

UCLA

AAPI Nexus: Policy, Practice and Community

Title

Perceptions of Dementia among Asian Indian Americans

Permalink

<https://escholarship.org/uc/item/08g310d0>

Journal

AAPI Nexus: Policy, Practice and Community, 6(2)

ISSN

1545-0317

Authors

Otilingam, Poorni G.
Gatz, Margaret

Publication Date

2008

Copyright Information

This work is made available under the terms of a Creative Commons Attribution-NonCommercial-NoDerivatives License, available at <https://creativecommons.org/licenses/by-nc-nd/4.0/>

Peer reviewed

Research Article

Perceptions of Dementia among Asian Indian Americans

Poorni G. Otilingam and Margaret Gatz

Abstract

We surveyed a convenience sample of 255 Asian Indian Americans (AIAs) aged eighteen to eighty-one years that assessed their perceptions of dementia etiology, help seeking, and treatment and their knowledge of symptoms of Alzheimer's disease (AD). In response to a vignette describing the early stages of AD, participants indicated a substantial willingness to seek help. Most participants knew that memory loss was the key symptom of dementia, yet most knowledge items were correctly answered by fewer than half of the sample. Participants who had more knowledge of AD were more likely than those with less knowledge of AD to state that they would seek help for an elderly relative showing symptoms of dementia. Relative to other psychosocial factors, loneliness was highly rated as an etiological factor and keeping mentally active was highly rated as a treatment. This study is the first to document dementia beliefs among AIAs, illustrating the need for culturally tailored dementia education and care for the AIA population.

Introduction

Despite enormous heterogeneity within the Asian American population (U.S. Bureau of the Census, 2000a, 2000b), some ethnic subgroups, including Asian Indian Americans (AIAs), referring to people of Indian heritage either born and/or currently residing in the United States, remain invisible in otherwise aggregated studies aimed at understanding "Asian Americans'" concepts of disease, diagnosis, and treatment (Srinivasan and Guillermo, 2000). Specifically, there is a paucity of information about AIAs' views of dementia and its etiology, symptoms, help seeking, and treatment, although such information exists for other Asian American

subgroups (Braun, Takamura, and Mougeot, 1996; Elliot et al., 1996; McBride and Parreno, 1996; Tempo and Saito, 1996; Hinton and Levkoff, 1999). Studies that describe AIAs' dementia perceptions are sorely needed. Although at one time it was thought that dementia had a particularly low prevalence among South Asian Indians, it is likely that this finding is driven—at least in part—by differences in life expectancy (Ferri et al., 2005). Importantly, prevalence of dementia among immigrant South Asian Indians tends to be higher than among South Asian Indians in India (Ganguli et al., 2000). This increased prevalence may reflect modifiable risk factors, an observation with clear public-health implications. Of particular concern is AIAs' increased risk for diabetes and hypertension (risk factors for dementia) (Stewart, Prince, and Mann, 1999; Jonnalagadda and Diwan, 2005).

It is well understood that culture influences disease perceptions (Kleinman, 1980; Cameron and Leventhal, 2003; Lawton, 2003), including health care beliefs (Kleinman 1980). As Kleinman (1980) suggests, disease perceptions interact with individuals' decisions as to whether to seek a healer and, if so, which healer to seek within local health care systems (e.g., folk, popular, professional). With regard to etiology, AIAs often do not distinguish between religious and medical beliefs when it comes to understanding disease (Ramakrishna and Weiss, 1992). Landrine and Klonoff (2001) suggest that an illness-attribution hierarchy also may exist, with supernatural forces as the most proximal and biomedical factors as the most distal. Treatment principles emphasize the need to restore emotional, bodily, interpersonal, and/or spiritual balance (e.g., mind/body, person/environment) (Ramakrishna and Weiss, 1992). AIAs also may supplement medical beliefs with health and illness principles obtained from a traditional Indian medical system otherwise known as Ayurveda. Ayurveda advocates limited means of treatment (e.g., dietary changes, herbal remedies usage) to restore a healthy balance in vital elements (Ghandi, 1965). Although Ayurveda is the dominant traditional influence, other influences on health beliefs exist, including folk cures, faith healers, rituals, tea consumption, and meditation (Ramakrishna and Weiss, 1992; Landrine and Klonoff, 2001). Additionally, differences have been found to exist when it comes to ethnic minorities seeking help for mental health care as compared to Caucasians (Sue et al., 1995). Dementia help seeking among AIAs, in the United States

or elsewhere, has rarely been studied (Bowes and Wilkinson, 2003); however, it has been shown that among foreign-born AIAs, mental help seeking is negatively associated with age at immigration (Panganamala and Plummer, 1998).

