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African American, Chinese, and Latino Family Caregivers' Impressions of the Onset and Diagnosis of Dementia: Cross-Cultural Similarities and Differences

Diane Feeney Mahoney, PhD, GNP, FGA¹, Jane Cloutterbuck, PhD, RN², Susan Neary, PhD, APRN, BC³, and Lin Zhan, PhD, RN, FAAN⁴

¹ MGH Institute of Health Professions, Boston, MA.

² College of Nursing and Health Sciences, University of Massachusetts, Boston.

³ Department of Nursing, Simmons College, Boston, MA.

⁴ School of Health and Environment, University of Massachusetts, Lowell.

Abstract

Purpose—We explored cross-cultural similarities and differences in minority family caregivers' perceptions of the onset and diagnosis of Alzheimer's disease in their relatives, with specific attention to clinical encounters.

Design and Methods—We performed a meta-synthesis of three qualitative studies conducted in Massachusetts with 22 African American, Latino, and Chinese caregivers.

Results—All participants conveyed striking similarities of thought about normalization of cognitive symptoms until one critical event, usually relocation, precipitated family awareness that an elder's behavior was not the result of "normal aging." A lack of knowledge about Alzheimer's disease, rather than culturally influenced beliefs, was the major deterrent to having an elder's memory assessed. Community physicians' failure to recognize Alzheimer's disease or refer to specialists was more problematic than language or ethnic differences. Physicians' disrespect for caregivers' concerns about memory loss was particularly noted by African Americans, stigmatization of persons with Alzheimer's disease was noted by Chinese, and fears that acculturation would end family home care was noted by Latinos.

Implications—Amid ethnocultural differences, there are many similarities in needs that offer providers the possibility to unify quality improvements in Alzheimer's disease outreach, education, and physicians' services. Suggestions include providing the public with more confidential access to Alzheimer's disease information, increasing dementia awareness among community physicians, motivating clinicians to adopt culturally sensitive communication patterns, and providing community education to reduce normalization by families and stigmatization of persons with Alzheimer's disease.

Keywords

Alzheimer's disease; Cultural competence; Race or ethnicity; Meta-synthesis

Address correspondence to Diane Feeney Mahoney, PhD, GNP, FGA, MGH Institute of Health Professions, Jacques Mohr Professor of Gerontological Nursing Research, Charlestown Navy Yard, 36 First Avenue, Boston, MA 02129. E-mail: dmahoney@mghihp.edu.

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There is a markedly growing racial and ethnic diversity among older adults. Currently, among the population of adults who are aged 65 or older, 8% are of African American descent, 5% are Latino–Hispanic of any race, and 2.3% are Asian–Pacific Islanders. By 2050, these percentages will increase to 12% for African Americans, 16% for Latinos, and 6.5% for Asian–Pacific Islanders. Although older Caucasians will remain in the majority, their numbers will decline from 84% in 2000 to 64% by 2050 (U.S. Census Bureau, 2000). Knowing the rates of change among racial subgroups does not, however, translate into an understanding of ethnic diversity. Ethnicity refers to a specific cultural group, with its unique language, customs, and attendant beliefs (Agar, 1994). Cultural sensitivity is an awareness of how culture shapes another person's values, beliefs, and worldviews, with not only an acknowledgment that personal differences exist but also a respect for these differences (Administration on Aging, 2001).

These demographic changes point to the need for research that examines the influence of culture, particularly cross-cultural research (Dilworth-Anderson, Williams, & Gibson, 2002; Fortier & Bishop, 2003). Moreover, the degree of immigrant acculturation interspersed with the length of time in the United States and the degree of proficiency with the English language are posited to be important variables in cultural research (Aranda & Knight, 1997; Coon et al., 2004). Researchers have stressed the particular need to evaluate the effects of increasing ethnic diversity on family care for elders with dementia (Aranda & Knight; Gallagher-Thompson, 2000). The exploration of cultural influences is critical, as culture affects understanding of dementia, utilization of services, and the psychosocial experiences of family members (Janevic & Connell, 2001; Valle, 1998; Yeo, 1996).

