, come to an understanding with the treatment team regarding the patient's wishes, and document the results of these discussions in the patient record.

Other Native American tribal communities have no difficulty speaking directly about death or dying situations, and wish to have all the information available. These tribes tend to look at death as a natural part of the circle of life, not to be feared, as it may include a reunion with the ancestors who went before.

Ample time should be given for consideration of information given, and consultation with other persons in the Native American community. Consultation may be sought from clan leaders, matriarchs, patriarchs, religious leaders, and/or medicine persons. Also, translation of written material and medical jargon may be sought from other sources. Medical procedures may be appropriate only on certain dates for an individual in consultation with traditional Indian healers.

After slow and deliberate consideration of treatment options, an elder may choose not to accept the procedure or treatment, or in some Native American traditions, an elder may choose not to allow treatment for a member of his/her family (Alvord, 1999). Use of a cultural guide, or spiritual leader, may be helpful if not already engaged, but ethical and confidentiality issues are at stake. Ultimately, empowerment lies with the patient.

Marbella, Diehr, G. Ignace, & G. Ignace (1998) surveyed 150 patients at an urban Indian Health Service clinic in Milwaukee, Wisconsin, on concurrent use of Native American healers and physicians. Authors reported that 38% were utilizing the services of a healer, and that 86% of those not seeing a healer would consider seeing one in the future. In this study, greater than one third of the patients received differing advice from the healer and the physician, and they were more inclined to follow the advice of the healer. Only 14.8% of this population shared this information of concurrent treatment with their physician. Respondents indicated thirty tribal affiliations, the largest numbers being Oneida, Chippewa/

Ojibway, and Menominee. This study underscores the need for culturally sensitive dialog with patients about concurrent treatment and collaborative relationships with American Indian healers.

Whenever possible, co-therapy with traditional healers and medicine persons or diagnosticians should be encouraged. In some situations it is possible for the traditional healer to participate as a member of the interdisciplinary team. If a Native American elder is hospitalized and requests it, arrangements may be made for ritual or ceremony at the bedside, which may include smudging with sage or sweet grass smoke. Other arrangements could be for Native American medicine pouches, bundles, or other specific items of sacredness and healing, that should not be disturbed or touched by health care personnel or hospital staff.

## CONCLUSIONS—

### MINORITY RESPONSE TO ADVANCE CARE DIRECTIVES

(<http://www.minoritynurse.com>, "Making Their Wishes Known", Barbara Marquand, Fall 2008)

Minorities are less likely to complete advance directives for a variety of reasons, including a lack of access to culturally and linguistically appropriate information. Mistrust of the health care system, misperceptions about advance directives and difficulties in understanding medical terminology and the long history of racism in this country can also create barriers.

Still other barriers stem from legal red tape. Each state has its own advance directive laws, and some states require advance directive documents to be notarized in the presence of a lawyer. This can be a problem for minorities who live in low-income or rural communities where there is little or no access to notaries and legal services.

"Although the advance directive laws were written with good intentions, they have created hurdles that are insurmountable for many patients," says Rebecca Sudore, MD, Assistant Professor of Medicine at the University of California, San Francisco.

In a study published in the June 2008 issue of the Journal of the American Geriatrics Society, a team of researchers headed by Sudore recommended that oral advance directives, based on patients' discussions with doctors, be made legally binding in all states. The study also emphasized the need for health care professionals and policymakers to facilitate opportunities for discussion about advance care planning in minority communities.

Of the 173 subjects who participated in the study, the majority (73%) were persons of color, and 31% had less than a high school education. The researchers found that subjects who had talked with family, friends or health care professionals about their end-of-life care preferences were more likely to take the next step and complete a written advance directive. Especially in communities where there is distrust of the health care system, says Sudore, the emphasis should be on getting people to think and talk about end-of-life planning rather than looking only at whether they have signed the legal documents.

