

## Pain and People with Dementia: Cultural Competence and Health Disparities

*"Of all the forms of inequality, injustice in health care is the most shocking and inhumane." ~ sDr. Martin Luther King, Jr.*

### **An African American Perspective**

As we know, people with dementia often receive poor pain management, particularly in the later stages, because of their difficulty in articulating their pain. However, oftentimes within the African American community this problem is compounded by other health disparities.

African Americans are two times more likely to develop Alzheimer's disease than whites due to a disproportionate rate of risk factors: obesity, heart disease, hypertension, diabetes. These factors often combined with generally lower socioeconomic status, income inequality, inadequate access to health care, limited access to private health insurance, problems with the Medicaid bureaucracy, and copays often result in people seeking medical attention only for emergencies.

Added to this, ethnic communities tend to be served by public hospitals which are often underfunded, with a high turnover of physicians. In addition, nursing homes in ethnic communities are often understaffed and/or experience high turnover of all staff. The too frequent result is that provider care is inadequate, with a lack of proper diagnosis, including an over-reliance on psychotropic drugs. For some people there is apprehension in using meds, and some may seek alternative treatments from herbs and home remedies. For all these reasons, many African

Americans experience a lack of trust in the health care system as a whole.

Within the African American community there are many who believe memory loss is a normal part of aging. Religious beliefs, including a strong belief in the power of prayer, can also play a role. Some people worry that they don't want to speak illness into existence. Finally, as is true for most people and families coping with dementia, there is also stigma and shame. All of these factors can have an impact that delays or prevents diagnosis and treatment.

Cultural competence is defined as a set of values, behaviors, attitudes and practices within a system, organization, program or among individuals which enables them to work effectively cross culturally. Further, it refers to the ability to honor and respect the beliefs, language, interpersonal styles and behaviors of individuals and families receiving services. At a system, organizational or program level, cultural competence requires a comprehensive plan that addresses policies, infrastructure building, professional development, in-service training, program administration and evaluation, the delivery of services, and enabling supports and consultants as needed.

On an individual level the health practitioner must be aware of his/her own cultural and family values, be aware of his/her personal biases

and assumptions about people with different values than theirs, be aware and accept cultural differences between themselves and individual patients, understand the dynamics of the difference, and adapt to and respect diversity.

### **Health Disparities and Cultural Competence in the Hispanic Community**

Hispanic people are the largest minority in the United States. There are an estimated 60.6 million, making up 18% of the total national population. Hispanics or Latinos can be of any race, any ancestry, any ethnicity, including Cuban, Mexican, Puerto Rican, and South or Central American.

Latinos are 1.5 times more likely than whites to develop Alzheimer's disease. According to the Administration on Aging, between 2008 and 2030 the Latino population aged 65 years and older will increase by 224% compared to 65% for the white population. As this occurs Latino communities, families, and systems of care will be confronted by increasing rates of Alzheimer's with the fewest resources to manage it.

It is significant to note that Hispanics have the highest uninsured rates of any racial or ethnic group within the United States and are most likely to underutilize available health care services. The lack of insurance in the Hispanic community is tied in part to a lack of health insurance in the

# RESOURCES

During the fall of 2020 CaringKind presented a four-part webinar series on *Pain and Dementia: Approaches that Work*.

This issue of *ADvancing Care* shares highlights from Session 4: *Pain: Cultural Competence & Health Disparities*, and focuses on presentations by Paula Rice, Manager of African American Outreach, CaringKind, NY, NY, and Niurqui Mariano, Bronx Outreach Manager, CaringKind, NY, NY.

Recordings of all four sessions can be found on the CaringKind website.




Campinha-Bacote, J. (2003, January 31). Many faces: Addressing diversity in health care. *Online Journal of Nursing*, (8) 1. Obtained from <https://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Volume82003/No1Jan2003/AddressingDiversityinHealthCare.html>

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workplace, where the rate of uninsured Hispanics is a disturbing 37.9%. Over one-third of working adult Hispanics are uninsured, compared to about a quarter of working adult blacks and an eighth of working adult whites.

One example of cultural incapacity was described in a study published in the *Journal of the American Medical Association*, which found that Hispanics who were treated for certain bone fractures at the UCLA Emergency Medicine Center were twice as likely as white patients to be denied adequate pain medication in the ER. The study found that ethnicity---not language, gender, or insurance status, was the main predictor for inadequate pain relief.

Little is known about Hispanic pain experience and the potential disparities that exist in pain treatment. Although Hispanics in general report less pain, a 2016 study in the *Journal of Pain* found that Hispanics report more pain severity and sensitivity in clinical and experimental pain studies than white participants. Hispanics are more reluctant to take strong pain medications such as opioids and many believe that pain should be overcome with natural or non-prescription medicines. Stoicism and religious manifestations are also common coping strategies for pain.

The provider/client/patient relationship is built through communication and the effective use of language. Because nearly a third of Hispanics in the U.S. are not fluent in English, many efforts to engage them begin with translation. But focusing on language alone can fall short, especially if the translation does not consider cultural differences. Culturally relevant translation must be relevant to the specific Hispanic subgroup targeted. Cultural awareness of accents, idioms and slang usage is necessary to avoid confusion and miscommunication. In addition, Hispanics tend to be highly attuned to others' non-verbal messages. Non-Spanish speaking providers should be particularly sensitive to this tendency when establishing a relationship with patients who speak only Spanish or who are nonverbal.

Hispanic families traditionally emphasize interdependence over independence and are far more likely to be involved in the treatment and decision-making process for a patient. Family involvement often is critical in the care of Hispanic patients.

Hispanic culture tends to view health as a continuum of body, mind, and *espíritu* (spirit). In addition there is an extensive practice of traditional medicine carried out by *curanderas*, *espiritistas*, or healers within the Hispanic community. Combining respect for the benefit of mainstream medicine, tradition, and traditional healing, along with a strong religious component from their daily lives, Hispanic patients may bring quite a broad definition of health to the healthcare setting. Respecting and understanding this view can prove beneficial both in treating and communicating with the Hispanic community, as well as useful for the culturally competent health care professional.

### **Finally, this reminder:**

"...when thinking about cultural knowledge, it is critical to remember the concept of intra-cultural variation — there is more variation within cultural groups than across cultural groups... no individual is a stereotype of one's culture of origin, but rather a unique blend of the diversity found within each culture, a unique accumulation of life, and the process of acculturation to other cultures."

— J. Campinha-Bacote, PhD, FAAN

**No one size fits all. Cultural competency is a lifelong learning process rather than an end in itself.**