Published in final edited form as:

J Aging Health. 2010 June ; 22(4): 419–433. doi:10.1177/0898264309360672.

Knowledge of Alzheimer's Disease, Feelings of Shame, and Awareness of Services Among Korean American Elders

Yuri Jang, PhD¹, Giyeon Kim, PhD², and David Chiriboga, PhD¹

¹ Department of Aging and Mental Health Disparities, University of South Florida, Tampa, FL

² Department of Psychology, Center for Mental Health and Aging, University of Alabama, Tuscaloosa, AL

Abstract

Objective—To explore predictors of knowledge of Alzheimer's disease (AD), feelings of shame if a family member were to have AD, and awareness of AD-related services among Korean American elders.

Method—Using data from 675 Korean American elders (mean age = 70.2, *SD* = 6.87), the study estimates hierarchical linear or logistic regression models.

Results—Greater knowledge of AD is predicted by higher levels of education and acculturation. Feelings of shame associated with family members having AD are more likely to be reported by individuals with lower levels of education, acculturation, and knowledge of AD. Those who are married have greater levels of education and acculturation, and those who have a family member with AD are more aware of AD-related services.

Discussion—The study findings underscore the pivotal role of education and acculturation in predicting knowledge of AD, feelings of shame, and awareness of AD-related services.

Keywords

Alzheimer's disease; Korean Americans; shame; acculturation

As emphasized in the growing literature on health literacy, knowledge is an important enabler for behaviors, and lack of knowledge is an impediment to appropriate help seeking (Institute of Medicine, 2004). In the context of Alzheimer's disease (AD), both early detection and successful interventions can be facilitated by proper knowledge of the disease and the utilization of relevant services (Alzheimer's Association, 2009; Chow, Ross, Fox, Cummings, & Lin, 2000; Jones, Chow, & Gatz, 2006). Unfortunately, a substantial lack of knowledge about AD, misconceptions, and underutilization of services are often reported in studies with racial and ethnic minority populations (Institute of Medicine, 2004; U.S. Department of Health and Human Services [USDHHS], 2001).

Asian Americans in particular are known to lack knowledge of AD (Ayalon & Areán, 2004; Hinton, Franz, Yeo, & Levkoff, 2005), although the body of research on the group as a whole and its subgroups is quite limited (Jones et al., 2006; USDHHS, 2001). Studies have also

Corresponding Author: Yuri Jang, Department of Aging and Mental Health Disparities, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Boulevard, MHC 1400, Tampa, FL 33612 yjang@fmhi.usf.edu.

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Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

reported that Asian American caregivers of AD patients have low utilization rates of such services as adult day care and respite programs (Braun & Browne, 1998; Chow et al., 2000). These findings underscore the importance of efforts to understand the status of knowledge and awareness of AD and AD-related services among Asian Americans.

The challenge of understanding the health beliefs and attitudes of racial and ethnic groups is daunting, especially when people from diverse cultures are the object of attention. Culture plays a significant role in shaping individuals' health beliefs and attitudes, including how members of a given culture conceptualize a disease, recognize its symptoms, and determine care-seeking behaviors (Dilworth-Anderson & Gibson, 2002; USDHHS, 2001). Studies have shown that cultural or ethnic background strongly influences individuals' knowledge of AD and attitudes toward service use (Jones et al., 2006). Cultural misconceptions and stigma relating to AD may be a major reason for delay in diagnosis and treatment (Ayalon & Areán, 2004; Dilworth-Anderson & Gibson, 2002). A recent survey by the Alzheimer's Foundation of America (2007) reported substantial misconceptions about AD among African American and Hispanic caregivers for AD patients and shed light on minority health education and outreach programs. Given the unique characteristics common to many Asian cultures—such as filial piety, familism, stigma attached to mental illness, and an emphasis on saving face (e.g., Braun & Browne, 1998; Kang & Kang, 1995; Mui & Shibusawa, 2008; Yeo & Gallagher-Thompson, 1996)—research on cultural misconceptions and stigma relating to AD in Asian American communities deserves much attention.

