Culture, Ethnicity, and Dementia

Kenneth J. Doka

The College of New Rochelle, kdoka@cnr.edu

Follow this and additional works at: http://digitalcommons.cnr.edu/facpubs

Part of the Gerontology Commons

Recommended Citation

CHAPTER 4

Culture, Ethnicity, and Dementia

Kenneth J. Doka

INTRODUCTION

One could possibly think that if any disease or condition were free of the influences of culture, it would be Alzheimer's disease. After all, in Alzheimer's disease and other dementias, memory and cognition deteriorate. With that decline, one could assume that connections to culture recess along with all other memories. Surely and sadly, the progressive decline of dementia should be a great leveler.

Yet, the reality of culture and dementia is very different. Culture affects dementia in dramatic ways. Culture influences the very form of dementia individuals' experience as there are significant differences in prevalence rates of different groups. The perception of the disease, of the meaning of dementia itself, differs between groups. These perceptions consequently affect treatment. For example, if the culture views dementia as a family stigma, the family may be less receptive to community-based programs. Persons with dementia may be well hid at home. In addition, each culture defines caregiving differently. Cultural norms vary on who is responsible for care as well as the limits to that responsibility. This affects a range of decisions, from whether to accept outside assistance to institutionalization in a nursing home facility, to end-of-life decisions. All of these factors interrelate to influence grief.
Culture may be described as a way of life shared among a group. Culture may be defined by a variety of factors: ethnicity, social class, spirituality, behaviors (such as the Gay/Lesbian/Bisexual/Transgendered culture), or shared condition (for example, Deaf culture). Since most of the research on culture and dementia emphasizes ethnic cultures, ethnicity will be the focus of this chapter.

Yet, there is a clear need for research that considers the ways that these other cultural groups experience and cope with dementia. This is important for a number of reasons. It is reasonable to expect that many of the differences that exist in ethnic subcultures may be mirrored in other cultural groups. In addition, such research can shed light on ethnic differences as well.

The current difficulty is that research that only looks at ethnicity is confounded by other variables. Ethnic groups, particularly in North America, have had diverse experiences. They immigrated at distinct times. They faced varied degrees of discrimination and prejudice. They are differently distributed within the social strata. Hence cultural differences may reflect distinctions not only in ethnicity but also in social class and other experiences. Differences may be less the result of ethnicity than of life-long poverty or stress influenced by patterns of discrimination.

Culture is a complex issue in dementia. Still, even with these limitations it is essential to examine the role that culture has in dementia—for both persons with dementia as well as their caregivers.

**Culture, Ethnicity, and Prevalence**

Ethnic, cultural, and demographic data always have been critical epidemiological clues—hints to the etiology of a disease or condition. The famous Broad Street pump could be said to be the birthplace of modern epidemiological science. Dr. John Snow followed demographical clues to find the source of the 1840’s cholera epidemic in the polluted water of the Broad Street pump. Similarly, occupational safety regulations first began in the eighteenth century after it was noticed that London chimney sweeps had unusually high rates of testicular cancer. The laws mandated a minimum age of eight years of age for apprentice chimney sweeps and required weekly bathing to remove the suspected soot. More recently, studies of
differential rates of lung and digestive system cancers among varied cultural groups added evidence to the role of smoking as a causative factor in cancer. In short, differences in the prevalence of disease amongst diverse classes, cultures, or occupational groups often yield critical clues about the causes of disease.

Are there differences in prevalence rates of Alzheimer's disease and other types of dementias? What do these differences suggest?

Clearly, there are ethnic differences. Studies have strongly indicated differences between ethnic cultures. For example, a Chinese study found that Alzheimer's disease accounted for 60 percent of all dementia while vascular disease was the identified cause of dementia in 28 percent of the cases (Zhang et al., 1990). In a Japanese study, Alzheimer's disease only accounted for 12 percent of the sample's case of dementia while vascular disease was the cause of 50 – 70 percent of the dementia cases studied (Ueda et al., 1992). In a Swedish study, the cases split—50 percent of the cases were caused by Alzheimer's disease while the other 50 percent were diagnosed as vascular (Skoog et al., 1993). This was similar to a Baltimore study that showed a similar division of cause among an African-American sample (Folstein et al., 1985). Yet, a study in Boston of a predominately Italian-American sample attributed 95 percent of the cases of dementia to Alzheimer's disease (Evans et al., 1989).

