

CULTURAL
COMPETENCY
IN WORKING
WITH LATINO
FAMILY CAREGIVERS

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and

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MARCH 2004



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CULTURAL COMPETENCY IN WORKING WITH LATINO FAMILY CAREGIVERS

INTRODUCTION

Demographic changes in the population over age 65 are making a critical impact on both the informal and formal caregiving networks in the U.S. (ASPE, AoA, 1998). Population changes, poverty, and disability among the aging population will have important implications for service providers in addressing the context of caregiving across diverse populations. (U.S. Census Bureau, 1993; Johnson & Tripp-Reimer, 2001).

Not all persons needing assistance are alike, and not all persons providing care and support do so within the same context. The appreciation of diversity in the caregiving experience, although not a new phenomenon, is taking center stage in the national debate on cultural competency in the provision of health, mental health, and human services for caregivers (ASPE, AoA, 1998, Alzheimer's Association, 2002; National Institute of Nursing Research, 2001). A major theme in this debate is that the provision of culturally competent services is no longer an exercise in political correctness, but an opportunity to respond to both ethical and sociodemographic imperatives relevant to quality services for older adults and their families (AoA, 2001).

Targeted towards health and human service practitioners who work with family and informal (unpaid) caregivers, this monograph addresses general principles of cultural competency with Latino caregivers vis-à-vis illustrations of selected case studies. We will present cultural competency guidelines that can assist providers in identifying and dealing with diverse caregiving situations followed by a list of resources for additional information.

Working definitions of diversity and cultural competence follow. According to Van Soest & Garcia (2003), *diversity* refers to differences between groups with distinctive characteristics and social identities based on culture, ethnicity, gender, age, sexual orientation, religion, ability and class. They also propose that diversity is inseparable from issues of oppression and social and economic justice. *Cultural competence*, on the other hand, “. . . refers to the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions and other diversity factors in a manner that recognizes, affirms and values the worth of individuals, families,

and communities and protects and preserves the dignity of each” (National Association of Social Workers, 2001, p. 11). Supporting the process of cultural competence is a set of specific standards, policies, practices, skills and attitudes used to increase the accessibility and quality of services. The goal, therefore, is to produce better intervention outcomes, although minimal attention has been given towards establishing the empirical relationship between specific characteristics of cultural competence and intervention outcomes (Sue, 2000).

SOCIODEMOGRAPHIC TRENDS: IMPLICATIONS FOR CAREGIVERS

The older population—persons 65 years or older—numbered 35 million in 2000. About one in every eight persons residing in the U.S., or about 12% of the U.S. population is over the age of 65. With the aging of the Baby Boom generation, we can expect to see a 34% increase in the number of Americans who will reach 65 over the next two decades (U.S. Census Bureau, 2002). Coupled with the overall growth in the 65+ population are several sociodemographic trends that have important implications for service delivery to caregivers. First, we have seen an increase in life expectancy such that in 2000, persons reaching age 65 had an average life expectancy of an additional 17.9 years (19.2 years for females and 16.3 years for males). Much of this increase occurred because of reduced death rates for children and young adults. However, the past two decades have also seen reduced death rates for the population aged 65-84. Life expectancy at age 65 increased by only 2.4 years between 1900 and 1960, but has increased by 3.7 years since 1960 (U.S. Census Bureau, 2002). Given the growth of the older adult population as well as the increase in life expectancy, we are faced with a greater number of persons living much longer than the generations before them.

Limitations in physical functioning appear to compound with increasing age. For example, limitations of ADL's are reported at 32% for those aged 75-79, 41% for individuals 80-84, and climbs to 58% for those 85 and older. For the fastest growing cohort of adults, those 80 and older (U.S. Census Bureau, 2002), over half (57.6%) had one or more severe disabilities and 34.9% require assistance as a result of a disability. Family caregivers by far provide most of the in-home care and assistance to older adults with disabilities. Thus, it is expected that health and human service practitioners will be presented with numerous challenges for the provision of support services targeted towards both caregivers and care recipients.

Another sociodemographic trend is the increased racial and ethnic diversity of the older population of caregiver and care recipients. For example, racial and ethnic minority populations are projected to represent 25.4% of the elderly population in 2030, up from 16.4% in 2000. Between 1999 and 2030, the white population 65+ is projected to increase by 81% compared with 219% for older minorities, including Hispanics (328%), African-Americans (131%), American Indians, Eskimos, and Aleuts (147%), and Asians and Pacific Islanders (285%) (www.aoa.gov/minorityaccess). Thus, we can expect more racial and ethnic minority caregivers requesting services than ever before.

Sociodemographic trends associated with poverty is another area that underscores the diversity of caregiving. According to the U.S. Census, about 3.4 million elderly persons (10.2%) were below the poverty level in 2000. Another 2.2 million or 6.7% of the elderly were classified as "near-poor" (income between the poverty level and 125% of this level) (www.aoa.gov/minorityaccess). One of every twelve (8.9%) elderly Whites was poor in 2000, compared to 22.3% of elderly African-Americans and 18.8% of elderly Hispanics. Higher than average poverty rates for older persons were found among those who lived in central cities (12.4%), outside metropolitan areas (i.e., rural areas; 13.2%), and in the South (12.7%). Older women had a higher poverty rate (12.2%) than older men (7.5%) in 2000. Older persons living alone or with nonrelatives were much more likely to be poor (20.8%) than were older persons living with families (5.1%). And lastly, the highest poverty rates (38.3%) were among older Hispanic women who lived alone or with nonrelatives (www.aoa.gov/minorityaccess).