One of the most common misconceptions about AD is that its symptoms represent a normal part of aging (Blay & Peluso, 2008; Lee, Lee, & Diwan, 2009; Werner, 2005). Studies have shown that racial and ethnic minorities are more likely to normalize AD than to view it as a medical condition (Ayalon & Areán, 2004; Hinton, Guo, Hillygus, & Levkoff, 2000; Kane, 2000; Lee et al., 2009; Werner, 2005). Another misconception that potentially leads to reduced help seeking is that AD is a stigmatizing condition (Benbow & Reynolds, 2000; Werner & Davidson, 2004; World Health Organization, 2002). People commonly associate AD with insanity (World Health Organization, 2002) and in some cases perceive AD as a punishment from God (Hinton et al., 2000; Kane, 2000).

Across Asian cultures, the impact of stigmatization may be compounded by the fact that stigma is attached not only to the individual with mental illness but often to the individual's family as well (Braun & Browne, 1998; Lin & Cheung, 1999). One's illness represents a threat to the homeostasis and harmony of the whole family. Following the cultural emphasis on saving face and bringing honor to the family, it is believed that having a family member with cognitive impairment negatively reflects on the family lineage and brings dishonor and shame to the family name. Such stigma linked to shame in Asian cultures may be responsible for a general reluctance to seek help outside the family (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Hinton et al., 2000; Leong & Lau, 2001). In the present study, therefore, we considered feelings of shame associated with AD as an outcome criterion equal in importance to knowledge of AD and awareness of AD-related services.

Recognizing the heterogeneity of Asian Americans, the present study focused on a single understudied and underserved subgroup: Korean American elders. Currently ranked as the fourth largest Asian American subgroup, Korean Americans are one of the fastest growing segments of immigrants in the United States (U.S. Census Bureau, 2007). Due to the recent history of immigration, only 7.6% of the current Korean American populations are aged 65 or older (the corresponding figure for non-Hispanic Whites is 14.5%), but an exponential increase in the Korean American elderly population is projected (U.S. Census Bureau, 2007), which also implies the substantial growth of the numbers of Korean American families affected by AD. Hence, there is a critical need to explore knowledge, perception, and awareness of AD

and AD-related services among Korean Americans. Such information may help identify ways to promote early detection and proper treatment of AD and utilization of appropriate services for the target population. In a recent study by Lee and colleagues (2009), substantial proportion of Korean American immigrants was shown to hold a stigmatizing view of AD as insanity and perceive AD symptoms as a normal process of aging. Focusing on older members of Korean Americans, the present study is designed to explore the status and associated factors of three outcome variables: knowledge of AD, feelings of shame, and awareness of AD-related services.

We expected that education and acculturation would be associated with favorable outcomes (i.e., better knowledge of AD, no feelings of shame, and awareness of services) and that the experience of having a family member with AD would increase knowledge and awareness of AD and AD-related services. Our hypotheses were based on literature showing the positive link between education and acculturation, and knowledge of and access to resources and services (e.g., Berry, 2002; Chiriboga, Black, Aranda, & Markides, 2002; Jang, Kim, Chiriboga, & Kallimanis, 2007). Studies have also reported that prior exposure and experience play an important role in shaping individuals' knowledge of and attitudes toward services (Jang, Kim, Hansen, & Chiriboga, 2007; Jones et al., 2006; Moon, Lubben, & Villa, 1998; Roberts & Connell, 2000; Tijhuis, Peters, & Foets, 1990). Finally, with respect to the outcomes themselves, we anticipated that lack of knowledge of AD would be linked to feelings of shame and unawareness of services.

Method

Participants and Procedures

With approval from the institutional review board at the University of South Florida, we conducted a survey of older Korean Americans (aged 60 years or older) from March to August 2008 in Tampa and Orlando, Florida. Because immigrant populations are often hard to identify by any single approach and also because a single-source sampling frame may lead to bias when dealing with such populations (Curry & Jackson, 2003), we combined several sampling methods in our recruitment efforts. These methods included contacting local Korean churches, other religious groups, senior centers, senior housing, and elder associations. When contacts were made, our research team visited the sites and arranged for surveys to be conducted.