Among ethnocultural groups, African American elders are more at risk of developing dementia than other ethnic groups (Baker, 1996); by the age of 90, they have four times the risk that Caucasians do (Tang et al., 1998). African American elders are predisposed to higher rates of multi-infarct dementia (Yeo, 1996), and they appear to be, by both incidence rates and cumulative risk, at higher risk of developing Alzheimer's disease, the most common form of dementia (Shadlin & Larson, 1999; Tang et al., 2001). However, the Alzheimer's Association (2004) estimates that there will be 1.3 million people of Hispanic–Latino origin with Alzheimer's disease by 2050. Hispanic–Latino caregivers have the most geographically diverse origins, as they come from North America, South and Central America, the Caribbean, and Spain. Investigators have noted the need for increased awareness of within-group diversity, especially among Hispanic–Latinos (Aranda & Knight, 1997; Connell & Gibson, 1997; Delgado & Tennstedt, 1997; Gallagher-Thompson, 2000; Morano & Bravo, 2002).

Among the minority groups, the paucity of dementia information is most noted for the Chinese. However, one longitudinal prospective study of cognitive impairment among elderly adults was conducted in Shanghai (Zhang et al., 1990). Findings from that study showed that the prevalence rate of dementia in persons aged 65 years and older was 4.6%, which is much lower than that from reports from Western countries. In addition, Ikels (1998, 2002) followed a sample of 200 elders from 1987 to 1991 in Canton, China and reported that the experience of dementia caregiving is psychologically less threatening for people there than for people in the United States, because in China there are cultural concepts that preserve the patients' sense of self longer and offer greater intrinsic rewards to the family caregiver. Whether the involvement of governmental representatives in the study interviews resulted in socially desirable responses was not discernable. Within the United States, researchers have reported difficulty in recruiting Chinese Alzheimer's caregivers (Elliot, DiMinno, Lam, & Tu, 1996; Hinton, Guo, Hillygus, & Levkoff, 2000) and other Asian caregivers who perceived shame in their culture for having a relative with this condition (Sue, 1994). Jones, Zhang, Jaceldo-Siegl, and Meleis (2002) reported on the struggles that Americanized Asian women have had in integrating the two cultural perspectives on caregiving.

Wackerbarth and Johnson (2002) noted the growing importance of early diagnosis of Alzheimer's disease as treatment options increase, yet they found that one fourth of the caregivers who responded in their study waited more than 2 years before seeking a diagnostic evaluation. Connell and Gallant (1996) explored the decision by caregivers to bring their relatives in for memory assessment, and they found the primary benefits were eliminating treatable diseases, gaining information, getting treatment, and allowing future planning. The main obstacles to diagnosis were cost, lack of time, lack of access to specialists, and not receiving a referral from the primary care physician. Boise, Morgan, Kaye, & Camicioli (1999) conducted focus groups with caregivers, and they found the caregivers delayed seeking a diagnosis because they lacked information about dementia, they believed the symptoms were signs of normal aging, they did not know which physician to ask, and they were overwhelmed by the situation. Wackerbarth, Streams, and Smith (2002) also affirmed these barriers. Notably, all of these studies were conducted with predominantly White caregivers, so the issue of whether minority caregivers perceive similar or different factors remains unanswered.

The meta-analysis by Pinquart and Sorensen (2005) of studies on ethnic differences in family caregiving revealed that the magnitude of the quantitative differences was quite small. They concluded that the lack of a predominant theoretical model on ethnic differences in caregiving is problematic. To move toward theory development, these investigators recommend more focused research on ethnic similarities and differences across a range of contextual variables. The present study aligns with their recommendation; it emanates from Leininger's trans-cultural model of nursing care, in which clinicians must understand the individual's perceptions in order to offer health care services that are congruent with the norms and values of the culture (Leininger, 1991; Leininger & McFarland, 2002). This model embraces the concept of cultural competence, which dictates that clinicians should have knowledge of cultural specific values, traditions, and health beliefs, and the interpersonal skills to communicate directly or through a translator with appropriate cultural etiquette (Administration on Aging, 2001). Our purpose in this study was to gain an understanding from a cross-cultural perspective of family caregivers' experiences when elder care recipients are in the early stage of Alzheimer's disease, with specific attention to perceptions about clinicians' cultural sensitivity. Our research question was as follows: What are the cross-cultural similarities and differences in African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of dementia?

Methods

To obtain the insights of cultural minorities, Lawrence (1995) asserted the need to focus on the role of *voice* and the tradition of storytelling to gain knowledge about marginalized groups whose voices have not been heard. Quantitative research, as the dominant scientific paradigm of scholarship in our society, is useful for identifying social and health inequities, but it depersonalizes and renders the voices of the marginalized minorities mute (Lawrence). Qualitative research is best suited to this stage of listening to the stories and voices of minority groups, and to further understanding of the phenomenon under study (Denzin & Lincoln, 2000). Qualitative research also has been recommended to help bridge the gap in understanding the lack of transference of quantitative findings into clinical practice (Devers, Sofaer, & Rundall, 1999).

