Alzheimer's caregiving: perspectives from chinese family caregivers

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Abstract Objective: This study explored caregiving experiences for persons with Alzheimer's disease in Chinese American family caregivers. Methods: Individual interviews were conducted among 4 family caregivers. Results: Revealed ethnocultural and structural barriers that Chinese family caregivers experienced, including stigmatization of dementia/AD in the Chinese community, a lack of knowledge about dementia and AD, a lack of culturally and linguistically appropriate dementia care services, negative interactions with healthcare providers, and difficulty with English. Conclusion: This study provided cultural knowledge and insights to dementia care providers. The study calls for overcoming barriers and working with the Chinese American family to improve access and dementia services for Chinese American patients and their families.

Key words Alzheimer's disease Chinese American family caregivers Ethnocultural perspectives

Approximately 4 million Americans have Alzheimer's disease (AD) or associated disorders. The prevalence of AD doubles every 5 years beyond ages of 65 (National Institute on Aging, 1999). Unless prevention or a cure is found, the number of Americans with AD could reach to 13 million 50 years from now. The majority of people with AD receive care at home from family and friends, totaling 3 million caregivers in the nation (National Academy on An Aging Society, 2000).

Effective interventions require understanding and meeting the needs of family caregivers. Family caregivers not only are most aware of the impact of the disease and experience the most emotional pain, but also are primary source of care for AD patients and a critical partner of the healthcare system in the efforts to provide quality care to this population (Drebing, 1999). Attention therefore needs to focus on identifying and describing the needs of family caregivers, on understanding their caregiving experience within the context of their frame of reference, and on designing intervention strategies and services to meet caregiving needs. Yet, a paucity of research data exists on the experience and effects of Chinese American family caregiving, their approach to caregiving, and the barriers and/or facilitators associated with their access to AD specific information and services (Elliot, Di Minno, Lam, et al. 1996; Yeo & Gallagher-Thompson, 1996). Increasing numbers of Chinese American families caring for persons with AD, the need to understand the impact of race, culture, and social economic dimension in caregiving, and the call for developing ethnoculturally appropriate AD interventions, all necessitate studies of caregiving experiences within the context of ethnocultural groups' frame of reference.

Method

1. Design: A qualitative approach using in-depth interviews was chosen for this study, considering an exploratory nature of the study.
2. Sample: A purposive sampling was used to include 4 Chinese American family caregivers for persons with AD in the Greater Boston area. Criteria for study participation included being identified as a Chinese or a Chinese American, a family caregiver for a person with AD, and cognitively intact. The majority of the participants were women, immigrants, middle-aged, college graduates, and had good economic means. Caregivers described their relationship with care recipients as niece, daughter, or son. All care recipients were elderly Chinese women, widowed, immigrants, lived in the US for more than 10 years, and received care from both family and non-family caregivers.
3. Sample Recruitment: The study received the approval from the Institutional Review Board of Boston's Hebrew Rehabilitation Center for Aged. The researcher contacted homecare agencies in Boston's Chinatown and presented the nature of this study including the purpose, sample criteria, and procedure. Written information on protection of human subjects and potential benefits and risks of the study were presented to each agency. The study flyer (in both English and Chinese languages) was posted in the agency's weekly newsletter, in several Chinese elderly

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housing sites in Chinatown, and directly distributed to Chinese American family caregivers who came to the agency. Most family caregivers refused to participate, indicating that "talking about AD can bring bad luck to the family." After several months of recruiting, 4 Chinese family caregivers participated and each was offered $15 stipend.

4. Data Collection: Semi-structured, open-ended questions were used for individual interviews. The interview guide was developed based on literature review and extensively discussed and content-validated by seasoned caregiving researchers. Priori to interviews, respondents were infomed about major topics for interview, including their initial awareness of AD; access to, barriers to, and opinions about AD/dementia care services; views and perceptions on AD; and personal reflections on caregiving experiences. Questions were open-ended to elicit unanticipated responses and to avoid imposing a priori frame of reference. Interviews lasted from 1/2 hours to about 3 hours long, and took place at a time and place convenient for each participant. All interviews were tape-recorded except one in which the participant was not willing to be tape-recorded but agreed to validate interview notes. Interviews were conducted after obtaining the informed consent. Demographic data were collected after each interview.