While there seem to be relatively wide differences in the causes of dementia among different ethnic groups, it is difficult to determine what these differences tell us. Larsen and Imar (1996) offer four possible explanations for these differences.

**Social**

This explanation stresses that the definition of Alzheimer's disease differs in varied ethnic and cultural groups. In some societies or within some subcultures, the definition of Alzheimer's disease may be extraordinarily stigmatizing. This may lead physicians to offer a more acceptable diagnosis, especially in the situations where alternative factors may be suspect. The differences in the rates may be more apparent than real, reflecting social constraints.
This suggests that the differences found may reflect more the complexity of assessing for dementia amongst different cultural groups than actual differences in prevalence rates. The evaluation instruments for Alzheimer’s disease reflect the cultures in which they are developed and tested. They may lose reliability and validity when used within other groups. There is the “Ardilla Effect”: less educated individuals who are functionally illiterate can test very much like brain-injured individuals (Ardilla, 1993a, 1993b). Ardilla (1993a) cautions that any assessment has to take into account education and that in turn, engages other variables such as social class, migration, and language. In addition, test items may not have ecological relevance when applied to different cultural groups (Baker, 1996). Time orientation may mean little in cultures that do not emphasize time. Baker (1996) also notes that only one test, the Short Portable Mental Status Questionnaire, has an adjustment for race and age.

Biological

Biological factors could also account for these cultural differences. However, these biological differences are complicated. There may be clear genetic differences that increase or decrease risk for certain types of dementia. Or, these differences may be the result of differences in longevity that result from the interrelation of genetic, biological, and social factors among cultural groups. Since chances of acquiring Alzheimer’s increase as a person ages, groups that live longer have more members at higher risk.

Environmental

Environmental factors also can be the cause of differences. Cultural groups differ in many aspects of their lifestyles including diet and environmental stresses. For example, the relatively high rates of dementia due to vascular disease found in the Baltimore study among African-Americans reflect the high rates of hypertension found within the African-American community. This increased hypertension may be attributed to a number of factors including diet, lifestyle, and the higher levels of stress induced by discrimination, prejudices, and consequently lower economic status of those living in the Baltimore area.
In summary, there do seem to be clear cultural differences in the prevalence rates of distinct types of dementia. However, further research will be needed to explain the significance of these differences and whether these differences will yield information about the nature of Alzheimer’s disease or of the other dementias.

**DEMENTIA AS A CULTURAL CONSTRUCTION**

Susan Sontag in her classic work, *Illness as Metaphor* (1978), reminds us that diseases are not only biological conditions. They are social and cultural constructions. Each society attributes meaning to a disease. In early eras, for example, syphilis was not merely a venereal disease; it was a mark of depravity. Leprosy was a curse. These social constructions become reflected in the language. The very word leper became stigmatized. It referred not only to a person who had Hansen’s disease but became a synonym for an outcast. Pox came to mean a curse. These meanings reflect not only on the disease. They have implications for the person with that disease. The ways cultural groups define a disease affects the ways that persons with that disease are perceived and treated.

In American culture, for example, the very term “senile dementia” carries meanings. The term *senile* associates it with older persons. Though the psychiatric definition of *dementia* merely refers to marked cognitive impairment, popular meanings of the term differ. Generally, *demented* connotes insane, even dangerous, behavior. Hence the very term *senile dementia* suggests that persons with the disease are unpredictable and to be feared. In Chinese, the word for dementia can best be translated as “silly”—a word that seems to imply less fearful attributes (Elliott, DiMinno, Lam, & Tu, 1996). It is valuable to listen to the language that individuals use to describe the condition and to explore, especially in groups where English is not the only language, the terms that are used to define the disease.

Other cultural groups may have different cultural constructions of Alzheimer’s disease or other dementias. They may have distinct understandings of cause. Not every culture, for example, shares the scientific and materialistic explanations of disease evident in Western medicine. Some cultural groups may see Alzheimer’s disease as retribution for family
misdeeds, the result of a curse or “evil eye,” God’s will, an imbalance of energy, or the result of improper alignment of either the person or the environment. Alzheimer’s and other dementias also can be defined as simply a mark of aging or a mental or physical illness. In some cultures it may be attributed to individual behaviors such as failure of care. In other cultures it may be considered evidence of a genetic flaw that can haunt the family for generations. It is not unusual that in many cultures, multiple meanings may abound. It is critical to explore these meanings within the family system.