A report on family caregiving in the U.S. provides specific caregiving demographics highlighting the diversity of caregivers (National Alliance for Caregiving, AARP, 1997). Family caregivers provide some type of care to at least 70% of persons with dementia receiving care in their home (National Alliance for Caregiving, AARP, 1997). Caregivers caring for elders with more disabilities experience physical or mental health problems. Minority caregivers, unemployed caregivers and lower income caregivers experience significant financial difficulties (National Alliance for Caregiving, AARP, 1997). Twenty-seven percent of Latino households provide informal caregiving to a friend or relative. Latino caregivers are primarily women around 40 years of age or older who are also caring for children under the age of 18 (www.aoa.dhhs.gov).

Although the research on Latino caregivers has focused primarily on non-probability sampling methods and different measures of psychological well being (Aranda & Knight, 1997; Dilworth-

Anderson, Williams, Gibson, 2002), the trend among existing studies supports that Latinos experience greater psychological distress—depression due to caregiving responsibilities (Adams, Aranda, Kemp & Takagi, 2002; Cox & Monk, 1993; Friss, Whitlatch, Yale, 1990).

While assumptions have been made about the availability and numbers of Latino social networks, it is not clear whether family caregivers who are currently available will be available in the future to provide care to elders with significant chronic illness (Aranda & Knight, 1997). In fact, studies have found that Latino caregivers have identified fewer networks for support (Phillips, Torres de Ardon, Komnenich, Killeen & Rusinak, 2000) and also do not believe that they have a caregiver available to them in the future should they require care (Talamantes, Cornell Espino, Lichtenstein, Hazuda (1996).

INTERPERSONAL/PRACTITIONER LEVEL COMPETENCY

For individual service providers, recognizing diversity in the caregiving context and incorporating cultural competence into care plans are two separate, yet interrelated, steps towards achieving positive outcomes in the professional helping context. Although in the U.S. cultural diversity typically has been linked with race and ethnicity, diversity takes on a much wider meaning, to include age, gender, socioeconomic class, sexual orientation, religion, physical abilities, geographic residence and so forth. We understand that diversity can include a host of other factors that are not discussed here. Currently, many cultural competency guides exist in the literature, representing a vast array of interests relevant to professional associations, practice settings, academic institutions, and government entities (see list of resources in the Appendix). Several domains relevant to the interpersonal/provider level of cultural competency appear to be consistent: (1) attitudes; (2) knowledge; and (3) skills (Devore & Schlesinger, 1999; Ivey, D'Andrea, Bradford Ivey, Simek-Morgan, 2002; Lum, 1996; Sue et al., 1992; Sue, Arredondo, & McDavis, 1992).

The general goal is for practitioners to develop an ongoing “toolkit” of knowledge, skills and attitudes so as to be able to provide effective service delivery to recipients and caregivers within diverse sociocultural contexts (see Table 1). This does not preclude practitioners from concurrently developing clinical- or social service-interventions based on current acceptable guidelines. For example, a provider should not only seek out educational and training opportunities to enhance understanding of diversity within specific client populations, but should be able to assess the clinical differ-

ence between stress related to caregiving, stress related to external factors such as discrimination and oppression, and the interaction of the two types of stress.

According to Bonder and his associates (2001), two main approaches appear to dominate the promotion of cultural competency for health care providers: the *fact-centered approach* and the *attitude-centered approach*. The fact-centered approach emphasizes the importance of acquiring factual knowledge about the target group in order to increase one's understanding of the group's values, beliefs, traditions, communication patterns, help-seeking behaviors and the like. Other sources of knowledge include more macro factors such as the group's sociopolitical history, organizational policies that affect access to services, power relationships within communities or institutions that impact the distribution of resources, etc. Thus, the acquisition of knowledge is considered important across several levels of practice: micro, mezzo and macro. The logic is that the more one knows about the target group's culture from a person-environment perspective, the more one is prepared to communicate cross-culturally.

The second approach to cultural competency is the attitude-centered approach, which has as its core belief an openness to embracing diversity. Embodied in this approach is not only a commitment to work with clients from different backgrounds, but to recognize one's own beliefs, attitudes, and behaviors that may parallel or conflict with those of the client's.

Drawing from the area of cross-cultural therapy, Dyche and Zayas (2001) posit that dynamic tensions exist between provider openness to diversity and knowledge of the client's culture. The main reasons for the tension lie in the danger of relying on normative or stereotypical facts about the client's background, and/or of assuming that personal attitudes of acceptance are easy to foster and maintain. Therefore, Dyche and Zayas propose that providers discover the ways in which clients experience their culture that deviate from the universal model of culture. Therefore, in order to reconcile this attitude-knowledge dilemma, *cross-cultural empathy* or *transcultural empathy* is considered a general skill or attitude that transcends the provider's integration of personal openness with the necessary knowledge and skill to work successfully across cultures (Dyche & Zayas, 2001). Cultural empathy involves not only "starting where the client is at," but constructing an interpersonal orientation of *scientific mindedness* (Sue, 2000)—an ability to gather facts (data about the client and her/his cultural identification), suspend evaluation or judgment (stereotypes, biases), form hypotheses regarding the client, test these hypotheses, and "act on the basis of acquired

data rather than preconceived ideas" (Bonder et al., 2001, p. 39). Cultural knowledge does not specifically predict the individual's behavior, but instead forms the basis for the practitioner and client *to discover together* the validity of the hypothesis regarding the client's experience.