We conducted a meta-synthesis of three qualitative studies of minority family caregivers. Meta-synthesis combines the findings from multiple qualitative studies in which the researcher has access to the original data and reanalyzes or synthesizes the results to answer a different question (Beck, 1999, 2002; Whittemore, 2005). The original studies were conducted during 2002 and focused on the caregiving experiences of African Americans, Latinos, and Chinese caregivers of elders with Alzheimer's disease; this study's coauthors collected the primary

data. We planned the meta-synthesis as part of the original study design to enable cross-group analyses. Our methodological approach is based on Spradley's (1979) principles for qualitative comparisons. The similarity principle guides which categories are determined by looking for units of information with similar content (constant comparative analysis) or by looking for terms that have similar meaning as a guide to identify commonalities in the data. The contrast principle is part of the comparative analysis and directs the search for mutual exclusivity. The research was approved by both the Hebrew Rehabilitation Center Institutional Review Board and the Elder Rights Review Committee of the Massachusetts Department of Elder Affairs.

Sampling

The sampling goal in the original studies was to enlist participants who had in common a family caregiving experience of having a member diagnosed with Alzheimer's disease but viewed it through different racial or ethnic lenses. This goal was achieved through purposive sampling that targeted caregivers who shared the characteristics of interest. According to Morse's principles of saturation (1995), the greater the cohesiveness of the sample sharing the characteristics that address the research topic, the faster saturation is obtained. Saturation is defined as *data adequacy* and operationalized as collecting data until no new information is obtained (Morse). The quantity of data in a category is not theoretically important to the process of saturation. Richness of data is derived from detailed description, not frequency counts, and there is no a priori sample size requirement (Morse).

To attain richly detailed data, eligibility criteria were developed to foster homogeneity of well informed, experienced caregivers who had in common Alzheimer's disease onset and diagnostic experiences. An eligible participant had to be (a) a nonpaid family caregiver for at least 6 months of a person with Alzheimer's disease, and (b) the family member who participated in the Alzheimer's disease diagnostic clinical encounters, provided caregiving assistance at least weekly, and participated in an Alzheimer's disease support group or community program.

Data Collection

Morse (1997) says the following:

When many investigators are simultaneously reaching out into a community to collect data, all members must be conveying the project in a similar light . . . thus the team reaches consensus on information sheets, consent forms, and a focus group guide. . . . Although this general consistency seems critical to ensure that the qualitative method is implemented in a way that allows the research goals to be reached, within this framework there is room for variability among investigators. Each investigator's way of carrying out the research work will be influenced by his or her unique knowledge, skills, and understanding. Such variation can be tolerated because of the foundational assumption in qualitative research that there are multiple realities that are socially constructed. In fact, the diversity contributes to the richness of the data. However, what is essential is that the variation be drawn upon during the data analysis process to clarify salient themes and patterns across the data. (p. 301)

Following Morse's guidelines, the investigators met as a team and gained consensus on the study protocol approach, consent forms, and interview guide. To ensure relevant data for cross-group comparisons, the investigators included and interspersed the following open-ended questions in each interview: When do you first remember noticing your family member's memory problem? Are there any beliefs about dementia and family caregiving that may be unique to your family or community? How was the decision to obtain an evaluation for memory loss made? What hindered or helped the evaluation process?

The investigators planned to collect the data through focus groups. Focus-group interviewing is a qualitative research technique that uses discussion among a small group of 4 to 12 persons in a comfortable environment (Morgan, 1988). Focus-group interviews provide opportunities for people to share experiences that affect their lives and decisions. Hence, it is a particularly efficacious methodology for doing research with ethnic minorities, because it is open to their stories, free from survey questions that do not translate literally, and limits control by the researcher (Denzin & Lincoln, 2000). Themes are described by the presentation of direct quotes from the respondents, thereby preserving their voices.

Recruitment of participants occurred in partnership with the Massachusetts chapter of the Alzheimer's Association. The association's African American and Latina outreach workers each approached the minority families with whom they worked and informed them about the project. These two trusted community "insiders" facilitated our entrée in these workers' caseloads and helped to overcome our status as outsiders. All families participated. Because of the greater within-group diversity among the Latino caregivers, additional respondents were recruited from the community so that we could attain data saturation. The association did not have an outreach worker for the Chinese community, but our research team included an investigator who was Chinese and was considered an insider by this community. She recruited participants through a community program in Boston's Chinatown.