Understanding perceptions of particular diseases, such as dementia, by specific ethnic populations is critical to identifying new ways to ensure timely dementia help seeking and to provide culturally embedded treatment interventions. The aim of the present study is to describe AIAs' perceptions of dementia etiology, help seeking, and treatment and their knowledge of symptoms of Alzheimer's disease (AD). Based on the data, we discuss implications for health care and social services and for public-health education related to differences in dementia perceptions.

Methods

Data Collection

Study location. The San Francisco Bay Area was chosen as the site of data collection for the following reasons. Asian Americans and Pacific Islanders are the United States' fastest-growing immigrant group (U.S. Bureau of the Census, 2000a, 2000b). The majority live in the western United States (U.S. Bureau of the Census, 2000a). AIAs constitute the third-largest Asian subgroup in the United States, with a population of more than 1.8 million (U.S. Bureau of the Census, 2000c). California has the largest concentration of AIAs (more than 314,000) (U.S. Bureau of the Census, 2000d). Moreover, six of ten places in the United States with a population of at least 100,000 that had the highest percentage of Asian Americans were in the San Francisco Bay Area (U.S. Bureau of the Census, 2000a).

Focus-group sample. A preliminary version of the measures was pilot tested among a snowball sample of fourteen (8 male, 6 female) AIA focus-group participants in order to determine which vignette better reflected the ambiguity families often report when seeking a diagnosis. Focus-group participants were asked to read two vignettes (Patel and Prince, 2001; modified and used with permission) designed to ascertain whether a layperson is aware that the hypothetical older adult relative with neurodegenerative symptoms presented in the vignette has either early or later stage dementia. Based on focus-group feedback, the early stage vignette was chosen for inclusion in the questionnaire (see Appendix). The

early stage vignette was modified to refer to a female relative rather than to an unspecified older adult.

Members were asked to complete the draft questionnaire, and based on feedback from focus-group participants, a “do not know” (DNK) response option was provided for relevant questionnaire items. Focus-group members were excluded from participating in the remaining portion of the study.

Survey sample. A convenience sample of 255 AIA adults was administered the edited questionnaire. The sample size was determined by a robust test of power based on the number of variables in the study. Recruitment was through flyers and discussions held by the first author at the following five locations: two Indian restaurants (N = 196); a religious event (N = 28); a high-technology corporation (N = 17); and an Indian senior community center (N = 14). Indian restaurants were chosen because they often serve as informal community-gathering centers.

Measures

Data collection entailed a self-administered cross-sectional survey with open- and closed-ended questions. Questions encompassed dementia identification, etiology, help seeking, treatment, and symptoms. We adapted existing scales and developed scales where none were available. Each group of items was refined through focus-group feedback and exploratory factor analysis, with the resulting scales subjected to an item analysis in order to obtain a Cronbach’s alpha estimate of internal consistency. Inclusion of items on subscales was decided based on factor loadings. Each survey consisted of 110 items and took up to thirty minutes to complete. The survey was administered in English.

Demographic information. Items included age, sex, race, marital status, completed educational level (in home country, host country, or elsewhere), birth country, amount of time spent living in the United States, religious affiliation, and household income. Level of education was grouped into two categories: college education or less (n = 105) and some graduate education or more (n = 149). One participant did not report education. Sample size was insufficient to delineate the educational subgroups further, particularly at the lower end (e.g., there were only 14 respondents who had a technical or associate’s degree or less in terms of formal education).

Vignette. Participants were presented with a modified vignette (see Appendix) of a hypothetical case of early stage dementia (Patel and Prince, 2001). To avoid cueing problems, the vignette appeared as the first item in the questionnaire. Vignettes may be used to elicit respondents' automatically generated beliefs and meanings (Alexander and Becker, 1978). The vignette was immediately followed by two questions. First, participants were asked to "describe what you believe is happening to this relative," and second, participants were asked to choose one of the following categories to describe what, if anything, the hypothetical older relative is experiencing: "physical disorder," "mental disorder," "combination of physical and mental disorder," "another type of disorder," and "not a disorder." Open-ended responses to the vignette were examined using emergent thematic analysis, in which themes were created from emergent rather than *a priori* codes (Miles and Huberman, 1994). Responses were then cross-checked against the entire dataset, and responses that clustered together were formed into four different themes, which are presented in the results. Themes and placement of responses into the four themes were confirmed by a second rater. Themes are shown in Table 1.

The terms *dementia* and *Alzheimer's disease* were not introduced in the survey until participants had been administered the vignette and its associated questions as well as items regarding their beliefs about dementia etiology, help seeking, and treatment. All of these items were asked in reference to "the problem that your relative is experiencing". The survey instructions then stated that the next questions would be about participants' knowledge of dementia. This instruction was followed by the items on general knowledge of dementia, specific knowledge of dementia symptoms, and demographics.