5. Data Analysis: The interview data were transcribed by a transcriptionist and entered into the WIN-Max Computer-Aided Qualitative Data Analysis Program for initial coding. Interview notes were validated by the participants and vague points from the transcribed data were clarified by follow-up telephone calls to participants. Interview data were analyzed to compare and examine themes and variations, according to the Ground Theory Methods as developed by Glaser and Strauss (1967). Content analysis of the interview transcripts included first coding data according to the broad categories elicited by the interview questions. Specific sub-codes were then assigned to data grouped under these broad categories. Selective coding then was employed to name and identify subcategories. Lists of coded information were developed and themes emerged. The caregiving research team was in agreement that these categories reflected the intent of participants' responses.

Findings

The data elicited during the interviews included family caregivers' initial awareness of signs and behaviors of AD, their descriptions of cultural views on AD, their perceived barriers and facilitators of obtaining diagnosis and AD services, their reflections on their caregiving experiences, and any identifiable themes emerged from the interviews.

1. Initial Awareness: Family caregivers noticed early signs and behavioral changes manifested by their loved ones such as "she repeated herself a lot;" "she was unable to find her familiar way;" "she burned some of her pots;" "she had mood changes and got angry for small things;" and "she mixed up with the time of the day." However, their initial awareness did not lead them to seek AD diagnostic evaluation until they were told by their family physicians. One caregiver described, "I did not know she had AD. We only knew when the doctor told us that my mom needed help." Only one caregiver said that because her uncle suffered from AD, she referred her aunt (the care recipient) to an AD specialist for diagnosis as soon as she noticed her behavioral changes.

2. Cultural Views: Analyzing the interview data revealed different views/perceptions of AD between family caregivers and caregivers' parents and family friends in the Chinese American community. Participants in this study defined AD as a brain dysfunction whereas their parents and family friends in the Chinese community stigmatized AD/dementia.

- "Some in the Chinese community attributed AD to a fate of a person;" (*fate*)
- "Some talked about this disease as if it happened to your family because you did something wrong and they made the family felt so ashamed to tell others that their loved one had AD;" (*wrong doing*)
- "People in Chinatown told me that my mom was getting old and became *Lao Hu Tu*;" (*Old age*)
- "They said that my mom worried too much about me and my family. Because of that, she got AD;" (*worry too much*)
- " Some said that a powerful force had taken my mother. She became crazy;" (*craziness*)
- "Some people in Chinatown when they found out

that my mother had AD they walked away from us because they were afraid that they would get AD as well. They thought that AD could be transmitted from one person to another." (*contagious*)

- "My dad's friends in Chinatown advised us to relocate because they thought my mom's AD was caused by a bad *Feng Shui*." (*Feng Shui*)

Data across 4 caregivers indicated strong stigma attach to AD in the Chinese families and the community. These strong negative responses to AD and associate disorders have brought shames to the family and isolated persons suffering from the illness from their ethnic community. This can be extremely difficult for older Chinese Americans since the Chinese speaking community remains the primary cultural and social environment for them (Lee, 1982).

Barriers

Family caregivers identified several barriers that impeded their access to AD services and their gaining support from the Chinese community. These barriers include: 1. not knowing about AD at the early stage of the disease, 2. stigmatization of AD, 3. a lack of family and community support, 4. negative interactions with healthcare and service providers, 5. a lack of culturally specific AD/dementia services, and 6. language difficulties.