The African American focus group was conducted at a local community organization and was facilitated by the African American researcher. It took approximately 2 hr to achieve data saturation, and, upon concluding, the facilitator summarized the session and obtained participants' feedback on her interpretive accuracy. Entrée into the Chinese and Latino communities uncovered strong resistance to discussing Alzheimer's disease in a focus-group format. Resistance to traditional face-to-face focus groups has arisen previously in qualitative research as a result of difficulties involving travel time, resource constraints, and when personal disclosure of viewpoints or behaviors may be perceived as threatening (White & Thompson, 1995). It is not uncommon in qualitative research for methods to change during the data-collection period when barriers to pursuing the research question arise and have to be addressed (Luft, 1986). Among the Latinos, making the time commitment and logistical arrangements to attend the group were most problematic, whereas among the Chinese, public discussion among community members was not desirable. In response, personal interviews were conducted with Latino and Chinese participants at a time and place most comfortable for them. The vast majority preferred their homes and chose a time in which their care recipients were absent. Interviews lasted 2 hr on average. The 22 caregivers who had consented to participate all completed their interviews or focus groups, and each received a \$15 honorarium for participation.

To ensure data integrity, all sessions were audio-taped, transcribed by professional transcriptionists, and rechecked for accuracy by the researcher who participated in the session. The African American researcher reviewed the text of her group along with the audiorecording to verify transcription accuracy. Interviews conducted in Spanish ($n = 2$) were transcribed by a bilingual transcriptionist and rechecked by the researcher and her translator. Interviews conducted in Chinese were similarly transcribed by a bilingual transcriptionist and rechecked by the Chinese researcher who spoke the same dialect. All of the participants' names were removed from the final transcripts. According to Morgan (1988), the litmus test of participant suitability is to view how readily and easily the informant embraced and discussed the topic in detail. Marked enthusiasm was noted in the original data collection and evidenced by lengthy transcripts that recorded the participants' control of the conversation with little guidance needed from the interviewer.

Analysis

Each of the researchers conducted an initial content analysis of her respective transcript. A content analysis is a standardized qualitative approach starting with a line-by-line review of the text, searching for key words and statements voiced in the discussion in response to the research question (Krueger, 1998). The unit of analysis was the sentence or a multisentence passage. The researchers labeled words and coded passages with similar themes. In the second step, the researchers reviewed their respective texts to capture themes related to each of the questions. The third step involved the researchers' reviewing the codes together as a team, coming to agreement about the coding categories, and then generating the themes. Finally, the original investigators revalidated the accuracy of the data interpretations with the focus group or individual respondents.

For the meta-synthesis, the lead author read the data transcripts, with the research questions guiding the focus; she extracted relevant data, using established and new coding categories, and conducted the thematic analysis. She achieved methodological rigor by meeting Whittemore's quality criteria for qualitative research reviews (2005). To ensure accuracy of interpretation (i.e., trustworthiness), the original investigators of the three studies reviewed and affirmed the coding and thematic interpretations. Findings were developed with consideration of the research literature (i.e., transferability), and input from the original investigators. The researchers shared results with members of the Alzheimer's disease community to determine if the audience recognized itself in the findings (i.e., confirmability). They gave professional presentations to see if the results mattered to clinical participants, as suggested by Miller and Crabtree (2000) for research with clinical implications, and they developed related study recommendations.

Results

Table 1 summarizes the 22 caregivers' characteristics by ethnocultural group. Half of the informants were Latino ($n = 11$; 50%), followed by African American ($n = 7$; 32%) and Chinese ($n = 4$; 18%). Caregivers were, on average, middle aged with a mean age of 53 years; the African Americans were slightly older (60 years) and the Chinese younger (48 years). The majority of caregivers across all three groups were female, married, well educated, and caring for their parents or spouses. Latinos differed from respondents in the other two groups in reporting lower education and income. The African Americans were more often born in the United States, whereas the Chinese and Latinos were typically not but had lived in the United States for more than a decade. Two Latinos, however, reported being in the United States for less than 2 years and they were not bilingual. The Latino participants demonstrated the most within-group diversity and required greater sampling to reach data saturation. The following section reports the thematic categories that emerged along with the exemplars, that is, quotes from the participants' voices that best represent the theme. We have edited some quotes for clarity, as noted by brackets, or brevity, as noted by ellipses.