She also stresses the need for advance directive documents that are easy-to-read, easy-to-understand and culturally and linguistically appropriate. In a previous study, Sudore's research team found that

patients in California overwhelmingly preferred a simplified advance directive form to the standard form used in the state. The simplified version, which Sudore created with input from health literacy experts, patients, social workers, nurses and attorneys, uses short sentences, large type and helpful graphics that illustrate the text.

## Cultural Resources

### WEBSITES

- Cross Cultural Health Care Program  
The Cross Cultural Health Care Program (CCHCP) addresses broad cultural issues that impact the health of individuals and families in ethnic minority communities in Seattle and nationwide. The mission of the CCHCP is to serve as a bridge between communities and health care institutions to ensure full access to quality health care that is culturally and linguistically appropriate.  
<http://www.xculture.org/>
- Culture Clues and End-of-Life Care Sheets <http://depts.washington.edu/pfes/cultureclues.html>
- DiversityRx  
Diversity Rx is a clearinghouse of information on how to meet the language and cultural needs of minorities, immigrants, refugees and other diverse populations seeking health care.  
<http://www.diversityrxconference.org/>
- EthnoMed  
Cultural Competency Resources and Patient Education Materials for: Amharic, Cambodian, Chinese, Eritrean, Ethiopian, Oromo, Somali, Spanish, Tigrean, Vietnamese and others.  
<http://ethnomed.org/>
- Every Culture  
History of the Hmong and their culture.  
<http://www.everyculture.com/multi/Ha-La/Hmong-Americans.html>
- Office of Minority Health, US Dept of Health & Human Services  
The mission of the Office of Minority Health (OMH) is to improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities.  
<http://minorityhealth.hhs.gov/>
- Health Management For Older Adults - African-American, Hispanic, Rural White  
Select Module #6: Ethnogeriatrics: Knowing the Difference  
<http://medinfo.ufl.edu/~gec/hmoa3/mods.html>
- <http://www.minoritynurse.com>, “Making Their Wishes Known”, Barbara Marquand, Fall 2008)
- National Institute of Health: “Racial and Ethnic Differences in End-of-Life Costs”, Hanshate, Kronman, Young-Xu, Ash, Emanuel, Arch Intern Med. 2009; 169(5): 493-501. <http://archinte.ama-assn.org/cgi/content/abstract/169/5/493>
- Network on Multicultural Aging (NOMA)  
The Network on Multicultural Aging (NOMA) is a national community of individuals and organizations who are concerned with diversity and working toward cultural competence on all levels.  
<http://www.asaging.org/noma>
- The Stanford Geriatric Education Center  
This website provides a comprehensive training module on culturally sensitive geriatric care and is an excellent source of ethnogeriatric information. Stanford also offers an ethnogeriatric IQ quiz which is helpful. <http://sgec.stanford.edu/>

## BOOKS

- Cultural Competence in Health Education and Health Promotion, Perez, M.A and Luquis, R.R., 2008
- Cultural Diversity in Health and Illness, Spector, R.E. 2004
- Cultural Sensitivity, A Pocket Guide for Health Professionals, Galanti, G. G. and Woods, M.S., 2007
- Culture and Health: Applying Medical Anthropology, Winkelman, M., 2009
- Culture and Nursing Care, A Pocket Guide, J.G. Lipson, S.L. Sibble, P.A. Minarik, 1997, pp. 280-290
- Explaining Illness Research, Theory, and Strategies, Whaley, Bryan B., Lawrence Erlbaum Associates, 2000, pp. 299-316
- Guide to Culturally Competent Health Care, Purnell, L.E., 2nd Ed., 2009

