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Asian Americans' concerns and plans about Alzheimer's disease: The role of exposure, literacy and cultural beliefs

Yuri Jang, PhD¹, Hyunwoo Yoon, PhD², Nan Sook Park, PhD³, Min-Kyoung Rhee, PhD¹, and David A. Chiriboga, PhD⁴

¹Steve Hicks School of Social Work, The University of Texas at Austin, Austin, TX, USA

²School of Social Work, Texas State University, Austin, TX, USA

³School of Social Work, University of South Florida, Tampa, FL, USA

⁴Department of Child and Family Studies, University of South Florida, Tampa, FL, USA

Abstract

Responding to the increase of the Asian American population and the growing imperative to address issues on Alzheimer's disease (AD) in diverse populations, this study examined Asian Americans' concerns about AD (both concerns about one's own development of AD and about becoming an AD caregiver) and plans for AD. Focus was given on exploring the role of AD exposure, AD literacy and cultural beliefs about AD in predicting AD-related concerns and plans. Using data from 2,609 participants in the 2015 Asian American Quality of Life survey (aged 18–98), logistic regression models of three outcome measures (concerns about one's own development of AD, concerns about becoming an AD caregiver and plans about AD) were estimated. AD exposure and literacy (perceived knowledge and awareness of services) were common predictors of all three outcomes. Beliefs that associate AD with a normal part of ageing and a matter of fate increased the odds of having AD concerns. The odds of having AD plans were found to be higher among those with such concerns. Findings not only identified the factors associated with the concerns and plans about AD but also informed ways to develop targeted AD interventions for Asian Americans.

Keywords

Alzheimer's disea	se; Asian Ame	ericans; concerns	s about Alzheime	er's disease; plans for
Alzheimer's disea	se			

Correspondence: Yuri Jang, Steve Hicks School of Social Work, The University of Texas at Austin, Austin, TX, USA., yjang 12@austin.utexas.edu.

ÖRČID

Yuri Jang http://orcid.org/0000-0001-8239-1778

DISCLOSURE

The authors have reported no conflicts of interest.

1 INTRODUCTION

With population ageing, Alzheimer's disease (AD) has become a public health priority (Alzheimer's Disease Education and Referral Center, 2016; Centers for Disease Control and Prevention, 2016). Currently, 5.4 million Americans are living with AD, and these numbers are anticipated to reach 16 million by 2050 (Alzheimer's Association, 2016). The total cost of caring for those with AD in 2016 was estimated to be \$236 billion, about 68% of which being covered by Medicare and Medicaid (Alzheimer's Association, 2016).

According to a national survey (Harris Interactive, 2011), AD ranked as one of the most feared diseases, but fewer than one in five Americans had made any plans for the possibility of getting AD, which may include designation of care providers, consideration of care options, family conversation and financial arrangement. Such unpreparedness is particularly notable in racial/ethnic minorities. Studies have consistently shown that racial/ethnic minorities have a lack of knowledge and misconceptions of AD, delayed AD diagnosis and underutilisation of AD-related services (Alzheimer's Association, 2016; Ayalon & Areán, 2004; Cooper, Tandy, Balamurali, & Livingston, 2010). Responding to the scarcity of information on Asian Americans, the aim of this study was to explore the underlying factors associated with the concerns and plans about AD in Asian Americans.

Although Asian Americans are the fastest growing minority group and the largest group of new immigrants (Pew Research Center, 2013; U.S. Census Bureau 2012), they are often underrepresented in national surveys, and not much is known about their preparedness for AD (Sayegh & Knight, 2013). Although a few studies have addressed AD-related issues using small samples of Asian subgroups (Jang, Kim, & Chiriboga, 2010; Lee, Lee, & Diwan, 2010; Sun, Gao, & Coon, 2015), the diversities within Asian American subgroups warrant a broader scope of investigation. Since Asian cultures place an emphasis on family care-giving (Knight et al., 2002), attention should be paid to concerns not only with regard to one's own development of AD but also with regard to the possibility of having to provide care for someone with AD. In addition, behavioural reactions such as planning and help-seeking activities should also be considered.

As a means of exploring AD concerns and plans, the Health Beliefs Model (HBM; Rosenstock, 1974) offers a useful framework. Originally developed as part of public health promotion efforts in the 1950s, the HBM remains as one of the most widely used theories in health services research (Glanz, Rimer, & Lewis, 2002). The model highlights the importance of the attitudes and beliefs of individuals in their health-related decision-making. Subjective perceptions of a disease and evaluations of the associated costs and benefits play a key role in initiating/maintaining health behaviours. The model has been modified to incorporate social and cultural factors (Sayegh & Knight, 2013) and applied to racial/ethnic minorities in the context of dementia-related care-seeking behaviours (Sayegh & Knight, 2013; Sun et al., 2015).