Attribution to Normal Aging: It's Just Old Age

Across the three groups, there were striking similarities in the reported lack of knowledge about early signs of Alzheimer's disease. Initial impressions of an elderly relative's loss of memory were attributed by every informant as normal aging and thus not deemed important to address. Each group had a unique way of expressing this attribution. Among African Americans, it was *old timer's disease*, whereas Latinos used the phrase *el loco* for craziness and the Chinese used *hu tu* for becoming forgetful in old age. The Chinese also attributed personality changes to the environment where bad *feng sui* created negative energies and effects that were detrimental to elders. One African American said this: "When I visited her [mother] she didn't remember

things. . . . I just thought it was her age she is now 90. . . . I would say to her, you know I don't remember either." A Latino said the following:

I think my dad is having such a hard time telling [his wife has Alzheimer's disease] because I think that deep down inside he does not understand it's an illness. He just thinks oh my wife went nuts. It's not crazy. It has a name. It's called Alzheimer's. . . . If I tell an American, like they see her and she starts babbling and just babbling and you don't know what the hell she's talking about, it's real easy for me to tell oh, she has Alzheimer's and I know you're going to be, oh, but when it's a Spanish person, I feel like they're already thinking my mother's crazy and my mother's not crazy. She's sick. So I have to tell them Alzheimer's. They're looking at me like I got three heads.

Another Latino said this: "I thought it was the old age, you know, that's what we call it in my country. But it was more, more than that. So say well oh, well, you never remember nothing." Yet another said, "She never had a good memory for the start." A Chinese individual stated that "It never occurred to me that my mom had AD even though I knew something was wrong. . . . People in Chinatown told me that my mom was getting old and became Lao Hu Tu [stupid/forgetful in old age]." Another said that "Friends suggested us to relocate our house . . . they thought mom's craziness was caused by bad feng sui."

Normalization of Symptoms: All Old People Forget Things

Similarities continued in the manner in which all three groups initially normalized their response to the early symptoms of memory impairment but differed in the ways this was accomplished. Among African Americans, there was a strong respect for elders that supported tolerance of behavioral deviations, and there was strong extended family support to help elderly family members:

[She told us] the children have taken my shoes. . . . Well we all lose our shoes. So we're thinking well this is probably normal. . . . Then wandering, she would leave the house but because it was such a close knit community and everybody knew her, the lady down the street would just bring her back home, you know, or they would take her to the shop and if she didn't have the money on her, somebody would buy the loaf of bread for her and just bring her back home. Even the taxi drivers, the bus drivers, everybody just knew everybody and they would just bring her back home.

However, one African American said this: [Besides my mother] I have an aunt who has Alzheimer's . . . she has nine children, my cousins who denied the fact that their mother had it.

Latino family members tried not to upset the elder until safety concerns arose:

She would forget when she cooked, she put the wrong stuff in the food, we used oil in our rice, she put that [Joy dishwashing liquid] in there and that's when my father said she can't do this anymore or she'll kill us.

When we went to the doctor, and they told me that ma was maybe Alzheimer's. Like I say, a year and a half ago they told me, I don't believe it. I refuse to believe. So she left home three times. She take off three times. One was really bad, 3:00 in the morning. So two police cars and three friends of mine, we was looking for her. That day, I just bought the alarms. I have an alarm in the kitchen and in here. Plus locks you can see in the door. And she kicked the doors when she wants to go out. She want to go to Argentina.

Chinese individuals reported that mental health problems were purposely hidden to avoid community awareness and social stigmatization. One Chinese person or participant said this:

“My family thought that my mom got old and forgot things; my dad thought she was crazy and it was too shameful to talk about.” Another said that “people talked about AD as if it happened to your family because your family did something wrong. They make you feel too ashamed to tell other people that your loved one has AD.”

Awareness Precipitated by Crisis: We Took a Trip

All respondents could name the event that triggered family awareness that an elder had more than normal aging changes. Examples given were the elder’s getting lost, wandering off, not recognizing family members, or having a car accident when a familiar route was forgotten. Universally precipitating these events was relocation by traveling either locally to visit relatives or at a distance such as back to the country of origin. In each situation, respondents experienced unexpected difficulties. One African American said the following:

We took a trip to Philadelphia and when we got to the hotel he kept saying there were things happening . . . he started accusing me of doing something to him; I thought maybe he had gotten a hold of some alcohol. The next day we went to hear Jesse Jackson speak and on the way out my husband was talking to some men. He told them someone stole his car. I didn’t know whether to laugh, cry or what. That was the beginning.