1. Not knowing: 3 family caregivers reported that even though they noticed their loved ones with behavioral changes, they did not link these to AD. Sample comments were, "I did not know why my mom could not find the place where we usually met for lunch;" "I did not know anything about AD until I was told by the doctor. My first question was 'what is AD?'" and "It never occurred to me that my mom had AD even though I knew something wrong with her." Prior to AD diagnosis, Chinese family caregivers in this study were outside the AD resource information dissemination loop. The lack of basic information and knowledge about AD and associated disorders may contribute to Chinese caregivers delayed responses to referring their loved ones to early diagnosis and intervention.

2. Stigma: Strong stigma attached to AD created barriers for Chinese families seeking early diagnosis. Caregivers reported, "My dad must have noticed my mom's behavioral changes for years. He thought that she was crazy and it was too shameful to talk about it. He never even mentioned about it until my mom's illness was quite advanced;" "my family thought that my mom got old and forgot things; I wish that we could refer her earlier for diagnosis and treatment;" "some of my dad's friends suggested us to relocate our house and they thought my mom's 'craziness' was caused by bad Feng Shui;" and "they (people in Chinatown) made you feel so ashamed that you're afraid of telling others about your loved one's illness. It is just so hard."

3. Lack of family support: Contrary to assumptions made about extensive social networks of Chinese Americans (Heok & Li, 1997), family caregivers in this study reported a lack of support from their family members and friends in the Chinese community. Descriptions from caregivers were, "as soon as my brother heard about my mom's diagnosis, he walked away from the situation;" "my friends in the Chinese community did not contact me after they heard about my mom's illness; " "I did not turn to my Chinese friends for support because they did not understand AD;" "Sometimes my relatives blamed me for arranging outsiders (home health aids) to my parents' house."

4. Negative interaction: Negative interactions with healthcare providers were noted. One caregiver said, "I knew it was a bad diagnosis, but I was not sure what it all meant. I was very upset that they (health providers) did not provide more support and information. You can't just tell the diagnosis and walk away. By thinking about now it still upsets me." Another caregiver described, "He (healthcare provider) never told me what the next step would be. It is like that you are a mouse in the maze. You can't go this way or that way. You are trapped."

5. Being rejected: Caregivers voiced their concerns about a lack of linguistically appropriate and culturally sensitive AD services in the area. One caregiver noted, "my mom's doctor told me that if I did not speak English, she would not refer us to a leading institute for AD diagnosis and treatment." Another caregiver reported, "I was looking for a long-term care facility for my mom. Staff at the facility told me that they would not take my mom because she did not speak English." In both cases, the Chinese family may have

lost access of AD care to English as a second language or found themselves being rejected or relegated to a lower level of AD services.

6. Language difficulty: Equally concerned was how language difficulties in Chinese elders created barriers for their gaining access to relevant AD information, getting diagnosis and treatment, and obtaining services. All elderly care recipients in this study were immigrants and three of them had difficulty with English. Caregivers described, "My dad did not refer my mom to AD service because they did not speak English at all;" "my mom knew something wrong but she was afraid to see a doctor since she did not speak English;" and "my dad had to totally rely on me to find services for my mom's care since he does not speak English at all." Because of linguistic isolation, older Chinese Americans may not know about AD and its services. Unfortunately, most of the AD information is disseminated in English. One caregiver articulated, "It is very hard in this country for the Chinese elders because they cannot speak English; they face a completely different culture; and they are lonely and isolated."

Facilitators

Family caregivers identified 4 factors that helped them understand AD, gain access to pertinent information, finance homecare service, and cope with daily caregiving stress. These facilitators included the Medicaid program, Chinese Homecare Agencies, the Alzheimer's Association, and the value of caring for the elders. Three caregivers reported that the Medicaid program - the principal health care insurance provided for the poor - assisted them to pay for some AD and homecare services. The local Alzheimer's Association, according to family caregivers, provided them useful educational materials such as information on AD diagnosis and treatment, AD service resources, homecare management, and AD care planning strategies. They also expressed that caregiver support group sessions helped them cope with stress.