Following the HBM, we conceptualised concerns about AD (both concerns about one's own development of AD and about becoming an AD caregiver) as perceived threats and planning for AD as behavioural reactions to the threat. Informed by related literature (e.g. Corrigan,

Morris, Michaels, Rafacz, & Rüsch, 2012; Cutler & Hodgson, 2001; Sayegh & Knight, 2013; Sun et al., 2015), we focused on three domains as potential predictors. The first domain is prior exposure to AD. Personal experience of having a family member or friend affected by AD influences an individual' perceptions and understandings of AD (Cutler, 2015; Lee et al., 2010). AD literacy, here defined as knowledge about AD and awareness of AD-related community and social services, is a second domain. Studies show that AD literacy plays a key role in determining individuals' attitudes towards the disease and careseeking behaviours (Jang et al., 2010; Lee et al., 2010; Sayegh & Knight, 2013; Sun et al., 2015).

The final domain is related to cultural beliefs. Misconceptions and negative views about AD held by a particular cultural group may not only increase concerns about the disease but also pose barriers to early detection and treatment-seeking (Dilworth-Anderson & Gibson, 2002; Sayegh & Knight, 2013). One of the most common misconceptions about AD is that its symptoms represent a normal—and thus unavoidable—part of ageing (Cahill, Pierce, Werner, Darley, & Bobersky, 2015). Such normalisation is also linked to a sense of helplessness and fatalism (i.e. developing Alzheimer's disease is a matter of fate).

Another belief has to do with stigma. Although avoidance of social contacts is a common form of stigmatisation towards persons with mental and cognitive impairments across cultural groups (Corrigan et al., 2012), dishonour and shame to the family name are disproportionately displayed among Asians whose cultures emphasise saving face and bringing honour to the family (Braun & Browne, 1998; Lee et al., 2010). Such stigma linked to shame in Asian cultures may be responsible for a general reluctance to seek help outside the family and, most importantly, the reluctance to place a family member with AD in a nursing home.

Based on the existing literature, we hypothesised that exposure to AD, AD literacy and cultural beliefs about AD would affect concerns about having AD and having to provide care to someone with AD. In addition, we expected that having such concerns would make people plan for the possibility of AD. The understanding of the factors associated with the concerns and plans about AD would be useful for developing AD-related social and medical services and programmes tailored to the unique needs of Asian Americans.

2 METHODS

2.1 Sample

Data were drawn from the 2015 Asian American Quality of Life (AAQoL) survey. The survey is part of the City of Austin's AAQoL initiative which had been prompted by the area's rapid growth of the Asian American population. Currently, an estimated 110,000–115,000 Asians live in metropolitan Austin, and the size of the Asian community has doubled every 12 years (City of Austin, 2017). The AAQoL survey was conducted with self-identified Asian Americans aged 18 and older living in the Austin area. Although the survey primarily relied upon convenience sampling, special efforts were made to mirror the ethnic composition of the Asian population in the area. As identified by the U.S. Census Bureau (2012), the five largest Asian groups in the Austin area include Asian Indian, Chinese,

Vietnamese, Korean and Filipino. These groups comprise about 87% of the total Asian population in the area and were the focus of recruitment efforts.

The 10-page questionnaire for the AAQoL survey was originally developed in English and then translated into the languages being used by the aforementioned major Asian groups: Chinese (both simplified and traditional Chinese versions), Vietnamese (Vietnamese), Korean (Korean), Asian Indian (Hindi and Gujarati) and Filipino (Tagalog). The initial translations were conducted by eight professional translators and graduate-level bilingual researchers. For each language, the translated version was reviewed for accuracy by two or more bilingual volunteers. Upon refinement of the questionnaire, each language version was pilot tested with 3–5 community members who were representative of the target group and spoke the target language; their feedback was incorporated into the final version.

