Perceived Threat of Alzheimer’s Disease Among Chinese American Older Adults: The Role of Alzheimer’s Disease Literacy

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Objectives. Guided by a Sociocultural Health Belief Model (SHBM), this study examined the roles of cultural beliefs of Alzheimer’s disease (AD) and scientific knowledge of AD in influencing the perceived threat of AD in a sample of Chinese American older adults.

Method. With the input from focus groups of 17 older Chinese volunteers, survey questionnaires were refined and then delivered through face-to-face interviews to 385 participants aged 55–100 in the Phoenix metropolitan area.

Results. Hierarchical regression analyses found that those aged 55–64 were more worried about AD than those aged 85 or older. Both cultural beliefs of AD and AD factual knowledge contributed to higher levels of perceived threat of AD. Education tended to moderate the effect of cultural beliefs of AD and AD knowledge on perceived threat of AD.

Discussions. Findings support inclusion of key factors in the SHBM relevant to perceived threat of AD and help enrich the understanding of AD literacy from both scientific and cultural perspectives. AD education programs and interventions should help address crucial cultural beliefs related to AD and the emotional consequences (e.g., concerns or fear of AD) that might be due to the exposure to AD factual knowledge, particularly for those with limited education.

Key Words: Alzheimer’s literacy—Chinese American elders—Knowledge of Alzheimer’s disease.

Alzheimer’s disease (AD), affecting over 5 million Americans, is the fifth leading cause of death among older Americans (Alzheimer’s Association, 2013). Despite its prevalence, there are widespread misconceptions of AD among the public (Connell, Roberts, & McLaughlin, 2007). In a Metlife Foundation survey of 1000 American adults (Harris Interactive, 2011), about two thirds reported they knew nothing or very little about AD. Meanwhile, AD was rated the second most feared disease right behind cancer and of particular worry to those aged 55 or older (Harris Interactive, 2006, 2011).

Overall, ethnic minority groups tend to have less knowledge of AD (Roberts et al., 2003), and some groups like Hispanics and Chinese were found to be more worried about developing AD in the future (Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009). Research indicates that ethnic minority groups tend to interpret AD symptomatology on the basis of folk wisdom rather than on neurological sciences (Dilworth-Anderson, Williams, & Gibson, 2002). Lack of AD knowledge, biased cultural beliefs regarding AD (e.g., belief of memory loss as a normal part of aging), along with service barriers such as limited English fluency or experience of discrimination may place these groups at heightened risks for delayed diagnosis and treatment of AD (Ayala & Areal, 2004; Vickrey, Strickland, Adams, Ortiz, & Hays, 2007).

AD literacy in this article refers to as people’s knowledge and beliefs about AD, which has yet to be as well acknowledged as health literacy, defined as people’s capacity to access, understand, and act on information to promote physical health (Berkman et al., 2004). People’s understanding of AD, influenced by their biomedical knowledge and culture beliefs, has the potential to aid or inhibit AD prevention, management, and treatment (Jorm et al., 2006). Guided by a Sociocultural Health Belief Model developed by Sayegh and Knight (2013) to understand dementia in diverse cultural groups, the purpose of this study is to shed light on the relation between factual knowledge of AD, cultural beliefs of AD, and concerns of developing AD in Chinese American older adults.

The Chinese American older population is one of the fastest growing ethnic minority groups (Administration on Aging, 2009) and deserves the attention of aging service providers. The fact that about 80% of the older Chinese population are foreign born (Gallagher-Thompson et al., 2007) and one third immigrated to the United States after age 60 (Mui & Shibusawa, 2008) indicates a nonnegligible influence of Chinese culture on their perceptions of AD. Yet, culturally sensitive dementia care services including educational programs are surprisingly lacking for this group (Emerson-Lombardo, Wu, Chang, & Hohnstein, 2007). It is essential to call for concerted efforts from service professionals to promote AD knowledge, to minimize the influence of biases in the cultural beliefs toward AD, and to decrease anxiety of developing AD for this population.
AD Literacy: Factual Knowledge and Cultural Beliefs

In line with Zarcadoolas, Pleasant, and Greer's (2005) definition of health literacy, AD literacy represents people's explanations of illness from both biomedical and cultural models (Kleinman, Eisenberg, & Good, 1978). It encompasses both scientific literacy of AD, referred to as the competence and knowledge of the disease, and cultural literacy, defined as the adherence to a set of collective beliefs of AD in a particular culture.