Across data, family caregivers expressed the value of caring for the elders. They felt psychologically rewarded by caring for the loved one, and they felt that this value helped them cope with stressful situations. Caregivers mentioned, "I just think about my mom's quality of life. I would do everything I could to maintain her life quality, that makes me feel good;" " I got to take care of my mom, no matter what;" "even though I sacrificed my own personal life, I had no regret for caring for my mom." In this study, all participants reported having positive relationships with their care recipients, which may play a role in mediating burden (Zarit, Reever, & Bach-Peterson, 1980), accepting their caregiving role, and motivating them to advocate, seek information, and figure out ways to maximize care for their loved ones.

Discussion

This study revealed strong and quite intense stigmatization of AD in the Chinese families and the community. AD was conceptualized as a mental illness; as one's "fate" "wrong doing" "worried too much;" and/or as "craziness" "normal aging" or "*Lao Hu Tu*." Although these stigmatic views were comparable to previous study reports (Elliot et al., 1996; Guo, 1999; Lee, 1982); strikingly, in this study AD was perceived as a result of "bad Feng Shui" and as a "contagious disease" by some in the Chinese community.

1. Reducing barriers: Cultural norms may influence the extent to which support is available to family caregivers (Aranda & Knight, 1997; Dilworth-Anderson & Burton, 1999). In this study, because of strong stigma attached to AD, when family caregivers needed help and support most, some of their friends and relatives walked away; some attributed AD to family sins; and some stopped contacting caregivers. Lack of social and family support may have added psychological stress to family caregivers. Moreover, stigmatization served as barriers for Chinese families to seek timely AD diagnosis and interventions. Evidently, three AD patients in this study were not referred to early diagnosis and treatment until the disease was advanced. Stigmatization may have also contributed to the difficulties in recruiting sample in this study.

Social status, language, literacy, and structural conditions are cofactors that influence health-seeking and health-receiving patterns and behaviors. Previous studies have cited the linguistic barrier and functional illiteracy as a major problem in obtaining healthcare services (Chen & Hawks, 1995; Lin-Fu, 1994; Zhan, 1999). Linguistic isolation and functional illiteracy may intensify stigmatization of AD. Many older Chinese immigrants have difficulties with English and some of them are functionally illiterate, and all of which can compromise their learning and hinder their access to relevant AD information, diagnosis, and treatment services. Therefore, AD service and clinical intervention need to be tailored with dimensions of these perspectives in mind.

The study findings corroborated anecdotal reports about Chinese American family caregivers experiences. All respondents reported similar perceptions and opinions about access to, barriers to, and experiences of care giving for persons with AD. The localized of this study limits generalizing the findings to other Chinese American family caregivers. Nonetheless, the findings about stigmatization and barriers to AD care are comparable to findings from other Chinese populations (Elliot et al., 1996; Lin-Fu, 1994; Guo, 1999; Yeo, 1996; Zhan, 1998; 1999).

The inequitable distribution of diagnostic AD care resources in the healthcare system is a critical factor that affects service linkage and usage for ethnic group members (Valle, 1998). It is unacceptable to relegate or reject AD services to Chinese families simply because their difficulty with English. Because of the lack of ethnoculturally sensitive, linguistically appropriate, and bicultural and bilingual personnel in AD specific clinics and services, Chinese patients and their families may have had limited access to AD services, contrast to patients and caregivers from the mainstream English-speaking culture who may have access to highly trained professionals not only speaking their language but also being generally in tune with their cultural beliefs and customs (Valle, 1998). All of these factors stem from social status and structural conditions. Nurses therefore need to examine all facets of an ethnic group to formulate a complete picture of the family's response to AD and associated disorders, and to integrate such assessment and understandings in AD education, service, and interventions.