DISPARITIES IN HEALTH CARE: DISPARITIES IN HEALTH OUTCOMES

A discussion on cultural competency and caregiving would be remiss without also considering the issue of disparities in health care and the subsequent effects of these disparities on intervention outcomes and the care recipient(s)' quality of life. As highlighted in the comprehensive work on health disparities by the Institute of Medicine (Smedley, Stith, & Nelson, 2003), disparities in health access and care are enduring and well-known consequences of a myriad of multilevel factors not the least of which are the stereotyping, biases, and uncertainty on the part of healthcare providers and institutions.

Encounters between the health or human service provider and the older adult and his/her family are influenced by such factors as access, the clinical needs and preferences of the person(s) requesting assistance, and the appropriateness of the intervention(s) available. Nevertheless, a major finding in the IOM's report is that even after controlling for important access-related factors such as patient's insurance status and income (as well as clinical need and preferences), racial/ethnic minorities tend to receive a lower quality of health care than non-minorities. This is evident across disease conditions (cardiovascular illness, diabetes mellitus, HIV/AIDS) and across racial/ethnic groups (Latinos, African Americans, American Indians, Asian Americans). Thus, we can assume that for some subgroups of caregivers who are able to at least initially access health and human service programs, they still will be confronted with significant barriers to *quality* care which can decrease the likelihood of desired health outcomes that are consistent with professional knowledge. Following this assumption, therefore, culturally competent providers must not only assess for differences between the provider and patient/family caregiver context, but how these differences affect the quality of care and eventual patient and caregiver outcomes.

CASE STUDIES

For U.S. Latinos, disparities in the provision of health and human services may be accentuated due to the issue of language barriers, heightened potential for misdiagnosis in the clinical encounter, stereotypes regarding the patient or family member's ability to

adhere to treatment regimens or care plans, and the like (Aranda, 1999; Smedley et al., 2003). In this section we will use three case studies to illustrate how diversity can manifest in the caregiving context with respect to Latino caregivers, how health disparities in the provider-patient/caregiver context can affect the quality of care and outcomes, and how to initiate care planning based on a diversity perspective. We use culture in its broadest sense, to include those characteristics that represent family culture, gender, socioeconomic status, and rural caregiving within the context of different health and human service settings. An underlying consideration across these three cases is assessing the degree to which the caregiver is willing to continue to provide care to the care recipient in the community. Following the cases a discussion provides the reader with recommendations for provider assessment and care planning from a provider-care recipient/caregiver perspective.

The Case of Mr. Acevedo

Mr. Justino Acevedo (age 75), a bilingual Latino male originally from El Salvador, is a retired construction supervisor with hypertension and severe osteoarthritis. He and his wife Janet, who is 69, have been married for 50 years, live in southern Florida, and have three children. Two of their sons live out of state and the youngest, a daughter, lives in the same city with her spouse and children. Mr. Acevedo is increasingly unable to provide care for his wife as a result of his own health problems and his wife's severe behavioral problems.

Mr. Acevedo has been the primary caregiver for his wife who was diagnosed with Alzheimer's disease two years ago. At the time of diagnosis, the physician provided Mr. Acevedo with a verbal overview of the disease and what he could expect in terms of his wife's diminishing capacity and prognosis. The physician did not provide Mr. Acevedo with written information about the disease and where he could obtain community-based resources and/or long-term care information. The physician assumed that Mr. Acevedo (who has a strong Spanish accent) did not read English, and therefore, could not avail himself of the information available in the written literature.

Mr. Acevedo brings his wife in to see her family physician, Dr. Parker, because she has become increasingly agitated and combative. Mr. Acevedo explains what has been happening for the past few months: that his wife "is not sleeping at night and paces throughout the house," and continuously tries to "sneak out of the house if left alone even for a few minutes." Mrs. Acevedo will no longer bathe herself and when Mr. Acevedo tries to remind her, she becomes aggressive and "foul-mouthed." On several

The Case of Mr. Acevedo (continued)

occasions she has struck out at him. He does not know how he can help his wife with her personal care and has a difficult time administering her medications. At times he will forego giving her medication just to avoid altercation with her.

Mr. Acevedo's voice cracks as he discusses his situation with Dr. Parker, and he shares that he feels uncomfortable asking for help from his family because they are "all busy working and have their own families and problems." He feels increasingly isolated and no longer visits with his friends because he is embarrassed and cannot leave his wife alone. Dr. Parker says he understands that family members may be too busy, but that Mr. Acevedo should explain what's going on with his wife before she becomes worse. He frequently calls his daughter for help at all hours of the day. His daughter is a teacher and has three small children and tries to help as much as she can.