Surveys were conducted using paper and pencil questionnaires in the participants' preferred language. Recognising that Asian Americans are often difficult to locate using standard recruitment strategies and that reliance on a single source can increase the chances for bias (Islam et al., 2010), multiple potential survey sites were contacted. In addition, the project was publicised through media and ethnic community sources, and referrals for individuals, groups and organisations were actively sought. From August to December 2015, a total of 76 survey sessions took place at churches, temples, grocery stores, small group meetings and cultural events across the City of Austin. Although surveys were self-administered, bilingual research assistants were present at each survey site for assistance. It took about 20 min to complete the 10-page questionnaire, and respondents were each paid US \$10 for their participation. The project was approved by the university's institutional review board (IRB), and the consenting procedure was conducted as instructed by IRB. A total of 2,614 individuals participated. After removing cases with missing information, the final sample size was 2,609. More information on survey procedures and sample characteristics is available elsewhere (City of Austin, 2017).

2.2 Measures

- **2.2.1 Concerns and plans about AD**—Concerns and plans about AD were assessed with three items adopted from the MetLife Foundation Alzheimer's Survey (Harris Interactive, 2011). The two questions ("How concerned are you that you may have Alzheimer's disease someday?" and "How concerned are you that you may someday have to provide care for someone with Alzheimer's disease?") address concerns about the possibility of one's own development of AD and of becoming a caregiver of an AD patient. The original four-point responses were dichotomised into "not at all"/"not very much" (0) and "somewhat"/"very much" (1). Plans about AD were measured by asking participants whether they made any plans for the possibility of having AD. Responses were coded as "yes" (1) or "no" (0).
- **2.2.2 Prior exposure to AD**—Participants were asked to indicate if any of their family members or friends had AD, using a "yes" (1) or "no" (0) response format.
- **2.2.3 Literacy about AD**—Knowledge level about AD was measured by asking participants how much they knew about AD on a 4-point scale. Responses were

dichotomised into "not at all"/"not very much" (0) and "somewhat"/"very much" (1). Awareness of AD-related services was measured by asking participants whether they knew of any local services and programmes for AD patients and family members, such as adult daycare services, support groups and home healthcare services. Responses were coded as "yes" (1) or "no" (0).

2.2.4 Cultural beliefs about AD—Five questions adapted from previous studies (e.g. Jang et al., 2010; Lee et al., 2010; Sun et al., 2015; Werner, Goldstein, & Heinik, 2011) assessed beliefs about AD. Participants were asked to indicate whether they agreed with each of the following statements: (1) Alzheimer's disease is a normal process of ageing, (2) developing Alzheimer's disease is a matter of fate, (3) social interactions with a patient with Alzheimer's disease should be avoided, (4) it is embarrassing to have a family member with Alzheimer's disease, and (5) it is not right to place a family member with Alzheimer's disease in a nursing home. Responses were coded as "yes" (1) or "no" (0).

2.2.5 Background variable—Covariates included age (0 = 18-39, 1 = 40-59, 2 = 60 and older), gender (0 = male, 1 = female), marital status (0 = married, 1 = not married), education (0 = high school), ethnic origin (0 = Chinese, 1 = Asian Indian, 2 = Korean, 3 = Vietnamese, 4 = Filipino, 5 = Other Asian), time in the United States (0 = 10 years), and self-rated health (0 = excellent/very good/good, 1 = fair/poor).

2.3 Analytic strategy

Descriptive characteristics of the overall sample and each of the ethnic groups were assessed. Ethnic group differences were assessed with chi-square tests. Where appropriate, Chinese were used as a reference group because they are the largest and most-studied Asian subgroup. Spearman's rank-order correlations assessed the associations among study variables. Logistic regression models were estimated for each of the three outcomes: (1) concerns about one's own development of AD, (2) concerns about becoming an AD caregiver, and (3) plans about AD. Both types of concerns were entered as predictors in the model of AD plans. All analyses were performed using IBM SPSS Statistics 24.

3 RESULTS

3.1 Characteristics of the sample

Sample characteristics are summarised in Table 1. The sample includes 2,609 participants: 640 Chinese (24.5%), 574 Asian Indians (22%), 471 Koreans (18.1%), 513 Vietnamese (19.7%), 265 Filipinos (10.2%) and 146 individuals from other Asian groups (5.6%). The mean age of the overall sample was 42.8 years old (SD = 17.1) with a range from 18 to 98. About 21% of the participants were aged 60 and older. More than half (55.2%) were female, 33.4% were not married and 18.6% had less than a high school education. The length of residence in the United States averaged 15.6 years (SD = 12.7) with 42% staying fewer than 10 years in the United States. Approximately 11% of the sample rated their health as either fair or poor.