Etiological beliefs about dementia were measured with thirteen items, prefaced by "how important do you believe the following factors are in contributing to what your relative is experiencing?" Items were answered on a five-point scale (1 = "not at all important" to 5 = "extremely important"). Original sources of these items are indicated in Table 2. A DNK response option that did not enter into subscale score calculation was added following focus-group feedback. An exploratory factor analysis with orthogonal rotation guided the creation of two subscales: "Western etiological beliefs" ($\alpha = 0.84$) and "Eastern etiological beliefs" ($\alpha =$

Table 1: Emergent Themes from Vignette Responses (N = 255)

Theme	Example responses	Frequency
AD or dementia		N = 123
Memory problems	<p>“she is getting old and senile”</p> <p>“normal old age; she is just losing her memory because of age”</p> <p>“losing control over memory; not able to register new information to the memory properly” “short term memory loss w[ith] age (old age)”</p> <p>”I think this relative is suffering from amnesia in which there is loss of memory so she gets confuses with different things & not able to remembr [sic] things properly”</p> <p>“chittabrahm—forgetfulness, comes to many old people but total forgetfulness as described above indicates something wrong with memory cell in the brain”</p>	N = 68
Normal aging	<p>“age is catching up which is normal with age”</p> <p>“I believe that its general, if people go above 75 it happens”</p> <p>“just becoming old; part of life”</p> <p>“old age syndrome”</p> <p>“I feel it’s a normal symptoms over 75 years . . . age and health condition is the cause for it . . . keep a close eye of her and take care of her”</p> <p>“old age is the problem and a sense that she may be coming towards the end of her life which is why she keeps talking about her past more often”</p>	N = 40
Mental health concerns	<p>“she must have some kind of psychological problem. In past she must have some worry or shock”</p> <p>“person is suffering from a progressing mental disorder”</p> <p>“this is because of age and loneliness . . . there must be no interaction for her with other people to make her healthy”</p> <p>“this relative is under heavy emotional stress . . . feels insecure about her subsistence”</p> <p>“mental stress”</p> <p>“she is feeling lonely . . . she has nobody [in] the family to talk [to]”</p>	N = 16

Table 2: Response Percentages for Etiological Beliefs about Dementia

Item	n	Not At All Important	A Little Important	Somewhat Important	Very Important	Extremely Important	Do Not Know
Stress ^{1,3}	254	2.8	8.7	27.6	34.7	19.3	7.1
Exposure to toxic materials (e.g., aluminum) ^{1,3}	251	6.8	9.2	24.3	18.3	10.0	31.5
Mental illness (e.g., clinical depression) ^{1,3}	254	2.8	4.7	28.0	29.6	24.0	11.0
Loneliness ^{1,4}	253	2.0	6.3	21.7	35.2	27.3	7.5
Karma (past misdeeds) ^{2,4}	251	49.0	13.6	10.4	4.4	4.0	18.7
God's will ^{2,3}	252	43.3	13.9	10.7	6.8	8.3	17.1
Genetics/heredity ^{1,3}	251	5.9	14.7	26.7	24.7	16.3	12.0
Evil spirits ^{2,4}	255	72.2	7.8	2.4	1.6	0.0	16.1
Supernatural forces ^{2,4}	255	70.2	8.6	3.5	0.8	1.6	15.3
Drinking alcohol too much ^{1,3}	252	16.3	11.9	19.1	19.4	17.5	15.9
Smoking too much ^{1,3}	252	15.9	9.9	24.2	17.1	17.1	15.9
Head injury ^{1,3}	252	8.7	6.4	21.8	27.4	25.0	10.7
Older age ^{1,3}	253	0.8	4.0	20.2	32.0	39.5	3.6

¹Western etiological beliefs subscale; range 1–5, where 1 = not at all important and 5 = extremely important.

²Eastern etiological beliefs subscale; range 1–5, where 1 = not at all important and 5 = extremely important.

³Source: Boston University Medical Center's Alzheimer's Disease Treatment and Illness Perceptions Survey (Roberts et al., 2003; Roberts, unpublished survey used with permission).

⁴Source: Focus-group recommendation.

0.78). Notably, of four items generated from focus-group feedback, three were categorized as Eastern beliefs.