People's scientific knowledge of AD includes their understanding of the disease's causes, consequences, symptomatology, evolution, and treatment (Hagger & Orbell, 2003). Since the first AD Knowledge Test published in 1988 (Dieckmann, Zarit, Zarit, & Gatz, 1988), several other scales have been developed to keep abreast of the latest neurosciences advances in AD research (Barrett, Haley, Harrell, & Powers, 1997; Carpenter, Balsis, Ottingam, Hanson, & Gatz, 2009). Using these knowledge scales, research has found that people's knowledge of AD helps them recognize and manage AD symptoms and seek timely treatment (Mahoney, Cloutterbuck, Neary, & Zhan, 2005; Werner, 2003).

Although somewhat intertwined with knowledge of AD, people's cultural beliefs of AD appear to be more difficult to quantify given the complexity and subtleness of various cultural influences. Studies on cultural beliefs of AD tended to rely on qualitative interviews (Jones, Chow, & Gatz, 2006). Using focus group discussions, Vickrey et al. (2007) found that AD-related stigma was more salient in African American, Chinese American, and Hispanic American dementia caregivers as they tended not to disclose AD diagnosis beyond the immediate family. African Americans tend to believe AD is a punishment from God as religion is critical to provide guidance in their daily life (Connell, Scott Roberts, McLaughlin, & Akinleye, 2009); Chinese Americans likely consider having an AD relative to be shameful due to prevalent stigmatization of mental illness in Chinese culture (Yang, 2007).

AD Literacy in the Chinese American Population

The cross-cultural variation in AD beliefs signals a need to examine AD literacy within specific ethnic groups (Dilworth-Anderson et al., 2002; Gallagher-Thompson et al., 2010). Chinese Americans are the largest Asian group in the United States. Among the estimated four million Chinese Americans, 230,000 are elders over the age of 65, and less than 20% of these elders are monolingual English speakers (Gallagher-Thompson et al., 2007; Mui & Shibusawa, 2008). In Chinese culture, there is no equivalent spoken term for the diagnostic term Alzheimer's disease (Vickrey et al., 2007). AD is often translated directly into "aging-related dementia," which contains negative connotations of "craziness" and "catatonic." Such negative images of AD have been reiterated in the caregiving literature (Sun, Ong, & Burnette, 2012).

Research evidence finds that Chinese American dementia family caregivers tend to have limited scientific knowledge about AD (Liu, Hinton, Tran, Hinton, & Barker, 2008). For example, Gray et al. (2009) found that Chinese family caregivers are likely to believe that AD can be diagnosed by a blood test. Chinese American family caregivers also hold salient beliefs of AD evidenced by experiences of AD-related stigmas in their culture (Elliott, Di Minno, Lam, & Tu, 1996). The stigma of AD among Chinese American families can be associated with an ideal concept of "family cohesion" in Confucianism (Chiu, Yu, & Lam, 2010). Practice of filial piety is essential to the maintenance of family cohesion (Cheng & Chan, 2006). On the one hand, a prominent Confucian ideal in Chinese culture emphasizes honor and love for one’s older parents. This may be manifested by addressing the health, housing, and financial needs of older parents and by respecting parental authority (Lai, 2009). On the other hand, elders in family should be able to undertake supporting roles as mentors and caretakers for the young family members. Such roles are disrupted when elders are affected by AD.

Predicting Perceived Threat of AD

As one of today's most dreaded diseases, AD worries many people worldwide (Low & Anstey, 2009; Werner, 2003). Variations of Health Belief Models (Janz & Becker, 1984; Janz, Champion, & Strecher, 2002) suggest that perceived threat of AD is a modifying factor that links AD knowledge and beliefs to possible coping adaptations that can eventually lead to health behavior change. Sayegh and Knight's (2013) Sociocultural Health Belief Model (SHBM) emphasizes the importance of AD knowledge, cultural beliefs, family-centered cultural values, and acculturation as critical factors influencing the decision to seek dementia care in ethnic minority groups. With regards to the current study, the SHBM posits that AD knowledge and cultural beliefs directly influence the perceived threat of AD.