A Latino respondent said this:

Well, we didn’t have any exact idea of what it was. But this disease they discovered it when she went on vacation to Colombia. And in Colombia she got lost in the house where she was staying and my sister took her to the doctor and then they discovered that it was this disease.

A Chinese participant said that, after going grocery shopping, her family member “was unable to find her way home. . . . [Her personality changed and she frequently] got angry. . . . [She would get distracted, forget she was cooking, and] . . . burned pots.”

Sources of Support and Advice: Family First

Universally, after the event that created the awareness, respondents across the three groups initially turned to family members to gain advice about what to do next. Family members in turn were influenced by word-of-mouth offerings from fellow community members. African Americans turned to their ministers, Latinos turned to their friends, and Chinese sought information privately at regional health centers. As one African American said, “among us Blacks, we tend to talk to our religious leaders about problems in our family. . . . Whites tend to talk to doctors whereas we go the other way . . . to the ministers.” One Latino respondent said the following:

We have this lady that’s a friend of ours that she comes and she helps us, but she leaves. At night, my friend, she comes here on vacation and she stays and then she doesn’t stay here the weekend. She goes to her family house and then my brother have to come . . . even . . . the priests, they don’t understand.

In contrast, a Chinese respondent said this: “I did not turn to friends in the Chinese community for support because they did not understand Alzheimer’s.” Another said this:

“Some people in Chinatown were scared when they found out that my mom had AD. They would walk away from us. There were afraid that they would get AD as well if they got close to us. It was just so hard.”

Cultural Factors and Acculturation: The Culture Is Changing

The three groups expressed different cultural factors that influenced their response to and actions as family caregivers of individuals with Alzheimer's disease. African American caregivers noted concerns about racism, which contributed to the reluctance of some elders to seek medical care. As one African American stated, "[Among some physicians, even today] there is an unconscious racism." Chinese respondents noted that the stigmatization associated with mental illness in their culture extended to Alzheimer's disease. Within the Latino community, *la familia* supports a family obligation to care for its members: "For us in the culture [Columbian] this means you have some obligation to take care of your mother until they die." There is also a strong cultural aversion to nursing home or institutional care:

The joke in Spanish is oh, you're going into a nursing home. That's just the American way. The White way. And we don't do that. We keep our parents at home until they pass and we already know what they want and they're going to be buried back home in the homeland.

However, acculturation issues arose as Latino participants worried that their children might forget their cultural traditions of caregiving and adopt what they believed to be the American way of institutionalizing elders:

The younger people, all right, are more in favor of at a certain point, put her in a nursing home, go and see her but let me have my life. Because they born here. They grown up here. They see what's going on in the American culture. Sometimes they don't even want to speak Spanish anymore because they feel like they are different and you know, the food too. Before the children used to [bring] rice and beans to school and the other children would laugh at them because everybody came with a sandwich. So they started changing to a sandwich instead of the rice and beans. So you know, it's changing. The culture is changing completely. I always tell my daughter, you put me in a nursing home God forbid, I can't handle [it]. I don't want to live with that. You put me in a nursing home and you go and see me every day.

The Chinese caregivers reported a cultural expectation that the firstborn son and his wife are the primary caregivers for aging parents, regardless of infirmity. However, as already mentioned, mental illness carries a strong stigma within their community and does not readily generate support. As one Chinese caregiver said, "As soon as my brother heard [that it was Alzheimer's disease] he and his wife walked away scared . . . [that it was] contagious. I had to move in to stay with my mom." Another stated that "my friends did not contact me after they found out."

Clinical Encounters: Disrespect and Disappointment

Respondents mentioned how difficult it was to bring their family members to the doctor and report their memory-loss concerns. Much energy and effort was expended in getting the elder there, usually amid protests, only to be disappointed at the encounter. Some physicians dismissed reported symptoms as simply old age; others believed the elders who denied problems, and they reported that these individuals were just fine. To African Americans, this amounted to disrespect for their concerns:

I put her in two different facilities and she was seen and told she was okay at the first one and just label her clothes and she'll be okay to travel, nothing wrong with her. Her memory is no worse than anybody else at 88. [The doctor said to me] What difference do you think it will make if we put a label on it?

I'm tired of you people [White doctors and nurses] always referring to the Black males as people who drink alcohol and then using that as an excuse for saying well this is

the reason for whatever is happening when in fact it's something else. My feelings are that the medical people don't take us serious.