Dementia help-seeking intentions were measured with six items shown in Table 3 concerning when to seek treatment ($\alpha = 0.73$). These items were developed for this study based on the social psychological literature about help seeking. Beliefs about help

Table 3: Mean Scores and SDs for Dementia Help-Seeking Belief Items

Item	Mean	SD
I believe that my relative needs to seek help at some point.	4.4	0.9
I believe that my relative's condition will continue to worsen if no help is sought.	4.3	1.0
I believe that my relative should seek help within one year.	4.1	1.2
I believe that my relative will get better on her own (R).	1.7	1.0
It is important to get an early diagnosis for whatever ails her.	4.5	0.8
It is not necessary to seek help unless or until the symptoms become more serious (R).	2.0	1.2

Note: (R) indicates an item that was reverse coded before computing a total score.

seeking were chosen for inclusion because health-behavior literature identifies the intention to seek help as the most salient predictor of actual help seeking (Ajzen and Madden, 1986; Ajzen, 1991; Ajzen and Driver, 1991). Presented with the instruction “read each statement about your relative and indicate the degree to which you agree or disagree, remembering to keep in mind the relative in the story from above,” each item was answered on a five-point scale (1 = “strongly disagree” to 5 = “strongly agree”).

Dementia treatment beliefs were measured with fourteen items listing potential treatments for dementia based on Roberts (Roberts et al., 2003; Roberts unpublished survey used with permission) and Parekh (2000) and modified after focus-group discussion to include the DNK response option and add items deemed missing (as shown in Table 4). Participants were instructed: “if your relative was to seek some sort of treatment or help, how effective do you believe the following are in reducing your relative’s memory troubles?” Responses were recorded on a five-point scale (1 = “not effective” to 5 = “extremely effective”) or a DNK response option that did not enter into the subscale score calculation. Exploratory factor analysis suggested three subscales: 1) traditional treatments characteristic of Eastern philosophy (Cronbach’s alpha

Table 4: Response Percentages for Dementia Treatment Beliefs

Item	n	Not Effective	A Little Effective	Somewhat Effective	Very Effective	Extremely Effective	Do Not Know
Medications (e.g., Aricept, Exelon, Reminyl)	252	3.2	9.9	37.7	26.2	7.9	15.1
Vitamins (e.g., Vitamin E) ³	249	2.8	14.1	28.1	10.8	3.6	40.6
Keeping physically active ²	252	0.8	7.9	25.4	37.3	19.1	9.5
Keeping mentally active ²	243	1.2	3.3	20.6	38.3	28.8	7.8
Prayer and/or religious ceremonies, rituals ¹	249	12.9	17.3	26.5	14.9	13.3	15.3
Estrogen replacement therapy ³	253	16.2	11.1	11.5	4.4	0.4	56.5
Herbal, natural, or dietary supplements (e.g., ginkgo) ³	252	9.9	12.7	25.4	9.1	4.4	38.5
Eating a proper, healthy diet ²	254	2.8	9.1	24.4	37.0	18.1	8.7
Keeping emotional stress low ²	254	1.2	6.3	20.9	35.4	29.1	7.1
Eating nuts (e.g., almonds) ³	249	14.5	10.8	16.1	7.2	5.2	46.2
Eating a vegetarian diet ¹	253	17.4	11.9	17.0	15.8	12.7	25.3
Seeking the advice of a spiritual astrologer ¹	255	51.0	11.8	12.2	2.8	2.4	20.0
A change of environment ¹	255	10.2	15.7	31.0	15.3	10.6	17.3
Attending a place of worship (e.g., a temple or church) ¹	255	13.3	17.7	27.1	14.1	10.2	17.7

¹Traditional treatments characteristic of Eastern philosophy.

²Activity-based treatment.

³Nutrition-based treatment.

= 0.81), 2) activity-based treatments (Cronbach's alpha = 0.85), and 3) nutrition-based treatments (Cronbach's alpha = 0.75). Based on the results of the factor analysis and item analysis, medication use could not be included on any of the subscales.

Symptom knowledge. General knowledge of dementia and specific knowledge of dementia symptoms were measured with eighteen true/false items shown in Table 5 from the Boston University Medical Center's Alzheimer's Disease Treatment and Ill-

Table 5: Percentage of Responses for Knowledge of Dementia and Dementia Symptoms

Item	Correct (%)	Incorrect (%)	Don't know (%)
General dementia knowledge (correct answer)			
The primary symptom of AD is memory loss (true) (n = 252)	66.3	2.4	31.4
Most people with AD live in nursing homes (false) (n = 252)	35.3	11.1	53.6
The first signs of AD usually occur before age 60 (false) (n = 251)	20.7	19.1	60.2
Men are more likely to develop AD than women (false) (n = 251)	9.6	19.1	71.3
Scientists have discovered a gene that causes most types of AD (false) (n = 250)	8.0	13.2	78.8
Drugs are available to treat the symptoms of AD (true) (n = 252)	40.9	9.9	49.2
Drugs are available to prevent AD (false) (n = 250)	28.4	9.6	62.0
There is no known cure for AD (true) (n = 251)	34.7	14.3	52.0
AD can be diagnosed by a blood test (false) (n = 251)	18.7	5.2	76.1
The number of people with AD is now higher than ever (true) (n = 247)	28.7	5.3	66.0
People with AD usually die within a year or two after developing the disease (false)	44.8	2.0	53.2
Dementia symptom knowledge (correct answer)			
Loss of memory (yes) (n = 252)	75.0	0.8	24.2
Increased physical pain (no) (n = 251)	28.7	13.9	57.4
Problems with sleep (yes) (n = 252)	38.5	6.0	55.6
Loss in initiative (less "get up and go") (yes) (n = 252)	46.4	6.0	47.6
Incontinence (losing control of bathroom functions) (yes) (n = 251)	28.7	7.6	63.8
High blood pressure (no) (n = 251)	13.6	7.2	79.3