Role of AD knowledge.—The relation between actual AD knowledge and perceived threat of AD might be counter-intuitive. In light of various health belief models (Janz et al., 2002; Sayegh & Knight, 2013), more knowledge about a specific disease would lead to more perceived threat, thereby resulting in more likelihood of a behavioral change in terms of help seeking. Despite two studies (Lee, Lee, & Diwan, 2010; Werner, 2003) that did not find a significant relation, the overall empirical evidence supports a positive relationship between AD factual knowledge and perceived threat of AD. For example, two studies (Graham, Ballard, & Sham, 1997; Proctor, Martin & Hewison, 2002) using samples of informal caregivers in England found that more knowledgeable caregivers experienced higher rates of general anxiety. Similarly, Roberts and coworkers (2003) found that African Americans perceived a lower threat of
AD in spite of the fact that they had less AD knowledge compared with their White counterparts.

**Role of cultural beliefs.**—Traditional Chinese cultural beliefs of AD, including thoughts of AD as an arrangement of fate or the stigma-related beliefs of AD as contagious, may exacerbate the perceived threat of AD. Given the fact that most Chinese American older adults were not born in the United States, they may be more likely to subscribe to cultural rather than scientific interpretations of AD (Jones et al., 2006). Such cultural interpretations include beliefs of AD as a shameful disease; the result of fate; retribution for the sins of the family or of one’s ancestors; or an imbalance between the body’s complementary forms of energy (Braun & Browne, 1998; Elliott et al., 1996; Gray et al., 2009). Yet, there is a need for additional empirical evidence, particularly quantitative data to help examine the relation between such cultural beliefs and the fear of developing AD in the Chinese American older population.

**Culture-related covariates and other factors.**—In line with the SHBM (Sayegh & Knight, 2013), the effects of culture-related variables consisting of acculturation and family-centered values need to be accounted for when examining the relation between AD literacy and perceived threat of AD. One study on Korean Americans (Lee et al., 2010) found that more acculturated Korean Americans had more AD knowledge. Family-centered cultural values, such as family connectedness and intergenerational support, fundamental values in the Chinese culture, may influence the way older Chinese interpret the meaning and consequences of dementia (Cheng & Chan, 2006; Chiu et al., 2010).

Several other background factors to be controlled in examining perceived threat of AD include sociodemographic variables such as age, education, and income (Janz et al. 2002); previous experience as an AD caregiver (Ayalon & Areán, 2004; Jang, Kim, & Chiriboga, 2010); and health status (Connell, Davis, Gallant, & Sharpe, 1994; Werner, 2003).

**Hypotheses**

To conclude, a review of the literature suggests a need to examine the relation between AD literacy and perceived threat of AD in specific ethnic minority groups using evidence beyond qualitative interviews (Liu et al., 2008) and small-scale survey studies (Gray et al., 2009). To advance knowledge in the field, this study focused on AD literacy and its relation to perceived threat of AD in a relatively large sample of Chinese American older adults. Two hypotheses were examined: (a) Greater scientific knowledge of AD would be significantly related to more perceived threat of AD after controlling for other known factors (i.e., background variables, acculturation, and family-centered cultural variables); and (b) more traditional Chinese cultural beliefs of AD would be related to more perceived threat of AD after controlling for covariates. To better illustrate, the major constructs are shown in Figure 1.

**Method**

This study employed a cross-sectional survey design. Structured questionnaires were created and refined with input from focus groups of older Chinese volunteers. Three focus groups, two Mandarin speaking and one Cantonese speaking, each spent about 90 min sharing their understanding of AD. Their information was used in revising the items in the cultural beliefs of AD and AD knowledge measurements. Cultural beliefs of AD as an inevitable and stigmatized disease are salient themes, but AD as an imbalance of “Ying and Yang” or as a normal part of aging was not
brought up in any focus group discussion and thereby were not included in the measurement of AD beliefs. Admittedly, several agreed that memory loss is normal as people age, but none accepted that AD is a normal part of aging. Focus group participants were more likely to reach consensus regarding the symptoms of AD than its causes, risk factors, and treatment, suggesting that questions on the AD knowledge scale target the latter to maximize response variability. Table 1 shows the demographic characteristics of focus group participants (n = 17).

Survey questionnaires were administered through face-to-face interviews with participants, with the purpose of increasing completion rates by minimizing problems associated with literacy or physical disabilities in Chinese older adults (Monett, Sullivan, & Dejong, 2002). Interviews were conducted in English or Chinese (Mandarin or Cantonese), depending on participants’ preference. Bilingual interviewers received 3 hr of training from the principal investigator to ensure that they understood the study purpose and questionnaire content, and grasped basic interview skills with the Chinese older adult population. Each interview took about an hour to complete.