About 16% of the sample reported they had a family member or friend with AD. While more than half (55.5%) reported that they were at least somewhat knowledgeable about AD, only about 8% knew of any local services and programmes related to AD. With respect to cultural beliefs, nearly a half of the sample believed that AD is part of the normal process of ageing, and 14% of the sample considered developing AD to be a matter of fate. A similar portion of the sample associated AD with social avoidance (5.6%) and family embarrassment (5.9%). More than a quarter (30%) of the sample presented a negative view regarding placement of a family member with AD in a nursing home. At a more personal level, about 18% of the sample indicated they had concerns about their own development of AD, and slightly more (21%) were concerned about the possibility of becoming an AD caregiver. Approximately 12% of the sample had plans for the possibility of AD.

Table 1 also presents ethnic group differences. All ethnic groups had a similar rate of personal exposure to individuals with AD. Chinese had the lowest level of reported AD knowledge of all groups (38.1% vs. 48.8%–70.8%). Compared with Chinese (6.9%), Filipinos (16.2%) and other Asians (13.4%) were more likely to be aware of AD-related services. Viewing AD as a normal process of ageing was particularly common among Vietnamese (63.2%). Except for the "other" Asian group, all ethnic groups were less likely to see the presence of AD as a family disappointment (2.4%–6.4%) than did Chinese (9.9%). Negative views on nursing home placement were most common among Filipinos (38%), followed by Vietnamese (36.1%) and Asian Indian (35.8%) groups.

All ethnic groups, except for Asian Indians, demonstrated a higher rate of having concerns both about their own development of AD (19.6%–29% vs. 11.5%) and about the possibility of becoming an AD caregiver (20.6%–29.7% vs. 17%) than did the Chinese. Finally, compared to Chinese (8.6%), a significantly higher proportion of Koreans (12.2%), Vietnamese (25.2%), and Filipinos (14%) had made plans for AD. On the other hand, the rate was significantly lower in Asian Indians (2.3%).

3.2 Correlations among study variables

Spearman's rank-order correlations among study variables were examined (not shown in tabular format). All coefficients were in expected directions, with the largest coefficient observed between the two types of concerns about AD ($r_s = .54$, p < .001). Individuals who were concerned about their own development of AD were also more likely to worry about the possibility of becoming an AD caregiver. Having plans for AD was moderately correlated both with concerns about one's own development of AD ($r_s = .18$, p < .001) and with concerns about the possibility of becoming an AD caregiver ($r_s = .16$, p < .001).

3.3 Predictors of concerns and plans about AD

Logistic regression models of concerns about the possibility of one's own development of AD, becoming an AD caregiver, and planning for AD were estimated, and findings are summarised in Table 2. For both types of AD concerns, higher odds were observed among women, Koreans and Filipinos (in comparison to Chinese), those with prior exposure to AD, those with AD knowledge and awareness of AD-related services, and those who associated AD with a normal part of ageing and considered it as a matter of fate. In addition, increased

odds of having concerns about their own development of AD were associated with the following characteristics: being in the middle-aged (40–59) and older adult (60 and above) groups (in comparison to the young adults aged 18–39). Vietnamese and other Asians (in comparison to Chinese), having a fair/poor health rating, and holding the belief that social contact with an AD patient should be avoided. Time in the United States was the only additional predictor of concerns about becoming an AD caregiver: the odds were reduced by 25% among those who had stayed in the United States fewer than 10 years.

In the logistic regression model of plans for AD, being in the older adult group (60 and above) led to higher odds of having plans compared to the younger age group (18–39). Compared with Chinese, three ethnic groups (Korean, Vietnamese and Filipino) demonstrated increased odds of having plans, but Asian Indians had significantly reduced odds. Knowing persons with AD, AD knowledge, and awareness of AD-related services also increased the odds of having plans for AD. Finally, both concerns about one's own probability of developing AD and about becoming an AD caregiver increased the odds of having plans.

4 DISCUSSION

Responding to the increase of the Asian American population (Pew Research Center, 2013; U.S. Census Bureau, 2012) and the growing imperative to address issues on Alzheimer's disease (AD) in diverse populations (Alzheimer's Disease Education and Referral Center, 2016; Centers for Disease Control and Prevention, 2016), this study examined Asian Americans' concerns about AD (both concerns about one's own development of AD and about becoming an AD caregiver) and plans for AD. Guided by the Health Belief Model (HBM; Glanz et al., 2002; Rosenstock, 1974) and related literature (e.g. Jang et al., 2010; Lee et al., 2010; Sayegh & Knight, 2013; Sun et al., 2015), this study focused on three domains of predictors: AD exposure, AD literacy and cultural beliefs about AD. Our analyses showed that a lack of knowledge and misconceptions of AD served as primary sources of concerns and unpreparedness. Findings not only identified significant predictors of the concerns and plans about AD but also found ethnic differences, providing implications for intervention strategies for diverse groups of Asian Americans.