ness Perceptions Survey (Roberts et al., 2003; Roberts unpublished survey used with permission). The response scale was modified to include a DNK category following focus-group discussion. Scale scores were calculated as the number of correct items with DNK responses included with incorrect responses. Two subscale scores were computed: general AD knowledge (Cronbach's alpha = 0.79) and specific AD symptom knowledge (Cronbach's alpha = 0.79). The latter were a group of symptoms prefaced by "which of the following symptoms do you think are commonly seen in people with Alzheimer's disease."

Analysis

The data were analyzed in SAS 9.0 (Statistical Analysis Software 9.0, 2002). Coefficient alphas and orthogonally rotated exploratory factor analyses were calculated for each study scale prior to data analyses. Standard descriptive statistics were used to summarize demographics and dementia perception characteristics. T-tests and one-way analyses of variances (ANOVAs) were used to compare groups that differed regarding age, gender, education, and proportion of life spent in the United States. As there were multiple comparisons, we adopted a 0.01 level of significance. ANOVAs were used to investigate average level of dementia perceptions and knowledge by type of vignette response theme.

Results

Sample Characteristics

All participants were AIAs. Participant age ranged from eighteen to eighty-one ($M = 33.7$, $SD = 11.5$); however, the distribution of age was negatively skewed, with 75 percent between ages eighteen and thirty-six. Most participants self-reported as being male (69.3%), born in India (97.6%), married (62.2%), religiously affiliated (86.1%), having a master's degree or higher (55.7%), reported annual income of \$80,000 or above (58.4%), and one's biological mother (86.1%) or father (78.1%) alive. Only 8.0 percent reported ever having a family member with dementia. Participants older than thirty had lived in the United States for a smaller proportion of their life compared to participants age thirty or younger, $\chi^2(130, N = 219) = 199.32, P < 0.0001$.

Compared with national census data on the AIA population (U.S. Bureau of the Census, 2000c), participants' median age (30.0

vs. 30.3) and marital status (62.2% vs. 67.4%) were similar. However, a higher percentage were born in India (97.6% vs. 75.4%) and education was higher (93.0% vs. 63.9% with a bachelor's degree or greater). Of those foreign born, a larger proportion of the study sample were more recent immigrants; 86.3 percent entered the United States between the years 1990 and 2004, as compared to 54.0 percent from the U.S. Census's 2000 report (U.S. Bureau of the Census, 2000c). Conversely, there were fewer who immigrated in earlier decades; 8.7 percent of the study sample entered the United States between 1980 and 1989 (compared to 27.8% in the U.S. Census), and 5.0 percent of the study sample entered the United States before 1980 (in contrast to 18.2% in the U.S. Census).

Responses to Vignette

In response to the open-ended question, the most frequent answer was that the hypothetical relative in the vignette was experiencing AD or dementia (48.2%; $n = 123$). The next largest set of answers specified memory problems (26.7%; $n = 68$). A smaller proportion judged the vignette to portray normal aging (15.7%; $n = 40$). Finally, mental health concerns were indicated by 6.3 percent ($n = 16$). Examples of responses coded for each theme are shown in Table 1.

When given a closed-ended choice of categories for classifying the hypothetical relative's condition, "mental disorder" was selected most frequently (39.5% of respondents), followed by "combination of physical and mental disorder" (34.7%), "another disorder" (5.6%), and "physical disorder" (4.8%). The other 13.3 percent chose "not a disorder."

Perceptions of Dementia

Etiological beliefs about dementia. Old age, loneliness, stress, mental illness, and head injury were seen as the most influential etiological factors (Table 2). These factors were seen as more important than genetics as causes of the condition described in the vignette. The Eastern etiological belief items— on average—were seen as not important or only a little important. The most DNK answers were given to exposure to toxic materials.

Dementia help-seeking intentions. Respondents strongly endorsed the importance of an early diagnosis and the need to seek help for the condition described in the vignette (Table 3).

