



■ As the proportion of culturally diverse elders increases, practitioners must recognize cultural differences and help caregivers adapt to disparate attitudes, values, and behaviors.

21st
Century
Caregivers

Diversity in Culture

By Dawn Lehman, PhD

The U.S. Census Bureau reports that the nation's population will be more racially and ethnically diverse, as well as much older, by 2050. Minorities, now representing about one third of the U.S. population, are expected to become the majority by 2042, with the nation projected to be 54% minority by 2050. The proportion of older adults from ethnic and racial minority groups is projected to increase exponentially by 2050, with the largest growth rates among Hispanics, followed by Asian-Pacific Islanders, American Indians, and African Americans.

In 2006, the U.S. Census Bureau indicated that 19% of the U.S. population aged 65 and older was minority. By 2050, 39% of the nation's older adults will be represented by minority groups.

The population increase of ethnic older adults is prompting research on ways to improve care for this population. Many practitioners, such as social workers, nurses, physicians, and community workers, acknowledge that they need to consider diversity when working with elder care recipients and their caregivers.

Research shows common characteristics of caregiving among various racial and ethnic groups in America, as well as differences based on attitudes, beliefs, and behaviors passed from one generation to another. It's essential for healthcare practitioners to be cognizant of cultural differences among clients and their families and tailor expectations and behaviors with respect to ethnic beliefs and values.

Communicating Cultural Values

Janet Bonet, an interpreter for the Nebraska and Iowa state courts and caregiver for her 95-year-old father-in-law, says, "Expectations are part of a person's cultural mores. How an elderly person expects to be treated, because he is an elder, varies across cultures and settings. Unfulfilled expectations cause frustration—even anger and depression."

Care partners are concerned with each other's well-being, yet they don't always know each other's preferences for care. Misperceptions about care preferences are common among diverse cultural groups. Caregivers often underestimate the amount of importance older adults place on a variety of care issues, often exacerbating the caregiver burden.

Research at the Margaret Blenkner Research Institute and the Benjamin Rose Institute indicates that interventions can help bridge this misperception gap and, in turn, lessen negative outcomes. Practitioners can enhance communication and understanding among care partners about care preferences and help them work together to develop a care plan that respects the preferences of the older adult and the caregiver's ability (or inability) to carry out those preferences.

Maggie Tang, PhD, an assistant professor of social work at the Richard Stockton College of New Jersey, examined the aspects of caregiving of Chinese American family caregivers

who provided care to their older adult relatives and determined the role of cultural values in predicting positive aspects of caregiving. She found that Chinese American caregivers with stronger cultural values tend to have more positive feelings toward caregiving.

"Service providers and social work practitioners need to understand the value system of elders and assess the extent to which caregivers hold on to traditional values," she says. "Practitioners need to take into consideration the national origin of the caregiver, age and gender of the caregiver, and the level of acculturation."

Tang advocates for service providers and social work practitioners to develop and implement service programs that empower Chinese American caregivers to uphold their cultural values. She expresses concern that younger Chinese Americans have become more autonomous and do not need elders the same way their parents did at a similar age. Tang emphasizes the need for more community education related to cultural values of older Chinese Americans.

Influence of Culture on Caregivers' Attitudes, Beliefs, and Behaviors

Cultural background exerts a significant influence on caregivers' attitudes, beliefs, and behaviors. In working with caregivers, practitioners should consider the cultural values, norms, and beliefs that shape the meanings caregivers assign to the elder's illness. Other considerations are who should assume the caregiver role and ways culture influences perceptions of that role.

Cultural values and behaviors can also determine caregivers' desire for support services, such as caregiver training, family support groups, and ethnic organization support groups. Cultural beliefs may also play a role in a caregiver's anxiety related to an elder's medical condition, problems with care, strains on family relations, and effects on a caregiver's personal health and well-being.

Caregivers' cultural backgrounds can also influence the relationship between the caregivers' support networks and their personal strain, as well as coping strategies that are employed.