In the overall sample, the proportion that indicated concerns about their own development of AD and those about the possibility of becoming an AD caregiver was 18% and 21%, respectively. When compared with the findings from the MetLife Foundation Alzheimer's Survey (Harris Interactive, 2011), the present sample demonstrates slightly lower rates of having concerns about becoming an AD care-giver (21% vs. 23%) and having plans on AD (12% vs. 18%). There were also significant variations by ethnic subgroup.

For both types of concerns, Koreans had the highest endorsement followed by Filipino, other Asian, Vietnamese, Chinese and Asian Indian. All groups presented a slightly higher level of concerns about becoming a caregiver than about their own development of AD. About 12% of the total sample reported that they had made plans for the situation in which they themselves would have developed AD. In ethnic subgroups, the rate ranged from 2.3% in

Asian Indians to 25.2% in Vietnamese. Ethnic differences should be attended in prioritising target groups and developing interventions specific to subgroups.

About 16% of the total sample had had a family member or friend with AD, and this rate was substantially lower than the 44% reported in the aforementioned national survey (Harris Interactive, 2011). The perceived knowledge level about AD, in contrast, was fairly high, with more than half of the sample (55.5%) reporting that they were at least somewhat knowledgeable. However, only a small proportion of the sample (7.8%) reported that they were aware of AD-related services being offered in their local community. In multivariate analyses, AD exposure and literacy (perceived knowledge and awareness of services) were found to be common predictors of all three outcome measures. Familiarity and knowledge seem to make individuals more susceptible to worries but enable them to prepare for the disease.

The various subgroups generally held beliefs about AD, which suggests that these groups might not seek formal help. For example, nearly half of the sample believed that AD is a normal part of the ageing process. Vietnamese, in particular, stood out; more than 63% of the Vietnamese sample reported this belief. The proportions of the sample considering the development of AD as a matter of fate and endorsing social avoidance were 14% and 5.6%, respectively, with no ethnic differences observed. Approximately 6% of the sample reported that having a family member affected by AD is an embarrassment, and the rate was notably high in Chinese (10%). With regard to nursing home placement of a person with AD, about 30% of the total sample expressed a negative reaction. Such rate was particularly high in Asian Indian (35.8%), Vietnamese (36.1%) and Filipino (38%) but low in Korean (15.8%). In multivariate analyses, the beliefs associated with normalisation and fatalism increased the odds of having concerns about one's own development of AD and possibility of becoming an AD caregiver. For the concerns about having AD, the stigmatism of social avoidance was also associated with increased odds. None of the cultural beliefs were found to be significant in predicting AD plans.

Based on the HBM (Glanz et al., 2002; Rosenstock, 1974), we conceptualised plans for ADs as behavioural reactions to the threat and considered both types of concerns as potential predictors of AD plans. At bivariate level, the correlations of having plans for AD with both types of concerns were significant but modest ($r_s = .16-.18$, p < .001). In multivariate analyses, increased odds of having AD plans were found in those who had concerns about their own development of AD (odds ratio [OR] = 1.70, confidence interval [CI] = 1.15, 2.52, p < .01) and those who had concerns about becoming an AD care-giver (OR = 1.51, CI = 1.03, 2.20, p < .05). Although the effects were modest, the finding confirms that the perceived threat or worry could prompt individuals to plan for the future actions.

Some limitations of this study should be noted. The foremost concern is the limited representativeness of the sample. Although the study successfully reached out to diverse groups of Asian Americans, our sample was regionally defined, and findings cannot be generalised to the larger population of Asian Americans. Another limitation is that the inference of causal directionality cannot be made with the current cross-sectional design. Furthermore, the measures employed in the survey were rather brief. Most constructs in the

study were indicated by a single item with a binary response format. Although the selected items intuitively represent the constructs that the study intends to address, future research should use multi-item instruments with good psychometric properties. Particular attention is needed on the measure of AD literacy since the present assessment relied upon individuals' subjective perceptions of their knowledge of AD and there has been empirical development in the measures of AD literacy (Jang et al., 2010; Lee et al., 2010; Sun et al., 2015). Future studies should also address the details on AD plans such as designation of care providers, consideration of care options, family conversation and financial arrangement.