Sampling and Participants

Purposive sampling was used to maximize the variation in sample sociodemographic characteristics. Participants were recruited from a variety of settings, including but not limited to, senior centers, senior housing apartments, different religious sites, community events, and senior social clubs. Recruitment flyers were distributed and posted in local bilingual newspapers to attract self-referrals.

The final sample size was 385. Participant eligibility criteria consisted of self-identification as a Chinese American or an immigrant from Mainland China, Taiwan, Hong Kong, or other Chinese speaking regions; aged 55 or older; being able to communicate either in English, Chinese Mandarin, or Cantonese; and living in the Phoenix metropolitan area. The 385 participants aged from 55 to 100 years (M = 72.43, SD = 8.67). About two thirds (64.2%) were women; more than 70% were married; about 32.2% had an education level below 12th grade; 71.9% were born in mainland China; and more than 88% were not working at the time of interview. Details are presented in Table 2.

Measures

Perceived threat of AD.—The perceived threat of AD scale contained nine items assessing the following five domains: (a) perceived likelihood of developing AD, (b) concerns about developing AD someday, (c) worries of AD relative to other medical problems, (d) thoughts that AD would be extremely stressful for individuals and their loved ones, and (e) thoughts about obsessively seeking AD information (Connell et al., 2009; Roberts & Connell, 2000). Participants responded to these statements on a five-point Likert scale from 1 = strongly disagree to 5 = strongly agree. Higher scores indicated more perceived threat of AD. An adapted version of this scale had acceptable reliability in Chinese Americans (Gray et al., 2009) and Korean Americans (Lee et al., 2010). The Cronbach’s alpha obtained for this sample was .74.

Knowledge of AD.—A sum of 24-item true/false statements was used to indicate the actual knowledge of AD symptoms, course, risk factors, diagnosis and treatment, and caregiving. The 24 items came from two sources: the 13-item Epidemiology/Etiology Disease Scale (EDS) by Roberts and Connell (2000) and the 30-item Alzheimer’s Disease Knowledge Scale (ADKS) by Carpenter and coworkers (2009). In light of the recommendations of Jang and coworkers (2010) in their study of Korean American elders in South Florida, the investigator chose items based on two criteria: Items must reflect the latest scientific evidence of

Table 1. Characteristics of Focus Group Participants (N = 17)

<table>
<thead>
<tr>
<th>Primary language</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cantonese</td>
<td>8</td>
</tr>
<tr>
<td>Mandarin</td>
<td>9</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
</tr>
<tr>
<td>Married</td>
<td>15</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Nineth grade or below</td>
<td>4</td>
</tr>
<tr>
<td>High school</td>
<td>3</td>
</tr>
<tr>
<td>Some college</td>
<td>5</td>
</tr>
<tr>
<td>College or higher</td>
<td>5</td>
</tr>
<tr>
<td>Born in the United States</td>
<td>2</td>
</tr>
<tr>
<td>Previous experience as an Alzheimer’s disease caregiver</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 2. Survey Sample Demographics (N = 385)

<table>
<thead>
<tr>
<th>Sociodemographic variables</th>
<th>N(%) or M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>72.43 (SD = 8.67)</td>
</tr>
<tr>
<td>55–64</td>
<td>80 (20.8%)</td>
</tr>
<tr>
<td>65–74</td>
<td>136 (35.3%)</td>
</tr>
<tr>
<td>75–84</td>
<td>141 (36.6%)</td>
</tr>
<tr>
<td>85 and older</td>
<td>28 (7.3%)</td>
</tr>
<tr>
<td>Female</td>
<td>247 (64.2%)</td>
</tr>
<tr>
<td>Married</td>
<td>276 (71.7%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Below 12th grade</td>
<td>124 (32.2%)</td>
</tr>
<tr>
<td>12th grade or some college</td>
<td>121 (31.4%)</td>
</tr>
<tr>
<td>College graduate or above</td>
<td>140 (36.4%)</td>
</tr>
<tr>
<td>Currently not working</td>
<td>341 (88.6%)</td>
</tr>
<tr>
<td>Living in senior housing</td>
<td>207 (53.8%)</td>
</tr>
<tr>
<td>Place of birth</td>
<td></td>
</tr>
<tr>
<td>The United States</td>
<td>30 (7.8%)</td>
</tr>
<tr>
<td>Mainland China</td>
<td>277 (71.9%)</td>
</tr>
<tr>
<td>Hong Kong</td>
<td>20 (5.2%)</td>
</tr>
<tr>
<td>Taiwan</td>
<td>37 (9.6%)</td>
</tr>
<tr>
<td>Elsewhere</td>
<td>21 (5.5%)</td>
</tr>
</tbody>
</table>
AD and must be appropriate for Chinese elders. Input from the three focus groups was sought regarding their common knowledge of AD. Thus, 11 items from the EDS scale were kept for its established appropriateness with Chinese American caregivers (Gray et al., 2009), and the other 13 items were derived from the ADKS (Carpenter et al., 2009), which assesses knowledge in AD diagnosis, treatment, and caregiving that is not included in the EDS scale. Total scores range from 0 to 24, with a higher score indicating greater knowledge of AD. The Cronbach’s alpha in this sample is .65.