Some of them will not tell you. They'll go about it in a way that hurts you. They don't realize maybe that they're hurting you by just giving you the cold shoulder or telling you that you'll do better over at XXX because it is closer to you . . . well it's not an Alzheimer's [evaluation center]. But I am pleased to say that there is a group of geriatric doctors who are Alzheimer's friendly and I do have their number.

Latinos differed in that, once they realized the memory loss might be a disease, they readily sought medical assistance from within their community where Spanish-speaking providers worked. However, problems remained with the local primary care physicians' not being able to recognize dementia. As one Latino said, "She [the doctor] was not that well trained to imagine that it was Alzheimer's and because in that time there were so many AIDS cases [the doctor misdiagnosed the father as having AIDS]." Another said this:

The doctor always said "No, that isn't anything." That my mother's had bad headaches, that she always dreamed that she was lost, she had nightmares, her mind, she couldn't keep it from thinking and thinking and she couldn't control it. We kept telling this to the doctor and the doctor said "No, that isn't anything." It was a Hispanic doctor.

Latino families also took it on themselves to gain information and education about Alzheimer's disease. As one Latino said, "There's no excuse that the people say 'I don't know how to do it' [find out if it's Alzheimer's disease] because [they have] wonderful books in Spanish and in English." As another said,

I very much respect medicine and I admire the doctors. But I must insist that when a patient says to a doctor "I feel like I am forgetting this thing," some small symptom, that the doctor should pay attention from the first time the patient says it.

Chinese caregivers differed in that they went outside of their community to avoid public disclosure within it, but then faced Western professional objectivity that conflicted with a core Chinese value of *guanxi* (i.e., developing personal and trusting relationships). Chinese families expected their healers to take time and make an effort to cultivate *guanxi* and talk with them. As one Chinese individual said, "You can't just tell the diagnosis and walk away." Another stated that "The doctor told me the diagnosis. He never told me what the next step would be. It was very hard. It is like that you are a mouse in a maze; you can't go this way, that way, and you are trapped."

Chinese caregivers also wanted information to be shared at the community level to reduce isolation and increase support: "We need education about AD in the Chinese community so that people can help one another, not walk away."

Discussion

This study adds to the literature that compares racially and ethnically diverse family caregivers of elders with Alzheimer's disease. Findings suggest striking cross-cultural similarities in the characterization of initial memory changes as normal aging. As dementia symptoms progressed, however, cultural differences emerged. Normalization appeared to be most prolonged among African Americans, stigmatization greatest among the Chinese, and acculturation of most concern among Latinos.

Issues of access to Alzheimer's diagnostic evaluation services and provider responsiveness to caregivers' concerns tended to be problematic across the groups. The fact that the local and ethnically similar Latino physicians failed to discern cognitive impairment highlights the need

for more minority clinician education about the differences between normal aging and early signs of dementia. Among these informants, physician expertise in Alzheimer's disease was valued over ethnic similarity, which challenges a prevailing assumption that matching ethnicity will improve doctor-patient communication and treatment (Cooper-Patrick, 1999). The need for physicians to improve communication with caregivers of elders with Alzheimer's disease was voiced by all three groups. Clinicians need to demonstrate more skill in balancing family caregivers' concerns about memory loss and patients' denial of it. The initial office visit is a critical juncture for many caregivers who have struggled to convince an elder to see a clinician and admit to memory-loss symptoms. Diagnosis as old age was seen as devaluing caregivers' concerns. When Alzheimer's disease is diagnosed, the practice of the predominantly White physician culture to directly inform a patient of a catastrophic diagnosis may exacerbate communication issues. This direct approach markedly differs from the protection-of-the-patient approach exhibited by the minority families in this study. Xu (2004) noted that the Western values of patient autonomy and illness disclosure derive from American values of individualism that are especially incongruent with the Asian value of collectivism.

The fear of public disclosure that arose among all the Chinese caregivers was mentioned by two of the Latino informants. The initial belief that calls to the Alzheimer's Association or that Web site contacts would be tracked arose as a barrier to usage. Consequently, the Alzheimer's Association and local affiliates should indicate on their call-in lines and post on the first page of their Web sites that tracking does not occur, and the association should explain their measures to ensure confidentiality. New ways are needed to conduct outreach to ethnic groups and family caregivers in more private ways. Evidence supports the effectiveness of using interactive CD-ROM programming to increase families' knowledge about the differences between normal forgetfulness and Alzheimer's disease in their relatives (Mahoney, Tarlow, Jones & Sandaire, 2002). Culturally specific CD or DVD consumer-education programs located in libraries and for purchase through commercial stores may be one way to increase public access and education for those with privacy concerns.