The way a disease is defined within a culture has many implications for treatment. In some cultures, these definitions may inhibit treatment. It may even discourage treatment. If the culture defines the disease as an inevitable aspect of aging, there may be little belief in the efficacy of intervention. If the disease is defined as God’s will, then there may be a perception that only God can change it.

Some definitions may be highly stigmatizing. For example, if the dementia is defined as retribution for family misdeeds, a mental illness, or a genetic curse, family members may hide the person, hoping that the condition remains a deep secret. The possibility of early diagnosis, treatment, or even receptiveness to the provision of services may be limited. If an affected individual fears the stigma, then he or she may make great efforts to mask his or her condition, again impeding early diagnosis and treatment. A strong belief that the disease is a genetic legacy can complicate caregiving. Family caregivers, especially adult children, may experience intense anxiety and depression, seeing in the disease their own future fate. In some cultures, the very presence of dementia may exacerbate stress. A recent study (Hinton, Haar, Geller, & Mungas, 2003) found that Hispanic caregivers experienced high levels of depression in dementia caregiving that were not apparent in other caregiving situations, even those where mild cognitive impairment was evident.

In other cultures, the disease may be taken in stride. Many African-American families who live under stressful conditions are accustomed to coping with crises, uncertainties, and changes. There is a pride of survivorship (Jackson, 1971). A person continues to be prized as long as he or she can function and relate even in the face of cognitive
impairment (Lewis & Chavis-Ausberry, 1996). This may explain some of the reasons that Black families tend to find dementia care less burdensome than White families (Aranda & Knight, 1997).

Culture not only defines the disease, it suggests the type of treatment preferred. Varied folk healers—acupuncturists, herbalists, or shamans—may be consulted. Cultural sensitivity suggests that it is important not only to assess prevalent explanations of the disease but also to understand treatments that previously have been tried or are presently being utilized. It is not unusual that in many cultural groups, individuals may mix Western medicine with traditional folk remedies.

CULTURE AND CAREGIVING

Culture not only influences the perception of the disease, it frames the caregiving experience. Each culture defines caregiving responsibilities. Culture defines who is responsible and how those responsibilities are to be fulfilled. This in turn affects caregiver burden and stress.

Cultural groups may have different access to available services (Janevic & Connell, 2001). There may be cultural barriers that inhibit groups from utilizing available services. Language may be a barrier. If the group is not primarily English speaking, they may not know of the service. If the service is only offered in English, the group may be unable to benefit or even take advantage of the program. There may be economic barriers where costs or eligibility rules inhibit involvement.

Sometimes the lack of cultural sensitivity may prove to be a barrier for utilization. The service may not offer a good cultural fit. A Meals on Wheels program that does not offer kosher or halal meals may inhibit Jews or Moslems from enrolling in the program. Even where there are no clear dietary restrictions, the food offered may be unappealing to members of any given culture. Similarly, a lack of sensitivity to homosexual relationships on the part of the aging network can disempower gay clients (Kimmel & Martin, 2001).

Interaction styles also may prove a barrier. In Hispanic culture, *personalismo* is valued. That means that personal relationships take preference over professional roles. Professionals may be expected to accept food or drink and engage in personal conversation prior to offering
services. The mutual discomfort that can arise when these expectations are not shared or met can inhibit utilization. Community programs and services would benefit from evaluating the utilization patterns of different groups within their communities and identifying potential barriers.

Cultures may vary in their receptiveness to services as well. Each culture differently defines who is responsible for caregiving. For example, in White families, spouses are the primary caregivers (Janevic & Connell, 2001; Connell & Gibson, 1997). In other cultures, caregiving responsibilities may be more diffused. In many Asian cultures, the concept of filial responsibility is stressed: supported in some cultures by the belief that a failure to perform obligations would bring future misfortune upon the family (Elliott, DiMinno, Lam, & Tu, 1996). In some cultures all the children share equal responsibility while in other cultures responsibility may be focused on the oldest child or the daughters. In Hispanic families, the extended family may be expected to help. In the African-American culture, quasi-family such as a church-based network may be looked upon for assistance (Lewis & Chavis-Ausberry, 1996).