## References & Resources for Culture Section

- Adler, A. R. (1995). Refugee stress and folk belief: Hmong sudden deaths. *Social Science and Medicine*, 40, 1623-1629.
- Alvord, L. A. (1997, October 31). Lecture presented at Stanford Medical School, Stanford, CA. [Dartmouth Medical School].
- Alvord, L. A., & Van Pelt, E. (1999). *The Scalpel and the Silver Bear: The first Navajo woman surgeon combines Western medicine and traditional healing*. New York: Bantam Books.
- Applewhite-Lozano, S. (1995). Curanderismo: Demystifying the health beliefs and practices of elderly Mexican Americans. *Health and Social Work*, Nov; 20(4): 247-53.
- Aranda, M.P., & Miranda, M.R., (1997). Hispanic aging, social support, and mental health, does acculturation makes a difference? In K.S. Markides (Ed.), *Research Issues in aging Hispanics*. New York: Sage.
- Blackhall, L.J., Murphy, S.T., Frank, G., Michel, V., & Azen, S. (1995, September 13). Ethnicity and attitudes toward patient autonomy. *JAMA*, 274 (10), 820-825.
- Braun, K. L., Pietsch, J. H., & Blanchette, P. L. (2000). *Cultural issues in end-of-life decision making*. Thousand Oaks: Sage.
- Caralis, P, Davis B, Wright K, & Marcial E. (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics*, 4:155-165.
- Clavon, A. M. (1986). The black elderly. *Journal of Gerontological Nursing*, 12(5), 6-12.
- Cox, C., & Monk, A., (1990). Minority caregivers of dementia victims: A comparison of Black and Hispanic families. *Journal of Applied Gerontology*, 9,340-354.
- Crow, K., Matheson, L., & Steed, A. (2000). Informed consent and truth-telling: Cultural directions for healthcare providers. *Journal of Nursing Administration*, 30, 148-152.
- Eleazer G.P., Hornung, C., Egbert, C. B., Egbert, J.R., Eng, C. Hedgepeth, J., McGann, R., Strothers, H., Sapir, M., Wei, M. & Wilson, M. (1996). The relationship between ethnicity and advance directives in a frail older population. *Journal of the American Geriatric Society*, 44:938-943.
- Fadiman, A. (1997). *The spirit catches you and you fall down*. New York: Farrar, Straus, & Giroux.
- Gallagher-Thompson, D., Talamantes, M., Ramirez, R., & Valverde, R., (1996). Services delivery issues and recommendations for working with Mexican American family caregivers. In G. Yeo & D. Gallagher-Thompson (Eds.), *Ethnicity and the Dementias* (pp.137-152). Washington, D.C.: Taylor & Frances.
- Haffner L. (1992) Translation is not enough-- Interpreting in a medical setting. *West J Med*. 157:255-259
- Hai, T. B., Eastlund, T., Chien, L. A., Duc, P. T., Giang, T. H., Hoa, N. T., et al. (1999). Willingness to donate organs & tissues in Vietnam. *Journal of Transplantation Coordination*, 9, 57-63.
- Hendrix, L. (1998). American Indian elders. In G. Yeo, N. Hikoyeda, M. McBride, S.-Y. Chin, M. Edmunds, & L. R. Hendrix (Eds.), *Cohort analysis as a tool in ethnogeriatrics: Historical profiles of elders from eight ethnic populations in the United States*. Working Paper Series No.12. Stanford Geriatric Education Center, Palo Alto, CA. (650) 494-3986.
- Hendrix, L. R. (1999). *Cultural support in health care: The older urban American Indian of the San Francisco Bay Area*. Dissertation. The Union Institute. Cincinnati, OH: UMI Dissertation Service, 1-800-521-0600.
- Hendrix, L. (2000). Unpublished survey, Indian Health Center of Santa Clara Valley, Inc. Hendrix, L. R. (2001a). Ethnicity and the dementias: American Indian/Alaska Native. A workshop presentation, Association for Gerontology in Higher Education Annual Meeting. San Jose, CA.

Hendrix, L. R. (2001b). Urban American Indian elders: Attitudes and experiences concerning spiritual practices and resources, pain management, and herbal remedies [Abstracts, p. 45]. Paper presented at the 13th annual Indian Health Service Research Conference. Albuquerque, NM.

Hennessey, C. H., & John, R. (1996a, September), American Indian family caregivers' perceptions of burden and needed support services. *Journal of Applied Gerontology*, 15(3), 275-293.