Despite these limitations, this study identified significant predictors of the concerns and plans about AD and explored ethnic variations. Findings hold implications for interventions with respect to the subgroups to be prioritised and the specific strategies to be employed. Given that a lack of knowledge and misconceptions of AD serve as primary sources of concerns and unpreparedness, the importance of educational interventions, focusing on improving knowledge and awareness of AD and AD-related services, should be highlighted. Reconstructing the beliefs associated with normalisation and stigmatisation of AD is also recommended as a way to ease psychological anxieties associated with AD. Since the concerns were found to serve as an enabler for action, ways to utilise them to promote AD planning should also be considered. Intervention efforts may be prioritised on the groups of individuals who are at particular risk.

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References

- Alzheimer's Association. Alzheimer's disease facts and figures. 2016. Retrieved from https://www.alz.org/documents_custom/2016-facts-and-figures.pdf
- Alzheimer's Disease Education and Referral Center. Alzheimer's disease fact sheet. 2016. Retrieved from https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet
- Ayalon L, Areán PA. Knowledge of Alzheimer's disease in four ethnic groups of older adults. International Journal of Geriatric Psychiatry. 2004; 19:51–57. [PubMed: 14716699]
- Braun KL, Browne CV. Perceptions of dementia, caregiving, and help seeking among Asian and Pacific Islander Americans. Health and Social Work. 1998; 23:262–274. [PubMed: 9834879]
- Cahill S, Pierce M, Werner P, Darley A, Bobersky A. A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. Alzheimer Disease and Associated Disorders. 2015; 29:255–275. [PubMed: 26207322]
- Centers for Disease Control and Prevention. Alzheimer's disease: Promoting health and independence for an aging population. 2016. Retrieved from https://www.cdc.gov/chronicdisease/resources/publications/aag/pdf/2016/alzheimers-agg.pdf
- City of Austin. Asian American quality of life. 2017. Retrieved from http://austintexas.gov/department/documents-3
- Cooper C, Tandy AR, Balamurali TB, Livingston GA. Systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. American Journal of Geriatric Psychiatry. 2010; 18:193–203. [PubMed: 20224516]

Corrigan PW, Morris SB, Michaels PJ, Rafacz D, Rüsch N. Challenging the public stigma of mental illness: A meta-analysis of outcome studies. Psychiatric Services. 2012; 63:963–973. [PubMed: 23032675]

- Cutler SJ. Worries about getting Alzheimer's: Who's concerned? American Journal of Alzheimer's Disease and Other Dementias. 2015; 30:591–598.
- Cutler SJ, Hodgson LG. Correlates of personal concerns about developing Alzheimer's disease among middle-aged persons. American Journal of Alzheimer's Disease and Other Dementias. 2001; 16:335–343.
- Dilworth-Anderson P, Gibson BE. The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. Alzheimer Disease and Associated Disorders. 2002; 16:S56–S63. [PubMed: 12351916]
- Glanz, K.Rimer, BK., Lewis, FM., editors. Health behavior and health education: Theory, research, and practice. San Francisco, CA: Jossey-Bass; 2002.
- Harris Interactive. What America thinks: MetLife Foundation Alzheimer's survey. 2011. Retrieved from https://www.metlife.com/assets/cao/foundation/alzheimers-2011.pdf
- Islam NS, Khan S, Kwon S, Jang D, Ro M, Trinh-Shevrin C. Methodological issues in the collection, analysis, and reporting of granular data in Asian American populations: Historical challenges and potential solutions. Journal of Health Care for the Poor and Underserved. 2010; 21:1354–1381. [PubMed: 21099084]
- Jang Y, Kim G, Chiriboga DA. Knowledge of Alzheimer's disease, feelings of shame, and awareness of services among Korean American elders. Journal of Aging and Health. 2010; 22:419–433. [PubMed: 20194682]
- Knight BG, Robinson GS, Longmire CVF, Chun M, Nakao K, Kim JH. Cross cultural issues in caregiving for persons with dementia: Do familism values reduce burden and distress? Ageing International. 2002; 27:70–94.
- Lee SE, Lee HY, Diwan S. What do Korean American immigrants know about Alzheimer's disease (AD)? The impact of acculturation and exposure to the disease on AD knowledge. International Journal of Geriatric Psychiatry. 2010; 25:66–73. [PubMed: 19551701]
- Pew Research Center. The rise of Asian Americans. 2013. Retrieved from http://www.pewsocialtrends.org/files/2013/04/Asian-Americans-new-full-report-04-2013.pdf
- Rosenstock I. Historical origins of the health belief model. Health Education Monographs. 1974; 2:328–335.
- Sayegh P, Knight BG. Cross-cultural differences in dementia: The sociocultural health belief model. International Psychogeriatrics. 2013; 25:517–530. [PubMed: 23237243]
- Sun F, Gao X, Coon DW. Perceived threat of Alzheimer's disease among Chinese American older adults: The role of Alzheimer's disease literacy. Journal of Gerontology: Psychological Sciences and Social Sciences. 2015; 70:245–255.
- U.S. Census Bureau. The Asian population: 2010. 2012. Retrieved from https://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf
- Werner P, Goldstein D, Heinik J. Development and validity of the family stigma in Alzheimer's disease scale (FS-ADS). Alzheimer Disease and Associated Disorders. 2011; 25:42–48. [PubMed: 20921880]