Chinese cultural beliefs of AD.—A sum of 10 items was used to indicate cultural beliefs of AD among Chinese American older adults. Based upon input from the three focus groups and previous literature on AD beliefs in Chinese Americans (Elliott et al., 1996; Gray et al., 2009) and other Asian American groups (Lee et al., 2010), we consider AD beliefs in Chinese culture are influenced by fatalism and their stigmatization of mental illness. Participants were asked whether they agree with “AD is a cause of fate,” “AD is a mental illness,” and “Sooner or later people must develop AD” on a five-point Likert scale. The other seven items derived from a Family Stigma in AD Scale (Werner, Goldstein, & Heinik, 2011) assessed individuals’ images of AD patients (e.g., “AD patient looks untidy”), emotional attributions (e.g., “I would feel shameful if my family has an AD relative”), and social interaction (e.g., “I would avoid social contact with an AD patient”). The Cronbach’s alpha of this measure in this sample was .64.

Background characteristics, acculturation, and family-centered cultural values.—In addition to age, gender, marital status, education, income, years in the United States, and nativity, background characteristics included previous experience as a dementia caregiver, health status, and income inadequacy. Health status was indicated by a self-rated health scale (1 = poor to 5 = excellent) and the 12-item Center for Epidemiological Studies Depression scale (CES-D). The CES-D has been validated in Chinese American population (Ying, 2006), with a Cronbach’s alpha of .76 in this sample. Income inadequacy was measured on a scale of 1 = no difficulty at all to 4 = a great deal as higher scores indicated more difficulty paying bills for daily living.

The acculturation scale, validated with the Chinese Americans (Gupta & Yick, 2001), contained 10 items assessing language use and preference, the same ethnic group social network, and choice and manner of social practices on a scale from 1 = completely disagree to 5 = completely agree. The composite scores range from 10 to 50, with higher scores indicating higher levels of acculturation. The Cronbach’s alpha of this measure in this sample was .88.

Family-centered cultural value measurement consisted of the Family Cohesion Scale (Alegria et al., 2004) and the family belief scale of intergenerational support. The 10-item Family Cohesion Scale assessed individual’s ratings of family closeness on a four-point Likert scale (1 = strongly disagree to 4 = strongly agree). An example was “Family members like to spend free time with each other.” Higher scores indicated greater family cohesion; the Cronbach’s alpha in this sample was .93. The family belief in intergenerational support scale assessed attitude toward mutual support between older and adult children using five items on a Likert scale (1 = strongly disagree to 5 = strongly agree). The Cronbach’s alpha obtained for this sample was .70. An example was “Adult children should live with older parents if older adults have no place to live.” The total score ranges from 5 to 25, with higher scores indicating more traditional belief in intergenerational support.

Procedures

The instruments were translated into Chinese using a translation/back translation process. As learned from previous studies on ethnic minority groups (Alegria et al., 2004), the investigator considered input from senior themselves to be important in refining measures in this study. Although scales used to assess AD knowledge and AD cultural beliefs have face validity and some established reliability, the feedback from practitioners helped tailor these questions to become more appropriate for the Chinese older adults. Focus group participants were recruited through a local senior center. The refined questionnaires were pilot tested on three older adults. The investigator finalized the questionnaire after considering all feedback received.

All participants in the focus groups and the survey completed a signed informed consent process approved by the University’s Institutional Review Board (IRB). All interviews were conducted in either English or Chinese in a convenient location with confidential areas such as the participants’ homes, meeting rooms at senior centers, or other participant preferred locations. Participants were asked to leave a phone number in case interviewers need to obtain any information missed during the interview. As seniors in Arizona tend to leave out of town to escape the hot summer, we collected 292 questionnaires between March 15th and June 15th in 2012, and the remaining 93 between October 15th and December 15th in 2012. Survey participants were given $10 after the interview as a token of thanks for their contribution to the study.