The survey instrument was a standardized questionnaire designed to be self-administered; however, trained interviewers were available for assistance. A Korean-language questionnaire was developed specifically for this project. Several of the measures had been translated into Korean and evaluated for psychometric qualities in our previous work (e.g., Jang, Kim, Chiriboga et al., 2007; Jang, Kim, Hansen et al., 2007). For additional scales, back-translation was used to confirm the appropriateness of initial translations into Korean (Brislin, 1970; Hambleton & de Jong, 2003). The final product was reviewed and reconciled by bilingual individuals who did not participate in the initial translation process. The structured questionnaire was pilot tested with 20 Korean American older adults who were representative of the anticipated sample. Because no specific difficulties or problems were reported in the pilot testing, no modification was made. For the convenience of the participants, survey questionnaires were printed using a large font.

The survey sites included 25 local Korean churches, two other groups with a religious affiliation, one Korean senior center, two senior housing facilities, and a local Korean elder association. To recruit individuals who were not affiliated with those groups or organizations, we made requests for referrals from respondents as well as other individuals associated with our primary data collection sites. A copy of the questionnaire and a self-addressed, stamped return envelope were mailed to all individuals with whom onsite contacts were not possible.

We supplemented this convenience sampling procedure with a systematic approach using a telephone directory of Korean residents provided by the Florida Korean American Association. A total of 2,000 Korean residents in Tampa and Orlando were listed in the directory. After excluding those who had already been recruited through our convenience sampling efforts, we called all remaining individuals to ask whether there were age-eligible members in their household. Up to five phone calls were made until the individual was considered unreachable. If there was an eligible person in the household, a mail survey packet was sent. This step was designed to improve comprehensiveness of the sample by including individuals who were not recruited by the convenience sampling efforts and to offset limitations associated with nonrepresentativeness of convenience sampling.

A total of 675 participants were included in our final sample. Of the sample, 73% of the participants were recruited through visits and about 27% were recruited through mail surveys. We conducted a series of comparative analyses to check whether there was any difference in sample characteristics by recruitment method. No significant difference was found for major demographic characteristics; however, compared to the individuals whose data were collected through mail surveys, participants recruited through visits were less educated ($\chi^2 = 10.3, p < .01$). This finding suggests that a sole reliance on mail surveys might have excluded individuals with low levels of education. All respondents were paid \$20 for their participation.

Measures

Knowledge of AD was measured using a 10-item true/false AD knowledge test. The items were selected from existing instruments (e.g., Alzheimer's Foundation of America, 2007; Ayalon & Areán, 2004; Dieckmann, Zarit, Zarit, & Gatz, 1988; Roberts & Connell, 2000), were reviewed by mental health professionals who work with older adults, and were pilot tested with a representative group of 20 Korean American elders. Because facts about AD continue to change (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009), items selected reflected current scientific knowledge. The appropriateness of the items for use with older adults was also considered because some of the original instruments were designed for use with college students or health professionals. The final instrument covered nature, symptoms, course, etiology, diagnosis, and treatment of AD. The total number of correct answers was used in the analysis. Total scores could range from 0 to 10, with a higher score indicating a greater knowledge of AD.

Feelings of shame were assessed by asking participants whether they agreed with the following statement: "I would feel embarrassed if I had a family member with AD." This item used a yes/no response format.

Awareness of AD-related services was measured using a single question asking participants whether they were aware of services for AD patients and family members, such as adult day care services, support groups, and home health care services, and this item used a yes/no response format.

Acculturation was assessed using a 12-item inventory (Jang, Kim, Chiriboga et al., 2007) adopted from several studies on acculturation (e.g., Hazuda, Stern, & Haffner, 1988; Suinn, Ahuna, & Khoo, 1992; Ying, 1995). The inventory included items representing language use, media consumption, food consumption, social relations, sense of belonging, and familiarity with the host culture. Each response was coded from 0 to 3. Total scores could range from 0 to 36, with a higher score indicating a greater level of acculturation to mainstream American culture. Internal consistency for the scale in the present sample was high ($\alpha = .92$).

Participants were also asked whether they had had a family member affected by AD. A yes/no response format was used for this item.