Challenges:

- 1) Assessment of health and mental health needs of both caregiver and care recipient
- 2) Assessment of environmental and home safety issues (medications; behavioral problems)
- 3) Assess gender-specific issues related to provision of personal care
- 4) Assess adult children's awareness of Alzheimer's disease and caregiving issues
- 5) Identification of family and nonfamily support systems
- 6) Linkage to community resources and long-term care planning
- 7) Identification of health disparities in the clinical encounter

Case Discussion:

This case highlights the importance of examining culture and gender-role expectations of late-life caregiving and underscores the opportunity for the primary care provider to participate with the family in an intervention. The trusted doctor-relationship bond that Dr. Parker developed with Mr. Acevedo will allow Dr. Parker to initially take a *fact-centered approach*. This approach will allow Dr. Parker to elicit the sociocultural framework under which Mr. Acevedo is operating and thus enhance his assessment and communication methods. For example, Dr. Parker takes into consideration that Mr. Acevedo belongs to a particular age and gender cohort that was brought up during the time when caregiving responsibilities followed gender-specific roles and expectations.

Dr. Parker identifies that Mr. Acevedo is uncomfortable with providing personal hygiene care to his wife given that his wife was typically the person in the family who provided hands-on care to their children, grandchildren and elderly parents. Second, Dr. Parker discerns that Mr. Acevedo is also reluctant to ask for outside help for fear that others, including his adult children, will become aware of his wife's bizarre and aggressive behaviors. Mr. Acevedo appears to want to protect himself and his wife from the stigma attached to his wife's memory loss and atypical behaviors. Third, Dr. Parker realizes that Mr. Acevedo, confused about his wife's medications and how they function, may be actually precipitating some of his wife's behavioral problems.

Under the *attitude/skill-centered approach*, Dr. Parker begins the doctor/patient communication process of listening to the patient and Mr. Acevedo's unique needs and care preferences. This is essential in order to avoid provider assumptions or stereotyping of Mr. Acevedo's knowledge of the disease and his beliefs about providing care to his wife as well as the role of his children. He engages in mutual exploration with the caregiver regarding his professional hypothesis that Mr. Acevedo's expectations and knowledge of the disease process and treatments are a function of his prior socialization process. Upon further assessment, Dr. Parker was able to identify that both Mr. and Mrs. Acevedo were clinically depressed and referred them to a mental health specialist who was a friend and colleague. Although Mr. Acevedo was at first hesitant to follow up with the referral, Dr. Parker allayed his fears by communicating that since the depression actually made his wife's cognitive impairment worse, going to the specialist would help her continue living at home for as long as it was safe.

Dr. Parker has several options in approaching Mr. and Mrs. Acevedo's case. Due to the limited amount of time that physicians have with their patients in a typical office visit, it is critical to note that the process of intervention may occur in several visits as well as include follow-up telephone calls. First, Dr. Parker should offer Mr. Acevedo more information both verbally and in written form regarding his wife's dementia, available treatments, and so forth. Before assuming that Mr. Acevedo's accent is an indicator of not being able to read English, he should provide literature in both languages and let Mr. Acevedo choose the reading material that can be of most assistance to both him and his family.

Second, because of Dr. Parker's medical training, which stressed the importance of self-determination and confidentiality of the patient, he was reticent about including the family as part of the patient treatment and intervention. Nonetheless, the physician failed

to evaluate the possibility of organizing a family meeting to include the couple's children. Dr. Parker should speak with Mr. Acevedo about the pros and cons of including his children in the caregiving situation, and offer himself as an "expert" to help facilitate the family meeting. Given the high importance that Latinos place on the authority of the physician (Aranda, 1999), Mr. Acevedo may feel less pressure to have to be the one who relays the message to his children regarding their mother's condition and needs. Also, because of his own limited knowledge regarding community resources for patients and families, Dr. Parker may refer the family to the local chapter of the Alzheimer's Association.

There are tools and resources available for Dr. Parker to use in his medical practice that can impact the patient care outcomes. Health-care professionals have been leaders in designing cultural competency models for training providers (Office of Minority Health, U.S. Health & Human Services, 2002). Additionally, the American Medical Association developed a practical self-assessment questionnaire for caregivers for preventive purposes of health risk. (www.ama-assn.org/ama/pub/category/4642.html).

The Case of Mrs. Suarez

Nelly Suarez is a bilingual, 55 year-old Mexican-born female, recently widowed, and living in a suburb in the county of Los Angeles. Nelly has recently gone to see a mental health specialist at the prompting of a close friend of the family. Nelly is caring for her elderly aunt, Señora Tapia who never married, never had children, and lives alone in an inner city housing development for low-income households. Although Señora Tapia was diagnosed with vascular dementia about eight years ago, she continued to be physically robust and able to live alone with the assistance of her part-time personal care attendant. Because she has lived for many years in a multi-unit apartment building, Señora Tapia has maintained close ties with her neighbors, many of who are elderly, Spanish-speaking persons themselves.