Analysis

Survey data were transferred to PASW 18 (formerly SPSS) for storage and analysis. Descriptive analysis and correlation analyses were run among interested variables. Most study variables had no missing values, few had less than 1% missing, and the total AD knowledge score had 3.6% missing cases. Across cases, the total missing cases were less than 5% when listwise deletion approach was used. We compared analysis results from using the listwise
deletion approach to those from using the Expectation-Maximization algorithm missing replacement procedure (Schafer & Graham, 2002); no significant differences were found. Given the low rate of missing in this study, we elected to report the results based upon the listwise deletion approach. A three-step hierarchical linear regression analysis was used to examine the relation of AD knowledge, AD beliefs, and perceived threat of AD. The three models were entered into the hierarchical linear regression analyses one at a time. The first model estimated the association between background variables and the perceived threat of AD; the second model added acculturation and family-centered cultural variables; the final model entered cultural beliefs of AD and AD knowledge.

**RESULTS**

Correlation and ANOVA analyses (table not shown) were conducted among background variables, acculturation, family-centered value variables, and perceived threat of AD. People with less than high school education (M = 26.37, SD = 8.80) had higher levels of perceived threat of AD than those with a college education or above (M = 23.27, SD = 6.12, Cohen’s d = .41). Four age groups were classified because the prevalence rate of AD varies greatly across these age groups (Alzheimer’s Association, 2013). Age tended to be inversely related to perceived of AD as those aged 85 or older (M = 25.64, SD = 6.36) and those aged between 75 and 84 (M = 23.91, SD = 7.11) had lower perceived threat of AD than those aged between 65 and 74 (M = 25.76, SD = 7.31) and those aged below 65 (M = 25.50, SD = 6.78). Among other background variables, those with previous caregiving experience (M = 25.81, SD = 7.24) had higher perceived threat with AD than those without (M = 24.47, SD = 7.38, Cohen’s d = .18). More depressive symptoms (r = .30, p < .01) and poorer self-rated health (r = −.12, p < .05) were associated with greater levels of perceived threat of AD. Acculturation was not related to perceived threat of AD, whereas family-centered values—family cohesion (r = −.14, p < .01) and beliefs in intergenerational support (r = −.10, p < .05)—were negatively associated with perceived threat of AD.

Table 3 presents the results of the three-step hierarchical regression analysis. The first model included background variables as predictors of the perceived threat of AD. Three background variables emerged as statistically significant. Those with college degree or above were less likely to worry about AD than those with less than high school education. Oldest old adults (aged 85 years or older) were less worried about AD than those age below 64. In contrast, more depressive symptoms were related to higher levels of perceived threat of AD. The second model entered acculturation and family-centered variables. Acculturation and family cohesion were not related to perceived threat of AD. However, beliefs in intergenerational support (B = −0.20, SE = 0.10, p < .05) were associated with lower levels of perceived threat of AD. The final model added the cultural beliefs of AD and AD knowledge variables. The significance of age, education, depressive symptoms, and beliefs in intergenerational support remained. In support of both hypotheses, older adults with more traditional cultural beliefs about AD (B = 0.25, SE = 0.06, p < .001) and those with more scientific knowledge about AD (B = 0.45, SE = 0.13, p < .001) had more concerns about developing AD. The explained R² was 15.5%.

**DISCUSSION**

To the best of our knowledge, this study is the first of its kind that examines Chinese American older adults’ AD knowledge, cultural beliefs, and perceived AD threat using a sizable sample. This study focused on AD literacy, an important concept that has both heuristic meanings and applied implications. Although previous public knowledge...
about mental illness has focused on schizophrenia and depression (Werner, 2005), this study advanced our knowledge of how AD, one of the most prevalent mental disorders among older adults, is understood by a specific ethnic group of elders. This study synthesizes knowledge and beliefs as two important components of AD literacy and tests the role of AD literacy in influencing individuals’ perceived threat of AD, a critical component of the SHBM (Sayegh & Knight, 2013).

Our findings indicate that the younger age group is more likely to develop concerns about AD than the oldest old group. It is possible that the age group between 55 and 64 is the primary cohort that provides care for an older dementia relative. Because of their caregiving experience, they tend to be more alert to AD symptoms given that AD has a genetic root. Another possible explanation is that those aged 85 or older who survived without having an AD believe that they have little reason to worry.