2. Education: To reduce stigmatization of AD, it is critical to educate the Chinese community and families about the disease, diagnosis, available services, and treatment options. Successful education about AD in the Chinese community requires nurses to learn about Chinese cultures since knowledge of a particular ethnocultural group is one of the most salient features of ethnoculturally competent practice (Gallagher-Thompson, 2000; Valle, 1998). Nurses need to assess cultural norms and beliefs of AD in the Chinese family since these norms determine one's patterns of interaction with the health and social services system, his/her healthcare decision-making, the extent to which social support is available to caregivers, and may also have implications for the psychosocial experience of family caregivers and the clients (Yeo, 1996). Nurses need to integrate some cultural beliefs in practice. *Feng Shui*, for example, the traditional belief embraced by some Chinese families needs to be recognized and assessed so that the placement of care recipient in the facility such as the room location or furniture arrangement can be planned in concert with such belief. Nurses may use the book "*Using Feng Shui*" (Beattie, 2001) as their reference since it details easy ways to use the ancient Chinese art of placement for happiness and prosperity.

Successful education requires healthcare providers to learn how to work with the Chinese families and the community. *Guanxi* - the Chinese word describing personal relationship - symbolizes one of the core values in Chinese culture. *Guanxi* emphasizes personal relationships of trust and reciprocity. Chinese families may expect health providers of taking time and making efforts to cultivate *guanxi*, which may be contrast to the impersonal style of professional practice in mainstream western practice. Nonetheless, carefully and deliberately cultivating *guanxi* by offering both diagnostic and treatment information and emotional support may serve nurses well for building rapport with Chinese families. It is important to recognize that reduction of stigmatization of AD in the Chinese community through education requires time, cultural knowledge and understandings, and continued interactions with members of Chinese community.

Conclusion

AD continues to devastate the lives of those with the disease and those who care for persons with the disease. Stigmatization of AD in the Chinese community impacts on how AD is perceived and conceptualized, how caregiving for persons with AD is supported, and how AD diagnosis and services are sought. To reduce stigma attached to AD in the Chinese community, healthcare providers, families, and the community need to work together toward better understandings of AD and cultural contexts of AD. Equally important is to work together toward a healthcare system that is culturally and linguistically accessible, appropriate, and adaptable to Chinese AD patients and their families.

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Analysis of post-traumatic stress disorder experienced by nurses due to 921 earthquake

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Abstract Objective: To analyze the related factors of PTSD (Post Traumatic Stress Disorder) experienced by nurses who had participated life-saving in the earthquake on September 21, 1999. 450 nurses were surveyed and they were all employed by the hospitals near the earthquake epicenter in Nantou Hsien, Taiwan. As a result of the earthquake, five most frequently experienced PTSD symptoms are identified. They are fear of reoccurrence of disaster, fear of reoccurrence of earthquake, anxiety, change of thinking pattern, and insomnia. The symptoms of PTSD are not associated with population characteristics. They are associated with the loss suffered by each individual in the earthquake, individuals receiving the "victim identification card", individuals whose family members were victims; individuals with chronic illness, individuals working in different hospitals, individuals experiencing tremendous work-related stress, stress of work, attitude toward work, pessimistic personality and avoidant personality disorder.

Key words PTSD (Post Traumatic Stress Disorder) Earthquake Nurses

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美國華人家庭對阿爾茨海默病病人照顧的探討

詹 林

摘要 目的：探討美國華人家庭對阿爾茨海默病病人照顧的經歷。方法：對4個家庭照顧者分別進行面談。結果：顯示美國華人家庭照顧者存在種族文化以及制度上的障礙，包括華人社區對痴呆的標籤、知識缺乏、缺乏合乎文化及語言的痴呆照護服務、與醫護人員的負面接觸、語言障礙。總結：為痴呆疾患的健康服務者提供文化上的認知及啟示，讓美國的健康服務人員解決與華人家庭共同合作之障礙，並改善華人痴呆患者及家庭對服務的可行途徑。

關鍵詞 阿爾茨海默病 / 痴呆 美國華人家庭照顧者 種族文化