Señora Tapia has always been a strong-willed woman who raised several of her nieces and nephews, and has had very strict rules regarding "how children should behave." She is remembered by her extended family as very domineering and rigid in her expectations of family members. Nelly is fond of her aunt and grateful to her for having sponsored her in her process of emigration from Mexico and eventual U.S. naturalization. Nelly cared for her own mother before her death some eight years ago. Although there are several nieces and nephews in the general geographical area, Nelly is the primary caregiver for her aunt. Nelly is well informed about vascular dementia as a result of participating in a caregiver support group and attending educational seminars regarding the disease and how it affects the caregivers.

The Case of Mrs. Suarez (continued)

About six months ago, Nelly's husband passed away unexpectedly of a heart attack. She has no children, but reports having a brother who lives nearby and is supportive of her. A sister, who lives in Mexico, is supportive as well, but is too far to help Nelly with her aunt. The major concern at this point is that Nelly is having difficulty in concentrating on her daily responsibilities, including those that revolve around her aunt's care. This is disturbing for Nelly, who typically is perfectionistic about her responsibilities. She reports that she sometimes forgets to pay her aunt's monthly bills, or does not have the energy or interest to follow-up with her aunt's doctor appointments. She realizes that she may be depressed as a result of losing her husband, but feels that she has "to continue providing care for her aunt who is the matriarch of the family, and who was able to help all of us without anyone's help."

Señora Tapia is increasingly more agitated and distrustful of her personal care attendant as shown by her accusations that the attendant is stealing from her, talking about her to the neighbors, and using her telephone without her permission.

During the initial counseling session, the mental health specialist assesses that Nelly is clinically depressed and will need an evaluation for medications. She also tells Nelly that she is "doing a great job of caregiving and is always happy to see how some people have such a strong family ethic and take care of their own."

Challenges:

- 1) Cultural issues regarding filial obligation, familism, and gender expectations
- 2) Exacerbation of pre-existing personality styles
- 3) Assessment of mental health status of both caregiver and care recipient
- 4) Issues of spousal loss and bereavement
- 5) Identification of resources and long-term care planning
- 6) Identification of health disparities in the clinical encounter (exaggerated emphasis on cultural value of familism)

Discussion:

As with many caregivers, caring for a family member with memory loss was an unexpected role for Nelly. As a first-generation Mexican American, she believed that caregiving for older family members was a woman's role, a notion that was easily supported by her siblings and extended family of nieces and nephews. The Latino value of "compromiso" (sense of obligation) was embodied in Nelly's belief that she was responsible for the care of her aunt who gave so

much to her family in her earlier years. A source of stress for Nelly was trying to balance her cultural values of filial responsibility for her aunt who was the surviving matriarch of the family, with the loss of her own husband and eventual grieving process.

Aside from cultural and gender influences, the case study highlights the importance of taking into account personality styles and their effect on the quality of the care recipient-caregiver relationship. Before the onset of her dementia, Señora Tapia was typically regarded by her family as strong-willed and domineering in her interpersonal relationships, traits which now continued to escalate gradually as her memory loss progressed. Although the aunt's personality style had been tolerated in previous years, the increased pressure her aunt placed on Nelly (multiple and daily phone calls) was overwhelming.

Nelly's own personality style also plays a part in the caregiving situation. Nelly is known in her family as a person "who gets things done." She personally attests to the fact that she obtains much satisfaction in completing her tasks with perfection and thoroughness, and expects the same from others, much like her aunt. With the increased caregiving responsibilities, decreased ability to control what occurs with her aunt, combined with the loss of her spousal confidant, she has less of an opportunity to receive personal gratification from her caregiving role.

These cultural, gender, personality, and grief influences combined, influence the degree of nonparticipation from other family members, namely Nelly's siblings, nieces and nephews. First, Nelly tends not to reach out for assistance or to relay recent stressors related to her aunt's changes. Second, Nelly and Senora Tapia's personality styles tend to push other family away as they perceive them to be too impatient and critical of their efforts when they do attempt to assist. For Nelly, who places a high value on familism (Keefe & Padilla, 1987; Sabogal et al., 1987), the reality that social support is lacking during this time of crisis, may have compounded her sense of loss and isolation, thus precipitating a depressive episode.

A provider, for instance from the mental health sector, can take the fact-centered approach by acquiring information regarding Nelly's cultural point of reference. This involves a combination of exploring the literature on Mexican American gender roles, filial obligations and familism, grief, perception of memory loss, etc. and making *tentative* assumptions (or hypotheses). With Nelly's assistance, the provider ascertains the potential meaning that she gives to these domains of personal and family life, in order to accurately understand what knowledge is relevant and what is not. For example,

the practitioner may place an exaggerated emphasis on Nelly's cultural value of familism given that she is first-generation Mexican American, and downplay her feelings of inadequacy in performing her modified role as caregiver. Thus, Nelly and the practitioner engage in a discovery of Nelly's diversity in all of its facets, eschewing preconceived notions on the part of the practitioner (and value statements placed on "caring for one's own"), and an acceptance of her experience (attitude-centered approach). This provides a framework in which Nelly and the practitioner can develop an intervention plan to deal with her depression, caregiver strain, and so forth, based on respect and self-determination.

The Case of Mrs. Ochoa

Mrs. Ochoa (age 60), a biracial Puerto Rican woman living in a small rural community in Illinois, has been caring for her husband (age 62) who suffered a spinal cord injury from a traumatic physical assault about 20 years ago. Mr. Ochoa retired early about five years ago due to the increasing disability stemming from the secondary effects of his injury. Mr. Ochoa is experiencing mobility limitations, increased fatigue, and chronic pain. Mrs. Ochoa quit her part-time job so she could care for her husband.