Dementia treatment beliefs. Treatments regarded as the most effective included keeping mentally active, keeping emotional stress low, keeping physically active, and eating a healthy diet (Table 4). The approved dementia medications were rated below these in effectiveness. Estrogen-replacement therapy, eating nuts, vitamins, and herbal supplements received the most DNK responses.

General knowledge of dementia and specific knowledge of dementia symptoms. Most of the items were answered correctly by fewer than half of the respondents (Table 5). The mean number correct was 3.3 (SD = 2.7) out of the 11 general dementia knowledge items, and 2.9 (SD = 2.1) out of the 7 items describing AD-specific symptoms. There was an accurate appreciation that AD entailed memory loss, and the majority correctly recognized getting lost or wandering as an AD symptom. A high rate of DNK answers occurred rather than outright incorrect responses. There was a moderately high correlation (Pearson $r = 0.72$; $P < 0.0001$) between the two knowledge scales.

Demographic Differences in Perceptions

Participants older than thirty had higher levels of general ($t_{253} = -4.38$, $P < 0.0001$) and symptom-specific ($t_{253} = -3.99$, $P < 0.0001$) knowledge. Those who had spent a greater proportion of their lives in the United States scored higher on both knowledge scales, $F(1, 156) = 24.82$, $P < 0.0001$ and $F(1, 156) = 9.81$, $P < 0.0002$, respectively. Female participants were more likely to endorse belief in activity-based treatments compared to male participants ($t_{190} = -3.11$, $P < 0.0021$). No other statistically significant differences by demographic characteristics were observed.

Differences in Perceptions According to Vignette Response

Responses to subscales were compared across the four themes (AD or dementia, memory issues, normal aging, and mental health concerns) that emerged from the open-ended responses to the vignettes.

There were no statistically significant group differences with respect to etiological beliefs.

There were significant differences across the different vignette themes regarding how likely participants indicated that they were to seek help, $F(3, 236) = 9.53$, $P < 0.0001$. Post-hoc comparisons using a Scheffe procedure indicated that those who said that the problem

in the vignette was AD or dementia ($M = 26.92$, $SD = 3.60$) were statistically more likely to seek help than those who saw the problem as normal aging ($M = 23.48$, $SD = 4.14$). No other vignette response groups differed significantly from one another.

Participants who interpreted the vignette according to different themes differed in their endorsement of traditional Eastern treatment beliefs $F(3, 234) = 6.35$, $P < 0.0004$. Post-hoc comparisons using a Scheffe procedure indicated that those who interpreted the vignette as a mental health concern ($M = 16.21$, $SD = 5.09$) were more likely to endorse traditional Eastern treatment beliefs than those who saw the vignette as AD or dementia ($M = 9.84$, $SD = 5.62$), memory issues ($M = 10.65$, $SD = 5.36$), or normal aging ($M = 12.28$, $SD = 6.34$). No statistically significant differences among vignette response groups were found for either endorsement of activity-based treatment beliefs or nutrition-based treatments.

There were significant differences among vignette response groups regarding general and specific AD knowledge, $F(3, 242) = 27.02$, $P < 0.0001$ and $F(3, 242) = 29.96$, $P < 0.0001$, respectively. In both instances, post-hoc comparisons using a Scheffe procedure indicated that those who saw the vignette as AD or dementia were more likely to have greater general ($M = 4.59$, $SD = 2.26$) or specific ($M = 3.98$, $SD = 1.46$) AD knowledge than those who reported the vignette depiction as memory issues ($M = 2.68$, $SD = 2.60$; $M = 2.29$, $SD = 2.13$, respectively), normal aging ($M = 1.15$, $SD = 1.87$; $M = 1.18$, $SD = 1.66$), or mental health concerns ($M = 2.00$, $SD = 2.62$; $M = 2.33$, $SD = 2.87$).

Discussion

This study addresses the absence of descriptive research about AIAs' perceptions of dementia. Close to half of the study's sample responded that the relative described in the vignette had AD or dementia, while slightly more than a quarter of the sample described that the condition was memory loss due to aging or other unspecified reasons. AIAs in this sample accurately endorse that AD involves memory loss and is a disease of old age, although loneliness and mental illness are reported as more important than genetics as causes of dementia. In general, these perceptions would appear to underestimate the role of genetics and give more credence to the role of social engagement than current epidemiological research findings generally suggest (Fratiglioni,

Paillard-Borg, and Winblad, 2004). There generally was a greater reliance on keeping mentally and physically active and keeping emotional stress low as treatments than there was on approved prescription medications. The endorsed treatments reflect tenets of Ayurvedic medicine (Fleischman, 1976–77) with its emphasis on restoring holistic balance (Landrine and Klonoff, 2001).