What Practitioners Need to Know About Caregivers

To provide quality support to caregivers, it's helpful for practitioners to become aware of cultural characteristics influencing caregivers. They play a significant role in shaping attitudes and behaviors of both older adults and caregivers. Among those characteristics are the following:

- **Time:** What is the meaning of time in a particular culture? When are taboo times? What are caregivers' expectations about time?
- **Space:** What are the cultural and/or religious customs regarding personal space and contact? What are caregivers'

preferences in terms of communication distance?

- **Communication:** What is the proper form of address? When is physical contact, such as a handshake or an embrace, acceptable or prohibited? What gestures are taboo? What facial expressions are acceptable? When should eye contact be avoided?
- **Family:** What is the concept of family? With which family members should you communicate? What are the best ways to communicate with them?
- **Social organization:** What dates are important to caregivers and their family members? What is the importance and use of rituals?
- **Diet:** What are the family's food customs? What foods are taboo?
- **Health traditions:** What is the meaning of health and illness? What practices are taboo? What types of remedies are used?

Additionally, when working with diverse caregivers, it is important to consider one's own cultural values and biases. Be aware of myths and stereotypes related to older adults. Understand distrust of institutions by some minority families. Communicate to caregivers an understanding of their views toward illness and medical treatment. Use culturally specific phrasing and patterns of expression to gain caregivers' trust.

Caregiving experiences and outcomes vary across racial and ethnic groups. Because differences exist within and between groups, generalizations may be inaccurate when applied to specific caregivers. However, some general knowledge of caregiving attitudes, beliefs, and behaviors among groups may help avoid misunderstandings and give practitioners a starting point from which to provide culturally appropriate services.

The following represent some research findings associated with caregiver responsibilities, decision making, formal and informal support, burdens, and coping strategies. These studies focused on samples of caregivers, and the findings may or may not represent the ethnic or racial groups as a whole.

- African American caregivers were more likely to discuss the older adult's care with clergy members.
- African American and Hispanic caregivers expressed strongly held beliefs of filial responsibility.
- African American and Hispanic caregivers were less likely than whites to be spouses and more likely to be another family member.
- African American female caregivers selected adult children and other relatives to help with caregiving, while African American male caregivers relied more on friends and neighbors.
- White caregivers were more likely to be caring for a spouse, and African American caregivers were more likely to be caring for a sibling, other relative, or friend.
- There is a strong cultural norm among Hispanics that women provide care to dependent elders.

- Among Asian Americans, the oldest son and his wife, in particular, were expected to take the caregiver role.
- Puerto Rican sons were more likely than daughters to report filial responsibility as the primary reason for providing care and stated that there was no limit to what they would do for a parent.
- Filial obligation is a significant predictor of financial support among Chinese, Japanese, and Korean American caregivers.
- For American Indians, caregiving reflected the cultural ethos of interdependency and reciprocity.
- Irish American caregivers tended to believe their ethnic friends and neighbors would provide a safe place for elders with dementia to live.
- Nonwhite caregivers provided care for more hours per week and reported a larger number of caregiving tasks.
- Hispanics and Asian Americans reported a lower relationship quality with the care recipient than whites.
- Among sources of help, God was seen as most helpful—even with physical care of the care recipient—for African American female caregivers.

Learning About the Family Caregiver

Cultural sensitivity involves a heightened awareness of and regard for the caregiver's cultural beliefs, values, and practices. Cultural sensitivity manifests itself in the practitioner's ability to interpret and respond to the caregiver's verbal and nonverbal cultural cues. Practitioners can help family caregivers, regardless of their ethnic background, by observing behaviors and asking questions about what is important to them in their caregiving role.

It's helpful to note attitudes, beliefs, and behaviors that orient a caregiver's disposition, determining whether he or she has recognized and accepted the role of caregiver. Practitioners can also assess the extent to which cultural norms and family conditions may influence the availability of support for the caregiver and the likelihood of taking advantage of such support.

It's important to consider the social support network, such as family, neighbors, friends, and clergy, who can provide support to both the caregiver and the older adult. Also at issue are the caregiver's beliefs about responsibility for the older adult. For example, African American caregivers have expressed strongly held beliefs of filial responsibility. Some caregivers are motivated by their belief in reciprocity, defined as giving back to the older adult; they believe it is an obligation to provide for those who provided for them. Don't overlook the caregiver's and elder's level of acculturation, and the possibility of internal conflict between traditional ethnic and contemporary American values.