Study-related practice recommendations and resources are summarized in Table 2. We have developed Points 1 to 3 on the basis of feedback to study presentations by clinicians who report feeling overwhelmed by the task of becoming culturally informed given the demands on their time. A limited number of key Web resources are provided that offer clinically relevant and concise information for clinicians as a practical starting point. Clinical incentives, such as covered time to view the materials, peer discussions about the content, and bonuses for incorporating the culturally relevant materials in patient care are suggested as motivators. Efforts to improve clinician-patient-family communication should be linked to related quality and clinician-performance indicators to support behavioral change. The informants' desires for respect, improved communication, better diagnostic expertise for memory loss, and referral to specialists have been previously reported as needs by White caregivers (Beisecker, Chrisman, & Wright, 1997;Boise et al., 1999;Connell, Boise, Stuckey, Holmes, & Hudson, 2004;Mahoney, 1998;Morgan & Ping, 1993;Wackerbarth et al., 2002). Thus, improvements in physician communication will benefit all caregivers regardless of ethnicity, but especially racial or ethnic minorities. We have targeted Points 3 to 6 to minority and Alzheimer's community-based educators and their Web sponsors to address the confidentiality and stigma concerns raised by the informants.

The study findings have to be considered in view of certain limitations. Concepts of culture and ethnicity are not generalizable even within a population. Race is becoming an obsolete scientific category as genetic diversity increases within a multicultural society. Whether there are regional differences superimposed upon cultural differences has yet to be researched, and further analyses are needed to determine that as well as the effects of acculturation, citizenship, generational differences, cohort age, education, and socioeconomic factors. Nevertheless,

findings from this study support a call for improvement in disseminating information about Alzheimer's disease in ways that match cultural preferences, motivate clinical providers to offer more culturally sensitive and competent care, and provide performance incentives to accomplish these recommendations.

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Table 1
 Characteristics by Ethno-Cultural Group ($N = 22$)

Characteristics	African American ($n = 7$)	Chinese ($n = 4$)	Latino ($n = 11$)
Age in years			
Range (28–78)	52–71	36–62	28–78
M (53)	60	48	52
Gender			
Female	5	3	9
Male	2	1	2
Marital status			
Married	3	3	8
Not married	4	1	3
Education			
College	4	4	4
High school	2		4
< High school	1		3
Income			
< \$15,000			4
\$15,000–\$29,000	2		3
≥ \$30,000	5	4	
Years in the US			
< 10			2
> 10	7	4	9
Relationship to care recipient			
Parental	4	3	6
Spousal	1		4
Other	2	1	1
Alzheimer's stage*			
Early	2		
Middle	2	1	2
Later	1	2	6
Deceased	2	1	3
Country of birth			
United States	6	1	
China		3	
Jamaica	1		
Dominican			1
Cuba			1
Columbia			2
Guatemala			1
Argentina			3
Puerto Rico			3

* Per caregiver report.

Table 2**Study-Related Recommendations and Resources**

1	Encourage clinicians' cross-cultural sensitivity and communication training. <ol style="list-style-type: none"> i. Administration on Aging's Web site for the <i>Cultural competency guide for providers and the community</i> at http://www.aoa.gov/prof/adddiv/addiv.asp ii. Community Partnerships for Older Adults Web site for resources at http://www.partnershipsforolderadults.org/resources. iii. Hablamos Juntos Project (2005) for resources for use with Latino patients at http://www.hablamosjuntos.org
2	Alert families about travel and relocation as potential precipitants of a crisis.
3	Customize memory-loss information in primary care and community settings. <ol style="list-style-type: none"> i. Chinese, Korean, and Spanish versions are available from the Administration on Aging at http://www.aoa.gov/alz/index.asp ii. Alzheimer's Disease Education and Referral Center (ADEAR) http://www.alzheimers.org iii. Alzheimer's Association's Partnering with your doctor in English and Spanish at http://www.alz.org
4	Offer community education reinforcing Alzheimer's disease as a recognized disease with social acceptability.
5	Address consumers' tracking concerns about using Alzheimer's disease Web sites; post web privacy policies on initial page and assure confidentiality and no tracking.
6	Develop consumer-education sources tailored to viewers' interests and linguistics without perceived need for public disclosure (i.e., DVDs or privacy ensured or anonymously accessed web-based programs).