Fewer than half of the sample correctly answered most knowledge items. Knowledge was associated with age. Despite living in the United States for a briefer amount of time, those older than thirty had higher amounts of general dementia and symptom-specific knowledge, which may be attributable to the disease's age of onset well into adulthood.

The paucity of other studies in this area of research creates a challenge when attempting to compare our findings with others. In a small qualitative study of health care needs among Indian and Pakistani Scots, Bowes and Wilkinson (2003) evaluated those caring for a family member with a diagnosis of dementia. Participants had several different explanations for the disease, including an "evil eye" was cast, regression to childhood, normal aging, and as a problem associated with an unspecific condition (Bowes and Wilkinson, 2003, 388). Help-seeking beliefs and practices were found to be grounded in filial piety, cultural tradition, and religious obligation (Bowes and Wilkinson, 2003). Additionally, many of the family members eschewed readily available health care services for potential fear of appearing to relinquish their familial and cultural responsibilities (Bowes and Wilkinson, 2003). In contrast, our help-seeking belief results suggested substantial willingness to seek professional help for mild dementia symptoms as described in the vignette.

The present study has several limitations. First is the limited generalizability of the study's findings to the broader AIA population. For example, the sample was all from the San Francisco Bay Area and was quite educated compared to national census data for AIAs. Moreover, dining in an Indian restaurant may denote a certain acculturative bias. Additionally, several scales used in this study have not yet been psychometrically evaluated. Furthermore, there was a high percent of DNK responses. The DNK option was added at the request of the focus groups. We did not expect such a high frequency of DNK answers as occurred, but it is plausible that participants truly were unsure of the answer for many of these

items. Survey research has found that DNK survey responses have low face validity, given the variability associated with the rationale of respondents endorsing this answer choice (e.g., not knowing the answer, unclear item, believing that data are not available to give a final answer to the item) (Beatty et al., 1998). Given the pace of research about AD, it is accurate that scientists have not finally resolved some questions about etiology and treatment; thus, an unknown proportion of DNK responses may reflect the uncertainty of the science. Finally, pegging the scales to the vignette entailed a trade-off in that responses to subsequent items may have been influenced by the construction of the vignette.

This study's strengths also bear mention. This is the first study, to our knowledge, that investigates AIAs' dementia perceptions. Further, to the extent possible, we employed measures that have been used in other populations.

Implications

The association between knowledge of dementia and help seeking evident in our findings is consistent with results from others (Sarkisian, 2002) to the effect that associating dementia with normal aging creates a barrier to early assessment. Taken together, these results argue for the importance of public education about AD and dementia.

Once care is sought, those providing health care and social services to AIA families facing a diagnosis of dementia must be ready to offer education about the disease and its course. Care providers are encouraged to consider the family structure when disclosing a dementia diagnosis and determining a treatment plan, that is, depending on a patient's acculturative level, the unit of autonomy in an AIA family may consist not only of the patient but also of one or more key family members (Periyakoil, 2006). Especially for families unfamiliar with dementia, there may be insufficient appreciation of the fact that the behaviors of the person with dementia reflect a progressive neurological disease. Given the preference for non-medical activity-based treatments, families should be encouraged to keep their loved one with dementia engaged. However, it should be made clear that AD has no known cure.

With respect to public health, the Healthy Brain Initiative of the Centers for Disease Control and Prevention and the Alzheimer's Association (2007) emphasizes that a first step must be to de-

termine how diverse audiences perceive and understand cognitive health and its association with lifestyle factors. Our findings provide a reminder that public-health efforts need to be firmly grounded in science, as participants' beliefs sometimes matched and other times did not match available scientific evidence. In particular, there is room for increased awareness that cognitive changes similar to those in the vignette likely signify dementia rather than normal aging. Moreover, participants showed greater reliance on the role of mental activity and loneliness but less reliance on the role of physical activity than current data about determinants of cognitive health might suggest.

Future research should continue to assess dementia knowledge to gain more understanding of how AIAs' dementia perceptions map onto dementia help-seeking behavior in clinical and nonclinical samples, including AIA dementia caregivers as compared to noncaregivers. Furthermore, it would be intriguing, particularly from a public-health educational perspective, to measure participants' exposure to and retention of dementia awareness campaigns in their home country prior to immigration, if they had emigrated.

Future replication of these findings will help to shape outreach efforts in micro- (e.g., clinical settings, with clinicians inquiring and assessing the feasibility of incorporating dementia beliefs held by patients and their families) and macro- (e.g., public-health educational efforts) venues to cast light on AIAs' knowledge about dementia. With a quickly growing AIA population in the United States, this is the first step to document AIAs' dementia perceptions within one sample with the hope that future studies delve into this area to further delineate AIAs' dementia beliefs so as to continue to inform and improve culturally tailored dementia education and care for AIAs and their families affected by dementia.