Other demographic information assessed included age (in years), gender (0 = *male*, 1 = *female*), marital status (0 = *married*, 1 = *not married*), and educational attainment (0 = *less than high school*, 1 = *high school or greater*).

Analytic Strategy

Multiple linear regression analysis was conducted to estimate a predictive model of knowledge of AD. For the two binary outcome variables, feelings of stigma and awareness of AD-related services, logistic regression analysis was performed. The sets of predictors were entered in the following hierarchical order: (a) demographic variables (age, gender, marital status, and educational attainment), (b) acculturation, and (c) experience of having a family member with AD. Each outcome variable was added to the models of the subsequent outcome variables as a final step. Bivariate correlations and variance inflation factors (VIFs) were assessed to detect collinearity. Analyses were performed using SPSS, version 17 (SPSS Inc., Chicago, IL).

Results

Characteristics of the Sample and Study Variables

As shown in Table 1, the sample consisted of 675 Korean American adults aged between 60 and 96 years; the average age across the sample was 70.2 years ($SD = 6.87$). More than half (58.8%) of the participants were women, and less than one quarter (23.4%) of the participants were not presently married. More than 70% of the participants had received a high school education or greater. The mean acculturation score was 15.8 ($SD = 7.56$) out of a possible 36 (range = 0–35). More than 12% of the participants reported that they had had a family member affected by AD. The mean score on the AD knowledge test was 7.01 ($SD = 1.45$) out of a possible 10 (range = 2–10). More than 14% of the participants reported that having a family member with AD would bring shame, and about 23% of the participants reported that they were aware of services for AD patients and family members.

Table 2 presents the individual items from the knowledge test and rates of incorrect answers. The latter ranged from 9.9% to 54.1%. The highest incorrect answer rate (54.1%) was found for Item 4, “AD is a normal process of aging.” Relatively high incorrect rates were also found for the following items: Item 9, “AD is generally fatal” (42.6%); Item 8, “Symptoms of depression are similar to those of AD” (42.3%); and Item 3, “AD is a form of insanity” (42.0%). Item 1, “AD could be contagious,” had the lowest rate of incorrect answers (9.9%), indicating that the majority of Korean American elders had the correct perception that AD is not contagious.

Multivariate Analyses

Prior to conducting multivariate analyses, we assessed bivariate correlations to assess underlying associations among the study variables. The variables were correlated in expected directions. The highest correlation coefficient was observed between education and acculturation ($r = .38, p < .001$), but it was not of a magnitude to raise concerns about collinearity. Also, collinearity diagnostics provided VIFs of less than 1.54, a value far less than 4, the suggested cutoff for multicollinearity (Montgomery & Peck, 1992).

Table 3 summarizes the results from hierarchical linear or logistic regression analyses on knowledge of AD, feelings of shame, and awareness of AD-related services. In the model for knowledge of AD, significance was obtained for education ($\beta = .14, p < .01$) and acculturation ($\beta = .09, p < .05$). Higher levels of both education and acculturation predicted a greater knowledge of AD.

The likelihood of reporting feelings of shame increased significantly when individuals had lower levels of education (odds ratio [OR] = 0.42, 95% confidence interval [CI] = 0.25–0.69) or lower levels of acculturation (OR = 0.96, 95% CI = 0.92–0.99). In the final model, where demographic variables, acculturation, and prior experience of having a family with AD were controlled, less knowledge of AD (OR = 0.75, 95% CI = 0.64–0.88) significantly increased the odds of reporting feelings of shame.

Finally, awareness of AD-related services was found to increase when individuals were married (OR = 0.50, 95% CI = 0.28–0.88), had more education (OR = 2.04, 95% CI = 1.23–3.38), or had a higher level of acculturation (OR = 1.03, 95% CI = 1.01–1.06). When demographic characteristics and acculturation were controlled, having a family member with AD (OR = 2.23, 95% CI = 1.33–3.74) significantly increased the odds of being aware of AD-related services. Awareness of such services was not associated with a better knowledge of AD (OR = 0.95, 95% CI = 0.93–1.09) or with feelings of shame (OR = 0.81, 95% CI = 0.44–1.49).