The Ochoa's daughter visited her parents during the holidays and was concerned about her father's deterioration and mother's level of exhaustion. During the visit, the daughter observed her father as being uncharacteristically disinterested and irritable. She also noticed that Mrs. Ochoa was very anxious about caring for her husband and was concerned about the mounting pharmacy bills. Also, her daughter reported that her mother seemed not to understand the disease symptoms, and therefore at times displayed unrealistic expectations of what her husband could do, "El puede hacer cosas, nada mas quiere que yo lo hago." (He can do things, he just wants me to do them for him).

Mrs. Ochoa must transport her husband once a month for medical visits with the neurologist; the closest provider is about 100 miles away. Her daughter called the local Area Agency on Aging to seek assistance for her parents. She also advised the agency that although her mother understood English, she is more comfortable in speaking Spanish and requested follow-up from someone from the agency who spoke Spanish.

Challenges

- 1) Assessment of health and mental health needs of both caregiver and care recipient.
- 2) Assessment of environmental (service isolation) and home safety issues

- 3) Assess adult children and other family members' awareness of caregiving issues
- 4) Identification of available resources and development of long term care planning
- 5) Identification of health disparities (lack of organizational structure to enhance Spanish-language capacity)

Discussion:

The challenges surrounding caregiving interventions in rural communities are numerous. In this case, there are both interpersonal and organizational cultural issues to be addressed. From an interpersonal level, assessing the sociocultural context of the caregiving situation will be necessary to determine both Mr. and Mrs. Ochoa's caregiving and other service needs. (At this stage, the provider must take both a fact-centered and attitude/skill-centered approach to exploring Mrs. Ochoa's willingness and capacity to care for her husband as the disease progresses.) Additionally, determining the adult children's involvement in assuming caregiving responsibilities will also be a key coordination factor as care plans are developed to address personal and long-term care issues.

From a cultural perspective, the relationship that Mr. and Mrs. Ochoa have had is a critical part of how Mrs. Ochoa perceives her role as a caregiver and Mr. Ochoa's care expectations. Assessing Mrs. Ochoa's and other family members knowledge of the aging process and how it interacts with spinal cord injury, is a part of the fact-centered approach. Mrs. Ochoa's comment regarding her husband's ability to do something versus his manipulation to get her to help him can be related to the fact that Mrs. Ochoa has always taken care of her husband's needs and now has a difficult time with his disability and deciphering his physical capacity.

From an organizational standpoint, there are many challenges to face when providing resources in rural communities, in particular when there is a special need for an assessment or intervention required in another language. Organizations have opportunities to examine the cultural domains as they exist within their organizational structures. Conducting an organizational assessment has been identified as an important tool for planning, evaluating, and monitoring cultural competency. The Area Agency on Aging (AAA) is challenged with assessing its organizational program capacity for providing culturally competent services.

Part of this formal assessment can include measuring the following nine domains of the organization and the employees as

recommended by the Health Resources and Services Administration (Health Resources Services Administration, 2001). These domains include:

- values and attitudes
- cultural sensitivity
- communication
- policies and procedures
- training and staff development
- facility characteristics
- capacity and infrastructure
- intervention and treatment models
- family and community participation
- monitoring and program evaluation.

The first challenge the AAA has is to identify Spanish-speaking staff that can talk with Mrs. Ochoa and determine her need for support. Whether the primary service agency to the Ochoa family would be the AAA or another agency within the rural community, examining the organizational capacity to provide cultural competency services—including services for limited English-speaking—will impact both the assessment phase and care planning for this family.

ORGANIZATIONAL-LEVEL COMPETENCY

Cultural competence should be approached within a person-in-environment perspective that integrates competence across larger social systems; competence goes beyond the realm of client-practitioner interactions, occurring within the context of the organizational setting (mission, policies, procedures, infrastructures, staffing, linguistic capabilities, etc.). Cultural competence at the organizational level entails a set of congruent practice skills, attitudes, policies, power relationships, and structures that together increase the organization's capacity to provide culturally appropriate and responsive care (Geron, 2002).

A barrier which contributes to Latino caregivers' awareness and ability to access health and social services is limited English proficiency skills. The inability to speak English, in particular, has been empirically associated with less care-seeking and diminished access to services (Robert Wood Johnson Foundation, 2001). Examples of caregiver barriers include:

- difficulty in making appointments and accessing basic information about the visit, when they seek care or services;
- inability to communicate adequately with health or social service staff;

- reduced client/patient satisfaction with cross-language visits, which may lead to a reluctance to return to the agency.
- More critical is the inability to understand or follow through with health recommendations such as medication compliance, nutrition, and physical activity requirements.

Thus organizations should develop comprehensive management strategies to address culturally and linguistically appropriate services including strategic goals, plans, policies, and procedures and evaluation methods.

