

Folk and Biological Perceptions of Dementia Among Asian Ethnic Minorities in Hawaii

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Objectives: *To study if Asian ethnic groups in Hawaii today maintain folk-based beliefs about dementia, have inadequate biomedical understanding of dementia, and differ among each other regarding perceptions of dementia. Design:* *The study adapts and expands a 2004 survey of ethnic groups on perceptions of Alzheimer disease demonstrating that ethnic minority groups hold more folk perceptions and less biomedical perceptions of dementia than Caucasians. This study surveys particular ethnic minority family members of elders admitted to four long-term care and inpatient facilities in Hawaii. Seventy-one family members completed surveys, including 23 Chinese, 18 Filipino, and 30 Japanese participants. Elders may or may not have had the diagnosis of dementia, though an estimated half of elders in all four facilities already held the diagnosis of dementia. Results:* *Findings indicated that Japanese and Chinese respondents in this study held perceptions about dementia that were more consistent with current biomedical understanding compared with their Filipino counterparts (mean differences/percent correct for Japanese: 57%, Chinese: 56% versus Filipino: 38%; $F = 6.39$, $df = 2,55$, $p = 0.003$). Filipino respondents were less likely than Japanese and Chinese respondents to report that persons with dementia can develop physical and mental problems—97% of Japanese participants and 82% of Chinese participants responded correctly compared with 63% of Filipino participants (Fisher's Exact test $p = 0.009$). With regard to folk beliefs about dementia, variation occurred with no consistent trend among the groups. Conclusions:* *Low levels of biomedical understanding of dementia were reflected by all three subgroups of Asians living in Hawaii with less prominence of folk beliefs compared with prior studies of ethnic minority perceptions. Education did not predict variability in dementia perceptions among the groups. Lower levels of acculturation, suggested by primary home language other than English, may correlate with a perception of dementia that is less consistent with current biomedical understanding of dementia. Persisting folk beliefs about dementia and the evident lack of biomedical understanding, particularly the belief that dementia is a normal part of aging, emphasizes the need for more culturally tailored strategies in patient education about dementia and the importance of early intervention. (Am J Geriatr Psychiatry 2014; ■:■—■)*

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Perceptions of Dementia in Hawaii

Currently in the United States, the population over age 65 is 12.9%. The U.S. Census estimates that by 2030, that population will be 20% of the total U.S. population. With more elders living longer, the numbers of elders living with cognitive decline and dementia is increasing. Growing numbers of such elderly present in crises to our emergency rooms. In many cases, the presentations are triggered by behavioral aggression that families and caregivers are no longer able to manage at home. This underscores the important role that family members and caregivers have in recognizing symptoms of dementia and seeking appropriate intervention with providers.

Earlier studies on ethnic differences in help-seeking behaviors have suggested that Asian ethnic groups, in particular, have later presentations for evaluation of dementia symptoms. Thus, some of the studies have emphasized the need to assess for barriers to care among these groups.^{1–7} Later help-seeking has been associated with perceptions of dementia that are culturally influenced but also influenced by level of education and acculturation. Some of the previous studies also suggest that western ethnicities^{1,8} have better knowledge of Alzheimer dementia and dementia as an illness that affects memory and function. The Western groups (termed Anglo) in the studies were also noted to hold some folk beliefs, though less than their minority counterparts. Overall, perceptions of the western ethnicities tended to be more biomedically based and their help-seeking behaviors began earlier than their Asian counterparts. Other studies have shown that ethnic and racial minority populations may have perceptions of dementia that are not consistent with those that are biomedically based.^{5,9,10}

Stigmatization and normalization have been recurrent themes in much of the existing literature about Asian American ethnicities' perceptions of dementia.^{4,5,7,11} Studies reviewed discuss various Asian subgroups' tendencies to view dementia as a natural part of aging. Braun, Takamura, and Mougéot found that Vietnamese interviewees expressed perceptions that both normalize dementia and regard the affected elder with great respect.¹² This kind of filial piety is common among Asian minority groups. On the other hand, there was also a widely held perception that the symptoms of dementia represent a state of confusion, moral compromise, and physical deterioration. Thus, dementia symptoms bring a

certain degree of shame to both the individual and his/her family, described as Goffman's term of "tribal stigma."¹³ One impetus for this study was to explore if such stigmas persist among the various Asian ethnic groups in Hawaii.

This study examines perceptions among Asian Americans who have a family member with or without a dementia diagnosis residing in a nursing home. We hypothesized that Asian ethnic groups in Hawaii today maintain folk-based beliefs about dementia, have perceptions about dementia that are not yet consistent with current biomedical understanding, and differ among each other regarding perceptions of dementia. The study adapted and expanded the Ayalon and Arean 2004 ethnic study,¹ which underscored the lack of biomedical knowledge of Alzheimer dementia among ethnic minorities. By better understanding the current knowledge as well as misconceptions about dementia, the hope is that health care providers and families can intervene earlier than they do presently. This optimizes the opportunity to reduce the significant morbidity, functional impairment, and psychiatric disturbance associated with dementia.

METHODS

Participants, Setting, and Design

This study evaluated knowledge of dementia among Chinese, Filipino, and Japanese family members of elders in four long-term care or inpatient facilities on the island of Oahu, Hawaii, from September 2010–March 2011. This was a convenience sample in which a family member was recruited by nursing or social work staff in the facilities when visiting their elder. Participants were asked to have a working command of the English language. Surveys were completed on-site or at home (without assistance) and returned to facility staff. Participation was voluntary and confidential. The study was exempt from the U.S. Department of Health and Human Services regulations and institutional review board review.

The dementia survey consisted of 25 true–false questions, utilizing the 17 questions from the 2004 ethnic survey¹ with the addition of 8 questions. The

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