Discussion

Responding to a need for more research on how racial and ethnic subgroups understand and cope with AD (Alzheimer's Foundation of America, 2007; USDHHS, 2001), the present study examined predictors of the three outcome variables (i.e., knowledge about AD, feelings of shame, and awareness of AD-related services) among Korean American elders.

One of the most common misconceptions was that AD is a normal part of aging, a perception endorsed by more than half (54.1%) of the participants. Studies of racial and ethnic minorities (e.g., Ayalon & Areán, 2004; Hinton et al., 2000; Jones et al., 2006) have frequently shown that AD is normalized rather than viewed as a medical condition. This finding is important because such normalization hinders early detection of AD and appropriate use of services (Kane, 2000; Werner, 2005). About 42% of the participants to the present study associated AD with insanity, and a similar percentage of participants were misinformed about its nature (e.g., "AD is generally fatal") and symptoms (e.g., "Symptoms of depression are similar to those of AD"). Given that such misconceptions are linked to stigmatization, can impede access to treatment, and can lead to unrealistic expectations about disease prognosis, efforts to promote knowledge in those areas should be prioritized.

Our results are similar in some respects and dissimilar in others to those reported by Lee and colleagues (2009). The latter found only 38% of Korean Americans living in Southern California felt Alzheimer's disease to be a normal part of aging. However, the same study reports that a surprisingly high proportion of the participants (74%) considered Alzheimer's disease to be a form of insanity. The differences between the two studies may reflect regional variations, differences in educational level, or even age differences, as the participants from the Southern California sample were, on average, more educated than the ones from the present sample and included middle-aged as well as older participants. Whatever the reasons for differences, results from both studies suggest that misconceptions are strong and worthy of attention from health professionals.

The results also demonstrate the need for informational campaigns targeting racial and ethnic minority groups such as older Korean Americans. As expected, greater levels of education and acculturation were associated with better knowledge of AD. Individuals with greater levels of education and acculturation usually have more access to and understanding of health information (Berry, 2002; Chiriboga et al., 2002; Jang, Kim, Chiriboga et al., 2007), and this also applies to knowledge of AD. Ayalon and Areán (2004) also reported an important role of education and acculturation: They found that education explained differences in knowledge of AD between White and Hispanic elders and that number of years of speaking English was

positively associated with knowledge of AD among Asian American elders. However, their study included only a small number of Asian American elders, all of whom spoke English. It is notable that the present study included Korean American elders representing a wide range of acculturation levels and that the results confirm the positive and independent impact of acculturation on knowledge of AD.

Recognizing the cultural emphasis in Asian societies on saving face, the present study used the presence or absence of shame resulting from a family member with AD as one of the outcome variables. More than 14% of the participants reported that having a family member with AD would bring shame. As feelings of shame are likely to be linked to a delay in seeking treatment (Braun et al., 1995; Hinton et al., 2000; Leong & Lau, 2001), elimination of such stigma is an urgent issue. Our analysis suggests that those who are less educated and acculturated are at greater risk for feelings of shame. Also, given its link to knowledge of AD, feelings of shame may be reduced by targeted dissemination of appropriate knowledge.

The last outcome criterion was awareness of AD-related services. Less than one quarter of the participants reported being aware of such services as adult day care services, support groups, and home health care services for AD patients and family members. The significant role of education and acculturation was again observed in the predictive model. It is notable that previous experience of having a family member with AD was associated with greater awareness of services. This finding is in line with other studies showing that personal resources and past experiences increase exposure to and familiarity with services (Jang, Kim, Hansen et al., 2007; Moon et al., 1998; Tijhuis et al., 1990). Roberts and Connell (2000) reported a high level of knowledge of AD among first-degree relatives of individuals with AD. In a qualitative study by Jones and colleagues (2006), those who were caregivers for AD patients at the time of study or those who had been past caregivers for AD patients (i.e., prior to the study) had better knowledge of available services than others who had no such experience.