Hennessey, C. H., & John, R. (1996b). The interpretation of burden among Pueblo Indian caregivers. Accepted for publication in the *Journal of Aging Studies*.

Higginbotham, J.C.V., Trevino, F.M., Ray, L.R., (1990). Utilization of curanderos by Mexican Americans: prevalence and predictors findings from HHANES 1982-84 *American Journal of Public Health*, Vol 80, December, 32-35.

Hopp, F. P. & Duffy, S. (2000) Racial variations in end-of-life care. *Journal of the American Geriatric Society*, 48, 658-663.

Jenkins, C. N., Le, T., McPhee, S. J., Stewart, S., & Ha, N. T. (1996). Health care access and preventive care among Vietnamese immigrants: Do traditional beliefs and practices pose barriers? *Social Science and Medicine*, 43, 1049-1056.

John, R., Hennessey, C. H., Roy, L. C., & Salvini, M. L. (1996). Caring for cognitively impaired American Indian elders: Difficult situations, few options. In G. Yeo & D. Gallagher-Thompson (Eds.), *Ethnicity & the dementias* (chap.16, pp. 187-206). Washington, DC: Taylor & Francis.

Klessig, J. The effect of values and culture on life-support decisions. *West J Med*. 1992;157:316-322.

Kramer, B. J., Hyde, J. C., and Polisar, D. (1990). 1990 study of urban American Indian aging. final report: Administration on aging, research grant AR0118.

Kramer, B. J (1991) Urban American Indian aging. *Journal of Cross Cultural Gerontology*, 6, 205-217.

Kramer, B. J. (1996a). American Indians. In J. G. Lipson, S. L. Dibble, & P. A. Minarik (Eds.). *Culture & nursing care: A pocket guide* (chap. 3, pp. 11-22). San Francisco: University of California–San Francisco Nursing Press.

Kramer, B. J. (1996b). Dementia and American Indian populations. In G. Yeo & D. Gallagher-Thompson (Eds.), *Ethnicity & the dementias* (chap.14, pp. 175-182). Washington, DC: Taylor & Francis.

Kwak, Jung MSW, and William E. Haley, PhD. (2005) Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups. *The Gerontological Society of America* Vol. 45, No. 5, 634–641.

Levy, J. E., Neutra, R., & Parker, D. (1987). *Hand trembling, frenzy witchcraft, and moth madness: A study of Navajo seizure disorders*. Tucson, AZ: University of Arizona Press.

Marbella, A. M., Harris, M. C., Diehr, S., Ignace, G., & Ignace, G. (1998, March-April 30). Use of Native American healers among Native American patients in an urban Native American health center. *Archives of Family Medicine*, 7(2), 182-185.

Markides, K.S., Boldt, J.S., & Ray, L. (1986). Sources of helping and intergenerational solidarity: A three generations study of Mexican-Americans. *Journal of Gerontology*, 41(4): 506-511

Miles, M. (1995). Disability in an Eastern religious context: Historical perspectives. *Disability and Society*, 10, 49-69.

Mebane, E. W., Oman, R. F., Kroonen, L.T., & Goldstein, M.K. (1999). The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision making. *Journal of the American Geriatric Society*, 47 579-591.

Mouton, C. P. (1997, March). Special health considerations in African-American elders. *American Family Physician*, 55(4), 1243-1253.

Mouton, C. P. (2000). Cultural and religious issues for African Americans. In Braun, Pietsch, & Blanchette, (Eds.) *Cultural issues in end-of-life decision making*. Thousand Oaks, CA: Sage.

Nakasone, R. Y. (2000). Buddhist issues in end-of-life decision making. In K. L. Braun, J. H. Pietsch, & P. L. Blanchette (Eds.), *Cultural issues in end-of-life decision making* (pp. 213-230). Thousand Oaks: Sage.

Olson, M. C. (1999). "The heart still beat, but the brain doesn't answer." Perception and experience of old-age dementia in the Milwaukee Hmong community. *Theoretical Medical Bioethics*, 20, 85-95.