What is known about this topic

• AD ranked as one of the most feared diseases, but most Americans had not made any plans for the possibility of having AD.

Asian Americans are the fast-growing but understudied population in AD-related research.

What this paper adds

- About 18% of the present sample of Asian Americans indicated that they had concerns about their own development of AD, and slightly more (21%) were concerned about the possibility of becoming an AD caregiver. Approximately 12% of the sample had plans for the possibility of AD.
- A lack of knowledge and misconceptions of AD served as primary sources of concerns and unpreparedness.

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TABLE 1

Descriptive characteristics of the sample

	Total $(N = 2,609)$	Chinese $(n = 640)$	Asian Indian ($n = 574$)	Korean $(n = 471)$	Vietnamese ($n = 513$)	Filipino ($n = 265$)	Other Asian ($n = 146$)
Background variable							
Age							
18–39	48.3	47.0	68.6	38.9 ***	39.0 ***	42.2 ***	47.9**
40-59	31.2	27.7	14.3 ***	40.2 ***	38.4 ***	41.4 ***	39.7**
+09	20.5	25.3	17.1 ***	20.9 ***	22.4 ***	16.3 ***	12.3**
Gender (female)	55.2	57.0	39.9	60.5	57.5	70.0	54.8
Marital status (not married)	33.4	36.3	25.2 ***	25.7 ***	41.7	40.3	36.6
Education (<high school)<="" td=""><td>18.6</td><td>14.2</td><td>7.6***</td><td>20.3 **</td><td>36.3</td><td>16.2</td><td>20.0</td></high>	18.6	14.2	7.6***	20.3 **	36.3	16.2	20.0
Time in the United States (<10 years)	41.7	41.0	86.0 ***	37.2	26.0***	30.8	37.9
Self-rated health (fair/poor)	10.6	16.3	7.0***	15.4	6.4 ***	6.1 ***	8.2*
AD exposure							
Had a family member and/or friend with AD	16.3	19.4	8.2	22.1	11.8	21.9	19.7
AD literacy							
Perceived knowledge about AD (somewhat/very much knowledgeable)	55.5	38.1	48.8 ***	70.8	62.2 ***	68.3 ***	61.4 ***
Awareness of AD-related services	7.8	6.9	4.5	7.1	7.3	16.2 ***	13.4*
Cultural beliefs about AD							
AD is a normal process of ageing	49.3	49.1	43.0*	48.6	63.2 ***	42.6*	40.6*
Developing AD is a matter of fate	14.0	13.3	15.2	11.2	15.0	16.0	14.7
Social interaction with people with AD should be avoided	5.6	4.3	5.9	6.0	6.1	6.5	5.6
It is embarrassing to have a family member with AD	5.9	6.6	6.4	2.4 ***	5.2 **	3.1 ***	5.6
It is not right to place a family member with AD in a nursing home	30.0	27.1	35.8**	15.8***	36.1**	38.0 **	31.4
Outcome variable							

	%						
	Total $(N = 2,609)$	Chinese $(n = 640)$	Chinese $(n = Asian Indian (n Korean (n = 640) = 574)$ 471)	Korean $(n = 471)$	Vietnamese $(n = 513)$	Filipino $(n = 265)$	Other Asian (n) = 146
Concern about having AD	17.7	11.5	8.7	29.0	19.6 ***	24.6 ***	23.6 ***
Concern about having to provide care for someone with AD	21.0	17.0	14.3	29.7 ***	20.6*	29.2 ***	25.2*
Plans for the possibility of AD	11.6	9.8	8.6 2.3 ***	12.2 *	25.2 ***	14.0*	7.0

 χ^2 analyses were conducted by comparing each ethnic group with Chinese.

p < .01; p < .01; p < .001.