Overall, the findings of the present study underscore the importance of educational interventions and outreach programs for racial and ethnic minorities. Given that education and acculturation served as common predictors that contributed to all three outcome variables, attention needs to be focused on those who are vulnerable, due to low education and/or acculturation levels. The results also underscore the importance of disseminating educational programs in the native language of the target population because a majority of those who are less educated and less acculturated may have limited English proficiency. A supplemental analysis showed that less than 20% of the participants reported having seen educational materials on AD in the Korean language. Culturally sensitive educational programs are, therefore, needed to reach the most vulnerable and at-risk immigrant populations. Also, relevant to the design of interventions was the lack of association between knowledge of AD and awareness of AD-related services. This suggests that independent modules should be developed for each of these domains.

Some limitations of the present study should be noted. Because the study was based on a cross-sectional design, caution must be exercised when drawing causal inferences. Moreover, because of the nonrepresentative nature of the sample, the findings are only suggestive and warrant further investigation. Further refinement of the measurement tools should be done in future studies. For example, despite a validity suggested by their associations with other variables, only single binary items were available as indicators in the areas of shame and of awareness of services. Future studies might also benefit from an expanded scope that includes structural and cultural variables as well as evaluation of the actual utilization of services and the perceived quality of the experience.

Acknowledgments

Funding

The authors declared the following financial support for the research and/or authorship of this article: project supported by the National Institute of Mental Health (1R21MH081094-01A1) and the Johnnie B. Byrd Sr. Alzheimer's Center and Research Institute (ARG-2007-31).

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Table 1Descriptive Information for the Sample ($N = 675$)

Variable	Value
Age, $M \pm SD$ (range 60–96)	70.2 ± 6.87
Female (%)	58.8
Not married (%)	23.4
High school education or greater (%)	70.5
Acculturation, $M \pm SD$ (range 0–35)	15.8 ± 7.56
Had family member with AD (%)	12.3
Knowledge of AD, $M \pm SD$ (range 2–10)	7.01 ± 1.45
Feelings of shame (%)	14.2
Awareness of AD-related services (%)	22.7

Note: AD = Alzheimer's disease.

Table 2

Descriptive Information on Alzheimer's Disease (AD) Knowledge Test

Test item (correct answer)	Percentage of individuals who provided incorrect answer
Item 1: AD could be contagious (false)	9.9
Item 2: All humans if they live long enough, will probably develop AD (false)	15.3
Item 3: AD is a form of insanity (false)	42.0
Item 4: AD is a normal process of aging (false)	54.1
Item 5: AD can be cured with medication (false)	26.9
Item 6: AD only occurs in the elderly population (false)	35.0
Item 7: The major symptom of AD is memory loss (true)	13.6
Item 8: Symptoms of depression are similar to those of AD (true)	42.3
Item 9: AD is generally fatal (true)	42.6
Item 10: AD can be diagnosed with a blood test (false)	19.2

Table 3
Regression Models of Knowledge of Alzheimer's Disease (AD), Feelings of Shame, and Awareness of AD-Related Services

Step	Predictor	Knowledge of AD		Feelings of shame			Awareness of services	
		β	<i>t</i>	OR	95% CI	OR	95% CI	
1	Age	.00	0.05	1.03	0.99, 1.05	1.00	0.97, 1.04	
	Female	-.06	-1.40	0.65	0.38, 1.09	1.26	0.83, 1.91	
	Not married	.08	1.76	1.23	0.69, 2.18	0.50	0.28, 0.88*	
	High school or more	.14	3.11**	0.42	0.25, 0.69**	2.04	1.23, 3.38**	
2	Acculturation	.09	1.97*	0.96	0.92, 0.99*	1.03	1.01, 1.06*	
3	Had family member with AD	.01	0.29	1.64	0.83, 3.20	2.23	1.33, 3.74**	
4	Knowledge of AD	—	—	0.75	0.64, 0.88***	0.95	0.93, 1.09	
5	Feelings of shame	—	—	—	—	0.81	0.44, 1.49	
Summary statistics		$R^2 = .03$ ($F = 3.12^{**}$)		$-2 \log \text{likelihood} = 476.4$ ($\chi^2 = 42.2^{***}$)		$-2 \log \text{likelihood} = 649.5$ ($\chi^2 = 35.8^{***}$)		

OR = odds ratio; CI = confidence interval.

* $p < .05$,

** $p < .01$,

*** $p < .001$.