Padilla, R., Gomez, V., Biggerstgaff, S.L., & Mehler, P.S. (2001). Use of curanderismo in a public health care system. *Archives Internal Medicine*, 161, May, 1336-1340.

Sabogal, F., Marin, G., Otereo-Sabogal, R., VanOss Marin, B., & Perez-Stable, E.J. (1987). Hispanic familism and acculturation: What changes and what don't? *Hispanic Journal of Behavioral Sciences*, 9(4): 397-412.

Sotomayor, M. (1992). Social support networks. *Hispanic aging research reports: Part I and Part II*, (p.p. 94-105) Bethesda, MD: National Institutes of Health, National Institutes on Aging,

Sotomayor, M. & Applewhite, S.R. (1988). The Hispanic elderly and the extended multigenerational family, In S.R. Applewhite (Ed.), *Hispanic elderly in transition: Theory Research policy and practice* (p.p. 121-134) Westport, CT: Greenwood Press.

Stein, Rob (3/12/07). The End of Life, a Racial Divide, *Washington Post*.

Talamantes, M.A., Fabrizio, D.K., Lichtenstein, M.L., & Hazuda HP (1996). Perceived caregiver burden among Mexican American Elderly and European American Elderly: The San Antonio Longitudinal Study of Aging (SALSA), paper presentation at the Gerontological Society of American Annual Meeting, Cleveland, OH.

Talamantes, M.A., Gomez, G., & Braun, K.L. (2000). Advance directives and end-of-life care: The Hispanic perspective: In K.L Braun, J.H. Pietsch, & P.L. Blanchette, (Eds.) *Cultural Issues in End of Life Decision Making*: (p.p. 83-100) Sage Publication.

Talamantes, H.D. (1992). Unpublished tape recorded oral history, El Paso, Texas.

Talamantes, M.A., Lawler, W.R., & Espino, D.V. (1995). Hispanic American elders: caregiving norms surrounding dying and the use of hospice services. *Hospice Journal*, 10(4): 35-49.

Thomas, Roger, Donna M. Wilson, Christopher Justice, Stephen Birch, and Sam Sheps. A Literature Review of Preferences for End-of-Life Care in Developed Countries by Individuals With Different Cultural Affiliations and Ethnicity. *Journal of Hospice & Palliative Nursing* 10.3 (2008): 142-61.

Villa, M.L., Cuellar, J., Gamel, N., & Yeo, G. (1993). *Aging and Health: Hispanic American Elders* (2nd edition), SGEC Working Paper Series, Number 5, *Ethnogeriatric Reviews*, Stanford Geriatric Education Center.

Villa, R.F. (1991). La Fe de la mujer. In M. Sotomayor (Ed.) *Empowering Hispanic families: A critical issue for the 90's* (pp.43-58). Milwaukee, WI: Family Services America.

Watson, W. H. (1982). *Aging and social behavior: An introduction to social gerontology*. Belmont, CA: Wadsworth.

Watson, W. H. (1983). *Stress and old age: Black aging and transplantation shock*. New Brunswick, NJ: Transaction Books. [See especially pages 1-11.]

Watson, W. H. (1984). *Black folk medicine: The therapeutic significance of faith and trust*. New Brunswick, NJ: Transaction Books.

Watson, W. H., & Maxwell, R. J. (1977). *Human aging and dying: A study in sociocultural gerontology*. New York: St. Martins.

Warda, M.R. (2000). Mexican American perceptions of cultural competent care. *Western Journal of Nursing Research*, 22(2):203, 224

Yee, Barbara W.K., PhD (2001) *Health and Health Care of Southeast Asian American Elders: Vietnamese, Cambodian, Hmong and Laotian Elders*. Bureau of Health Professions Health Resources and Services Administration U.S. Department of Health and Human Services.

Yeo, Gwen, PhD. (2001) *Ethnogeriatric Curriculum* 2nd Edition. Bureau of Health Professions Health Resources and Services Administration U.S. Department of Health and Human Services.