The acceptance of formal services may differ among cultures. In some cultures that may be fully acceptable while in other cultures it may not. In Chinese culture, the acceptance of outside assistance reflects poorly on the family, indicating an inability to fulfill traditional and expected responsibilities (Elliott, DiMinno, Lam, & Tu, 1996).

These cultural differences can exacerbate or facilitate caregiver stress and burden. Each culture defines who is expected to help, what they are expected to do, and when and if it is acceptable to seek formal help.

**Working Across Cultures**

All of this has implications for working with different cultural groups. It suggests that any assessment of the individual client and the family system should consider cultural background. This assessment should begin with knowledge about the client. What is the cultural background? How significant is that background in the life of the client? Culture can be seen as a continuum. Some individuals are highly assimilated into the larger culture while others are immersed within their home culture. Yet, for even clients who seem highly assimilated, their own cultural roots can still subtly
influence behaviors. What is the client’s language? When did the client immigrate? What experiences did the client have prior to and during that immigration? This can be a critical issue as clients with Alzheimer’s disease or other dementias can sometimes revisit earlier traumatic experiences.

The assessment should naturally include the client’s intimate network. Who is available to the client? Who has obligation to assist? In some cultures, the network might be relatively restricted. Only immediate family may hold obligation. In other cultures, a wide range of individuals, children, extended kin, godchildren or even members of the faith community, may be looked upon for assistance. How does the family perceive or define the disease? If the disease evokes a strong sense of shame, then families may be reluctant to seek outside assistance. What is the family’s view of their own caregiving responsibilities? How are decisions made within the family? Who makes those decisions?

Working with diverse cultural groups can be a challenge. Communication is inevitably complicated. Communication occurs on three levels: verbal, nonverbal, and paraverbal. Verbal communication can be difficult especially when English may not be the client or family’s original tongue. The use of translators may be problematic. Translation is an art as words rarely have a direct, equivalent meaning across languages. Moreover, the ethos of translation may vary. In some cultures, it may be considered impolite or inappropriate to translate bad news or convey unseemly feelings. Even when a language is shared, there may be differences in the “universe of discourse,” that is, individuals may not share, perhaps due to profession or class, a common vocabulary. In addition, communication occurs at nonverbal and paraverbal levels as well. Nonverbal use of space, gesture, and time and the paraverbal codes regarding tempo, tone, or volume may not be understood between cultures, complicating communication.

It is little wonder it may take time to develop trust between clients and helpers. This can be particularly difficult when clients are from cultures that have experienced a history of discrimination in this country or have emigrated from oppressive nations. Sometimes the simple question, “What do I need to know about your own cultural background to assist you more effectively?” can demonstrate receptiveness and a willingness to reach across the cultural divide.
Organizations as well as individuals can assess their abilities to effectively serve diverse cultures. This can begin with an environmental scan. What do people see when they enter the organization or facility? How diverse is the staff? What languages does the staff speak? What languages are evident in our materials or even the reading matter left for clients? What does the photography, art, or decorations say about this organization? What type of music is played?

A second procedure may be a process evaluation. A process evaluation asks whether an organization is delivering services to a given population. Are they meeting community needs? What groups are underrepresented? Do members of different cultures disproportionately fail or cease to utilize services? Are the services sensitive and user-friendly to the different cultural groups served? What types of training are offered that can assist staff in dealing with cultural diversity? What linkages does this organization have to ethnic or other cultural communities that are served? These questions can assist organizations in identifying and surmounting any cultural barriers that exist.

It is always useful to identify and build relationships with institutions within each culture. These relationships will have to build incrementally so that trust and communication issues can be slowly surmounted. Yet, once these ties are developed, these institutions can be sources of credibility as well as referral, advisement, and even training.

Valle (1989) once wondered whether we could ever develop either culture-free or culture-fair ways to assess Alzheimer’s disease. It is still a potent challenge. Yet, a larger challenge looms for all in the field. How can we create services that are culturally sensitive to those with dementia and to their caregivers?

REFERENCES