Our first hypothesis that higher levels of AD factual knowledge is related to more perceived threat of AD was confirmed. In light of the SHBM (Sayegh & Knight, 2013), the positive relation between AD knowledge and perceived threat of AD may be that people who are more knowledgeable about AD tend to realize the susceptibility and severity of this disease and thereby have more concerns about developing AD. The speculation is that having more factual knowledge of AD does not ease people’s worries of developing AD in that the current knowledge regarding AD and its care management suggests a pessimistic future for AD patients (e.g., there is currently no cure for AD patients).

However, the cross-sectional nature of this study does not rule out that the possibility that people who are more concerned of developing AD seek out additional information on AD and consequently obtain more AD knowledge. Again, this finding needs to be examined in future longitudinal and experimental studies.

Although unplanned, a post hoc analysis offered a new perspective of the relation between AD knowledge and perceived threat of AD by considering an interaction effect with education (i.e., high school or below vs college education or above). To illustrate, the interaction program (http://www.danielsoper.com/Interaction/) was used to graph the moderation effect. Figure 2 presents two estimated regression lines of perceived threat depending on the levels of education and AD knowledge while controlling for other covariates. Increased knowledge in people with less than a high school education was related to more worries of developing AD, whereas the effect of increased AD knowledge on perceived threat of AD tended to be minimal for those with a college education or above. It is highly likely that better educated people have more coping resources that prevent worry resulting from AD knowledge.

Another explanation is inspired by studies on the relation between low education and increased risks of AD or related dementia in populations including Chinese populations (Ngandu et al., 2007; Zhang, Gu, & Hayward, 2008). Despite the differences of lifestyle factors due to education, research has found that the highly educated people tend to have cognitive reserve that can inhibit the manifestation of dementia (Ngandu et al., 2007). Thus, we suspect that those with better education levels might have developed over time.

Figure 2. An Interaction effect of education level and Alzheimer’s disease (AD) knowledge on perceived threat of AD with covariates controlled.
a mental mechanism that restrains the expression of excessive worry about dementia. Future studies on the relation between formal education and AD incidents may include an examination of the perceived threat of AD.

Our second hypothesis that traditional cultural beliefs of AD contribute to higher levels of perceived threat of AD was also confirmed. It is understandable that subscribing to traditional Chinese beliefs of AD can lead to more concerns of developing AD because the traditional beliefs measured in this study tended to reflect fatalism (AD is something that must happen) and stigmatization of AD (AD brings shame to the family). Beliefs of AD as an unavoidable arrangement by fate might engender excessive anxiety; AD as a stigmatized disease might lead to concerns of losing family honor, which is critical to Chinese American elders. Similarly, we found that the influence of cultural beliefs tended to be more salient in those with less than high school education than those with college education or above (see Figure 3), indicating a potential buffering effect of education. Post hoc analysis suggests that higher levels of subscribing to Chinese cultural beliefs about AD tended to result in less worry in people with a college education or above than in those with less than a high school education. The speculations of more coping resources or a protective mental mechanism that inhibits the manifestation of worry for those highly educated may still apply there. Yet, the effect of formal education remains to be verified in future studies with other Chinese American samples.

One family-centered cultural variable, beliefs in intergenerational support, was also identified as a protective factor for perceived threat of AD. Filial piety is emphasized in Confucian teaching where adult children are supposed to provide physical, emotional, or financial support to their parents when they are in need (Lai, 2009). Considering the lack of access to formal services in United States (Yu, Huang, & Singh, 2004), Chinese American older adults’ strong beliefs in intergenerational support may reduce their worries and lead them to believe that their service needs will be met through the assistance of their adult children should they develop AD. Perceived intergenerational support may be essential to reducing worries about developing an age-related brain disorder.

The role of acculturation on perceived threat warrants further study. The current study did not find a significant relation between the two, implying AD equally concerned people across acculturation levels. Another possibility is that the variation in level of acculturation (70% with a score of 23 or below on a scale ranging from 10 to 50) was not sufficient to identify a significant difference, especially when one considers that the majority of elders were not born in the United States, and there are few culturally specific educational programs for this population (Wu, Emerson-Lombardo, & Chang, 2010).

Another potential risk factor for perceived threat of AD may be people’s depressive symptoms because depression may shape a more pessimistic view of the future including additional worries about AD. Still, it is possible that people with more concerns of developing AD tend to feel depressed, as was found in a study of patients with diabetes that suggested the perceived threat of diabetes lead to depressive symptoms (Connell et al., 1994).