PUBLIC POLICY IMPLICATIONS AND RECOMMENDATIONS

The demographic changes that are currently unfolding magnify the importance of addressing caregiver issues at several levels: client (caregiver/care recipient), provider and systems. Increased federal, state and private funding will allow organizations to support initiatives to assist communities in capacity-building to better serve diverse caregivers. At a systems level, organizations must include in their mission statements a commitment to providing services for the Latino caregiving population while at the same time instituting policies and procedures to recruit, train and retain staff at all levels that can provide bilingual, bicultural services as required. Boards of directors must reflect the diversity of the communities being served. Organizations should incorporate community participation in the planning, development, implementation and evaluation of services for caregivers addressing Latino cultural and linguistic needs. Coalition building and organizational involvement at grass-roots levels using existing best practice models of outreach strategies (e.g., Family Caregiver Alliance) would ensure that caregivers would receive support to care for their family members.

As mentioned before, it is crucial for organizations to increase their capacity to serve the Latino caregiving population by increasing staff to conduct outreach and provide services. Latino family caregivers require the education, resources and tools to continue the caregiving they currently provide. Educational programs, media (Spanish radio/television) outreach programs, and counseling/support programs are crucial interventions that will provide Latino caregivers with skills to increase caregiver capacity (Gallagher-Thompson, Hargrave, Hinton, Arean, Iwamasa, Zeiss, 2003; Gallagher-Thompson, Arean, Coon, Menendez, Takagi, Haley, Arguelles, Rubert, Lowensten, Szapocznik, 2000). Effective public policy legislation that applies standards which provide relevant guidelines that organizations model their programs after will enhance services for Latino caregivers.

An excellent example of the influence of public policy on service delivery is embodied in the Office of Minority Health's "National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care" (Federal Register 65 (247. 80865-80879) published in March, 2001. In brief, the three primary areas in the CLAS standards include culturally competent care, language access services, and training resources in federally funded programs. Although these standards are primarily targeted towards health care organizations to implement culturally and linguistically appropriate services at all levels, other social service organizations can use this model for developing standards within their own organizations.

SUMMARY

The process of achieving cultural competency from the interpersonal to the organizational level has been defined as a process (Evans, 1997). The fact- and attitude/skill-approaches to cultural competency and the aforementioned domains (knowledge, attitudes and skills) are critical elements that should be incorporated into any curricular models and intervention plans with Latino caregivers. Noteworthy are several core cultural competency models, methods and guidelines which are available in the various health and human service disciplines and can be found in the list of Cultural Competency Resources in the Appendix.

Core concepts are recommended for understanding how the cultural systems of caregivers and care recipients operate and move beyond the traditional domains of race and ethnicity. As seen in the previous cases, other factors such as gender, rural residence, socioeconomic status, etc., play an important role in assessment and delivery of services to caregivers.

Cultural competency does not substitute for sound clinical practices in the area of assessment and evaluation. For example, caregiver assessment of late-life families affected by dementia should follow the state of the art caregiver assessments provided in the literature. (See monograph, "The State of the Art: Caregiver Assessment in Practice Settings, Family Caregiver Alliance, 2002). Moreover, any type of translation of caregiver assessment tools and informational resources should undergo the necessary back-translation and validation to ensure the accuracy of conceptual and contextual equivalence of the meaning of the tool or resource (including literacy level adaptations).

As the caregiving community continues to grow nationwide, the diversity of caregivers and caregiving needs and situations will also expand. The better informed and prepared that providers are to address caregivers' needs from a sociocultural perspective, the more likely we will be able to see more favorable outcomes in service provision.

Table 1.

Examples of knowledge, attitudes, skills in cultural competency with caregivers at the interpersonal/practitioner level.

Attitudes

- An eagerness to work with clients from diverse backgrounds
- A willingness to accept that there are multiple ways of perceiving the world even by those who identify with the same group
- A willingness to examine how one thinks, feels, and behaves in relation to the client's background and experiences (self-assessment)
- An awareness of one's personal biases and their impact on professional behavior
- An openness to engage with the client in a mutual discovery of her/his experience with caregiving
- An openness to seek out educational and training experiences to enhance one's understanding of diversity in multiple contexts
- A willingness to seek consultation with, and/or make referrals to, other providers with expertise in diversity.

Knowledge

- Knowledge of the particular group being served, e.g., cultural, social, psychological, economic, sociopolitical, etc.
- Knowledge of the client's own ethnic identification (country of origin, regional background, generational level, religion (spirituality), language(s) spoken, etc.)
- Knowledge of the client's perception of health and wellness, aging and disability, caregiving and long term care, illness and treatment, grief and bereavement, etc.
- Knowledge of the client's family life, values, gender expectations, customs and traditions related to caregiving, etc.
- Knowledge of power relationships in the family—and in the community—that serve to maintain the caregiver in an oppressed status
- Knowledge of the social network members or potential members of the caregiver/care recipient dyad

Table 1. (continued)

- Knowledge about how availability, accessibility and acceptability of the service/resource will impact the caregiver
- Knowledge of strategies for the development of culturally appropriate verbal and nonverbal communication skills
- Knowledge of community resources available to the client that are culturally competent, and that utilize empowerment-focused interventions for groups that are oppressed and underserved