Toward Cultural Competency

Madeleine Leininger, RN, PhD, professor emerita from the School of Nursing at Detroit's Wayne State University and an internationally renowned transcultural nursing expert, defines

culturally congruent care as “those cognitively based assistive, supportive, facilitative, or enabling acts or decisions that are tailor made to fit with individual, group, or institutional cultural values, beliefs, and life ways in order to provide or support meaningful, beneficial, and satisfying healthcare or well-being services.”

Barriers to Accepting Community Services

For the caregiver, the strong influence of personal beliefs, family expectations, and role models guide the decision to provide care. Family history, family structure and size, resources, level of acculturation, language limitations, concepts of illness, and competing demands may influence a caregiver's decision to not use community services. The following are some of the common perceptions that prevent caregivers from taking advantage of such services:

- No one can care for my father as well as I can.
- My mother would never accept help from anyone other than me (or family).
- Caregiving is entirely my responsibility.
- My family members expect me to be the caregiver.
- My father's care should be handled by family in our home.
- I owe it to my mother to be the primary caregiver because she has done so much for me.
- We do not want to go outside the family for help. We do not want others to know our family business.
- My family members don't want others to think we are not taking adequate care of my mother.
- Seeking help is a sign of failure.
- I don't want anyone to know that my father is ill.
- I don't want my grandmother to know her condition or treatment plan.
- I feel guilty taking care of myself when my family member is ill.
- Practitioners do not understand my needs and my father's needs.
- It's too hard to communicate my grandfather's needs.
- My family does not support my efforts to get interpreter services.
- I shouldn't spend money on a service that I can do.
- Service providers do not understand traditional ways of dealing with my mother's illness.
- My grandmother and I do not want a stranger in our home.
- I do not know the right questions to ask.
- It is stressful seeking help outside my family.
- My family does not accept nursing home use.

Behaviors enabling cultural awareness, sensitivity, and competence are important for practitioners because such concepts as illness and caregiving mean different things to different people. While it is important to understand that not all people are fixed in cultural traditions and unable to modify their behavior and learn new ways, knowledge of common patterns and customs provides a foundation for specific assessment of the caregiver and older adult relationship. By playing a critical role in the development and delivery of services that are responsive to diverse caregivers' needs, practitioners address new demands for quality healthcare for an aging U.S. population.

Caring for the Caregiver

Family caregivers must deal not only with the tasks of providing care but also with the impact of caregiving on their own lives and emotions. Research suggests that given the physical health problems in response to stress among caregivers, interventions should focus on caregivers' physical health and psychological well-being. Caregivers can take advantage of the increasing number of tools that can diminish the negative effects of caregiving.

Among them are Powerful Tools for Caregivers, a six-week online educational program developed by Stanford University for family members who are caregivers for individuals with chronic medical conditions such as Parkinson's disease, Alzheimer's disease, or stroke. Evaluation has shown that the program reduces caregiver stress and depression, increases self-care behavior, and increases confidence. Caregivers report that they are better able to manage their situations and find solutions.

Videocaregiving.org is a new Web site from Terra Nova Films dedicated to providing educational material to family caregivers. The video series on this Web site uses real people in real situations to illustrate caregiving techniques.

Sage for Aging is a Web-based program developed at the University of Illinois (Urbana-Champaign) that provides practical caregiving advice. Practitioners and/or caregivers learn to analyze the most important factors in caregiving situations and then use that analysis to quickly find practical, useful advice that is specially tailored to the needs of the older adult. Practitioners also can learn about extended online resources beyond the Sage for Aging Web site.

Although these tools can't eliminate caregiving challenges, they can help caregivers manage difficulties better and assist in finding solutions. They can help caregivers, regardless of ethnic and racial background, to thrive as individuals.

— Dawn Lehman, PhD, is a cultural anthropologist and director of education at Mather LifeWays, a not-for-profit organization committed to developing and implementing ways to age well.