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TABLE 2Regression models of concerns and plans about Alzheimer's disease (AD)

	Odds ratio (95% confidence	interval)	
	Concern about having AD	Concern about having to provide care for someone with AD	Plans for the possibility of AD
Background variable			
Age (ref = 18–39)			
40–59	1.67**(1.23, 2.25)	1.08 (0.81, 1.42)	0.94 (0.64, 1.38)
60+	1.44*(1.01, 2.04)	0.92 (0.66, 1.27)	2.11 *** (1.42, 3.14)
Female	1.33*(1.04, 1.69)	1.31*(1.05, 1.63)	1.02 (0.77, 1.36)
Not married	1.05 (0.81, 1.39)	0.95 (0.74, 1.22)	1.03 (0.75, 1.43)
<high school<="" td=""><td>0.96 (0.71, 1.29)</td><td>1.20 (0.91, 1.60)</td><td>1.24 (0.88, 1.74)</td></high>	0.96 (0.71, 1.29)	1.20 (0.91, 1.60)	1.24 (0.88, 1.74)
Ethnicity (ref = Chinese)			
Asian Indian	0.98 (0.64, 1.50)	1.02 (0.71, 1.45)	0.27***(0.13, 0.54)
Korean	2.65 *** (1.86, 3.79)	1.60**(1.16, 2.23)	1.56*(1.01, 2.42)
Vietnamese	1.66*(1.13, 2.44)	1.11 (0.79, 1.58)	3.78***(2.52, 5.68)
Filipino	2.12**(1.39, 3.22)	1.55*(1.06, 2.27)	1.91*(1.15, 3.18)
Other	2.11**(1.28, 3.51)	1.49 (0.94, 2.39)	1.05 (0.51, 2.18)
Time in the United States <10 years	0.90 (0.69, 1.17)	0.75*(0.58, 0.96)	0.99 (0.72, 1.37)
Fair/poor rating of health	1.52*(1.06, 2.18)	1.13 (0.79, 1.62)	1.04 (0.66, 1.65)
AD exposure			
Had a family member and/or friend with AD	1.95****(1.48, 2.55)	2.35 *** (1.83, 3.03)	2.75 *** (1.96, 3.87)
AD literacy			
Perceived knowledge about AD	1.81 *** (1.40, 2.35)	1.63***(1.29, 2.06)	1.84**(1.29, 2.62)
Awareness of AD-related services	1.66**(1.15, 2.42)	1.51*(1.06, 2.17)	6.51 *** (4.32, 9.81)
Cultural beliefs about AD			
AD is a normal process of ageing	1.63 *** (1.28, 2.07)	1.39**(1.12, 1.73)	1.36 (0.99, 1.88)
Developing AD is a matter of fate	1.65**(1.22, 2.25)	1.37*(1.03, 1.84)	0.90 (0.58, 1.42)
Social interaction with people with AD should be avoided	1.67*(1.02, 2.71)	1.52 (0.96, 2.43)	0.82 (0.41, 1.65)
It is embarrassing to have a family member with AD	1.01 (0.58, 1.73)	1.00 (0.61, 1.65)	1.87 (0.98, 3.58)
It is not right to place a family member with AD in a nursing home	1.09 (0.84, 1.41)	1.21 (0.96, 1.54)	1.04 (0.75, 1.46)
AD concerns			
Concern about having AD	-	-	1.70**(1.15, 2.52)
Concern about having to provide care for someone with AD	-	-	1.51*(1.03, 2.20)
Summary statistic	−2 Log likelihood = 1,891.3	-2 Log likelihood = 2,163.9	−2 Log likelihood = 1,181.

Odds ratio (95% confidence	interval)	
Concern about having AD	Concern about having to provide care for someone with AD	Plans for the possibility of AD
$\chi^2/df = 232.6^{***}/20$	$\chi^2/df = 173.3^{***}/19$	$\chi^2/df = 324.6^{***}/22$

Sample sizes are 2,234, 2,228 and 2,209, respectively, for the models of the concern about having AD, concern about having to provide care for someone with AD, and plans for the possibility of AD. Reference group for the variable with more than two attributes is noted in the parentheses.

- *p < .05;
- ** p<.01;
- *** p<.001.