Figure 3. An Interaction effect of education level and cultural beliefs of Alzheimer’s disease (AD) on perceived threat of AD with covariates controlled.
This study has several limitations including limited generalizability to Chinese Americans outside the study sample. In addition, the Chinese Cultural Beliefs of AD scale has face validity but less than ideal internal reliability (Cronbach’s alpha = .64). Factor analyses suggested that two factors (three items on fatalism and seven items on stigma) would explain 37% of the variance compared with 19% of the variance by a single factor. However, because Cronbach’s alpha is related to the number of items, Cronbach’s alphas for each subscale were found to be even lower. Thus, considering the nascent nature of this scale (Schmitt, 1996), we kept the 10 items as a scale and recommend additional validation with different samples. Finally, the relation between AD literacy and perceived threat of AD needs confirmation using longitudinal research designs that include behavioral outcome variables (e.g., help-seeking behavior, coping behaviors) for intervention purposes. In line with the SHBM, cultural beliefs of AD, such as shame and stigma, are related to the barriers to action, leading to less likelihood of seeking formal services; the lack of accurate knowledge of AD is considered another barrier that would lead to less likelihood of seeking evaluation or treatment. Both actual knowledge of AD and cultural beliefs were found to be positively related to the perceived threat of AD. Yet, the perceived threat of AD scale that mostly taps dementia worry may influence help seeking in a nonlinear way. A moderate level of AD threat will trigger people to seek evaluation if they perceive there is a benefit, but very high levels of threat may result in completely avoiding diagnosis or obsessively seeking tests (Kessler, Bowen, Baer, Froelich, & Wahl, 2012). A natural next step is to examine the relationship between the perceived threat of AD and dementia-related help-seeking behaviors, while controlling for knowledge of AD, cultural beliefs of AD, and service barriers.

**Implications**

This study focused on a rapidly growing ethnic population that demands service professionals with greater competence but has not yet received sufficient attention in the literature (Wu, Emerson-Lombardo, & Chang, 2010). Theoretically, our findings support the inclusion of several key factors (cultural beliefs, AD knowledge, perceived threat of AD, acculturation, family-centered values, and sociodemographic factors) included in the SHBM, an empirically based model of dementia care seeking among ethnic minority older adults (Sayegh & Knight, 2013). Although our study examined only a few of the key factors related to perceived threat of AD, the findings emphasize that cultural beliefs about AD are as crucial as factual knowledge of AD, in helping understand AD literacy, at least among Chinese American older adults. Moreover, there appears to be a dynamic interplay between levels of education, AD knowledge, and perceived threat that warrants additional investigation, particularly in terms of guiding AD education and intervention efforts in this underserved community. From a psychological science perspective, these findings create a complex picture for those interested in working with the Chinese American community to help provide information about AD and related programs and services and reduce barriers to help seeking. Additional investigations are needed with Chinese American families affected by AD to help identify ways to effectively address key cultural beliefs including those related to fatalism and stigmatization of AD in outreach, education, and intervention programs to overcome barriers to help seeking related to AD. The relation found between AD literacy and perceived threat of AD in this study lay the foundation for future tests of a full SHBM model that includes behavioral outcomes.

Some practice implications are also noted. The sample in this study was derived from Chinese older adults living in the Phoenix metropolitan area. Although most previous studies focusing on Chinese Americans have derived their samples from those living in California or New York City (Gallagher-Thompson et al., 2007), places with large concentrations of Chinese Americans, it is important to expand study samples of Chinese Americans into geographic areas where resources are less available to this population. Arizona is a state that has witnessed a growth in Chinese population in recent years; nevertheless, it does not have an established and organized Chinese community. Slightly over 50% of our sample came from four senior housing facilities that mainly accommodate Chinese Americans, whereas the rest of the sample from the community lives widely dispersed across the valley. Currently, there are few effective AD education and intervention programs available for patients and family caregivers of this population. Future AD education programs, interventions, and services need to be made available to those spread out in the community and should be tailored to address the needs of those with limited formal education.

Our findings suggest that changing AD knowledge alone may not necessarily address the worries or concerns of developing AD. Rather, exposure to more AD knowledge might increase the uncertainty or fear of AD in an ethnic group that uses denial and silence as a popular coping strategy for a mental illness (Yang, 2007), which is particularly true for those with limited education. Future AD education programs, interventions, and services need to include components addressing the worry and other psychological concerns of developing AD. Several other modifying factors such as participant depressive symptoms and beliefs on intergenerational support should be considered in designing community-based practices and interventions for the Chinese American older population.

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References