Skills

- Ability to apply professional ethical standards to practice with diverse populations
- Ability to speak the client's language of preference or to seek qualified interpreters to assist in the interview
- Ability to engage in the client and family's modes of communication
- Ability to establish a helping relationship with the client using cultural empathy (i.e., connecting emotionally with the client and engaging in a mutual discovery of the client's diversity experiences)
- Ability to conduct culturally appropriate assessments that are respectful of individuals and families
- Ability to identify benefits and weaknesses of using different types of trained interpreters
- Ability to describe the process and use of translation/back-translation to achieve better conceptual equivalence of materials and assessment tools
- Ability to conduct a cultural health assessment including elicitation of:
 - a. background/contextual data,
 - b. clinical assessment domains,
 - c. problem specific information (including explanatory models),
 - d. intervention specific data, and
 - e. outcomes criteria
- Ability to accurately assess the meaning that the client attributes to her/his diverse experiences in the caregiving context

Table 1. (continued)

- Ability to make appropriate referrals and set up interventions
- Ability to distinguish between stress which is related specifically to caregiving, or intrapsychic factors, and stress related to external factors from the social structure (e.g. acculturative stress exposure, discrimination, oppression, etc.)
- Ability to self-reflect, understand, and work through one's own attitudes, values and biases regarding the client and his/her reference group(s) that may influence the work to be done with the client
- Ability to engage in empowerment-oriented strategies at the personal level, organizational level, and at the community and societal level

Table 2.

Examples of attitudes, program planning, community capacity-building skills in cultural competency with caregivers at the organizational level.

Attitudes

- An eagerness to create and maintain organizational responsiveness to an increasingly diverse target population and community of caregivers
- A willingness to participate in an ongoing assessment of the organization's commitment and response to the target population's cultural background and experiences (self-audit)
- A willingness to accept difference and to foster an environment that respectfully manages the dynamics of difference
- An openness to partner and collaborate with various groups and representatives of community groups and consumer stakeholders

Program Planning

- To allocate necessary resources to support strategic goals pertaining to cultural competency and family caregiving
- To implement an organizational self-audit that critically evaluates the organization's capacity to address the dynamic needs, preferences, and strengths of the target population's background and experiences

Table 2. (continued)

- To develop a strategic plan that systematically incorporates the background and experiences of the target population and insures ongoing monitoring and evaluation
- To develop a system of care (i.e., organizational policy, structures and practices) that insures services compatible with the target population's culture and language
- To promote diversity throughout the organization including hiring, retention, and promotion of diverse staff
- To evaluate organizational policy, structures, and practices, and evaluation systems as to their effectiveness in fostering cultural competence throughout the organization

Community Capacity-Building

- To develop participatory and collaborative partnerships with community organizations, informal groups or networks of culturally diverse populations, consumer and family groups, and other key community stakeholders
- To develop and disseminate information regarding community-capacity building efforts and accomplishments

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APPENDIX

ADDITIONAL CULTURAL COMPETENCY RESOURCES

Government Agencies

Administration on Aging, U.S. Department of Health and Human Services. *www.aoa.gov/minorityaccess/guidebook2001*

Office of Minority Health, Public Health Service, U.S. Department of Health and Human Services, *www.omhrc.gov/clas/guideintro.htm*

Office for Civil Rights, U.S. Department of Health and Human Services. (2000). Title VI of the Civil Rights Act of 1964: Policy guidance on the prohibition against national origin discrimination as it affects persons with limited English proficiency. Federal Register, 65 (169), 52762-52774. *www.hhs.gov/ocr/lep*

Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, Cultural Competence Standards in Managed Care Mental Health Services: Four Underserved/Underrepresented Racial/Ethnic Groups. *http://mentalhealth.org* or *www.wiche.edu/mentalhealth/CCStandards/ccstoc.htm*

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Healthfinder en Español: *www.healthfinder.gov/espanol*

U.S. Department of Health and Human Services. (2001). Achieving cultural competence: A guidebook for providers of services to older Americans and their families.

Professional Associations

American Medical Association, Cultural Competence Compendium, *www.ama-assn.org/ama/pub/category/4848.html*

American Nurses Association

American Academy of Physician Assistants, APAP

American Psychological Association, Guidelines for Providers of Psychological Services to Ethnic, Linguistic, and Culturally Diverse Populations, *www.apa.org/pi/oema/guide.html*

National Association of Social Workers National Committee on Racial and Ethnic Diversity (2001). www.naswdc.org/standards/cultural.htm

Society of Teachers of Family Medicine, Core Curriculum Guidelines, www.stfm.org/corep.html

National Alliance for Hispanic Health (2000). Quality Health Services for Hispanics: The Cultural Competency Component. Washington, DC: U.S. Department of Health and Human Services: Washington, DC. (DHHS Publication No. 99-21). National Alliance for Hispanic Health. www.hispanichealth.org

Academic-Affiliated Organizations

National Center for Cultural Competence, Georgetown University Center for child and Human Development, University Center for Excellence in Developmental Disabilities, www.georgetown.edu/research/gucdc/ncccl/index.html

Other Caregiver Resources

Family Caregiver Alliance
690 Market Street Ste. 600
San Francisco, CA 94104
(415) 434-3388
(415) 434-3508 fax
www.caregiver.org

Family Resource Coalition
www.casanet.org/library/culture/competence.htm

Diversity Rx, Multicultural Health Best Practices
www.diversityrx.org/BEST/index.html

AARP
www.aarp.org