Appendix

An older adult relative close to you is seventy-five years old and lives in the United States. Recently she has begun to be forgetful. She confuses peoples' names, even those she knows well. She often seems not to be able to remember things from one moment to the next. One example was when she went to the market to buy food and came back with nothing, having forgotten what she went out for. She repeats herself in conversation, and always seems to talk about the past. Your family first noticed the problem one year ago. Since then it has been getting steadily worse.

Acknowledgments

The authors would like to thank Beth Meyerowitz, Ph.D. and Jerald Jellison, Ph.D. for reviewing previous versions of this paper and for their assistance in the development of the help-seeking measure. The authors also express gratitude to peer colleagues for reviewing previous versions of this paper. During this research, Poorni Otilingam was supported in part by NIH Grant No. F31 AG021879.

References

- Ajzen, Icek. 1991. "The Theory of Planned Behavior." *Organizational Behavior and Human Decision Processes* 50(2): 179–211.
- Ajzen, Icek, and Beverly L. Driver. 1991. "Prediction of Leisure Participation from Behavioral, Normative, and Control Beliefs: An Application of the Theory of Planned Behavior." *Leisure Sciences* 13(3): 185–204.
- Ajzen, Icek, and Thomas J. Madden. 1986. "Prediction of Goal-Oriented Behavior: Attitudes, Intentions, and Perceived Behavioral Control." *Journal of Experimental Social Psychology* 22(5): 453–74.
- Alexander, Cheryl S., and Henry J. Becker. 1978. "The Use of Vignettes in Survey Research." *Public Opinion Quarterly* 42(1): 93–104.
- Beatty, Paul, Douglas Herrman, Cathy Puskar, and Jeffrey Kerwin. 1998. "'Don't Know' Responses in Surveys: Is What I Know What You Want to Know and Do I Want You to Know It?" *Surveying Memory Processes* 6(4): 407–26.
- Bowes, Alison, and Heather Wilkinson. 2003. "'We Didn't Know It Would Get This Bad': South Asian Experiences of Dementia and the Service Response." *Health and Social Care in the Community* 11(5): 387–96.
- Braun, Kathryn L., Jeanette C. Takamura, and Thanh Mougeot. 1996. "Perceptions of Dementia, Caregiving, and Help-Seeking among Recent Vietnamese Immigrants." *Journal of Cross-Cultural Gerontology* 11(3): 213–28.
- Cameron, Linda D., and Howard Leventhal, eds. 2003. *The Self-Regulation of Health and Illness Behaviour*. New York: Routledge.
- Centers for Disease Control and Prevention and the Alzheimer's Association. 2007. "The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health." Chicago: Alzheimer's Association.
- Elliot, Kathryn Sabrena, Mariann Di Minno, Darrick Lam, and Alicia Mei Tu. 1996. "Working with Chinese Families in the Context of Dementia." Pp. 89–108 in *Ethnicity and the Dementias*, ed. Gwen Yeo and Dolores Gallagher-Thompson. New York: Routledge.
- Ferri, Cleusa P., Martin Prince, Carol Brayne, Henry Brodaty, Laura Fratiglioni, Mary Ganguli, Kathleen Hall, Kazuo Hasegawa, Hugh Hendrie, Yueqin Huang, Anthony Jorm, Colin Mathers, Paulo R. Menezes, Elizabeth Rimmer, Marcia Scazufca, for Alzheimer's Disease International. 2005. "Global Prevalence of Dementia: A Delphi Consensus Study." *Lancet* 366 (9503): 2112–17.

- Fleischman, Paul R. 1976–77. "Ayurveda." *International Journal of Social Psychiatry* 22(4): 282–87.
- Fratiglioni, Laura, Stephanie Paillard-Borg, and Bengt Winblad. 2004. "An Active and Socially Integrated Lifestyle in Late Life Might Protect Against Dementia." *Lancet Neurology* 3(6): 343–53.
- Ganguli, Mary, Vijay Chandra, M. Ilyas Kamboh, Janet M. Johnston, Hiroko H. Dodge, B. K. Thelma, Ramesh C. Juyal, Rajesh Pandav, Steven H. Belle, Steven T. DeKosky. 2000. "Apolipoprotein E Polymorphism and Alzheimer Disease: The Indo-US Cross-National Dementia Study." *Archives of Neurology* 57(6): 824–30.
- Ghandi, M. K. 1965. *Nature Cure*. Bombay: Pearl.
- Hinton, W. Ladson, and Sue Levkoff. 1999. "Constructing Alzheimer's: Narratives of Lost Identities, Confusion and Loneliness in Old Age." *Culture, Medicine and Psychiatry* 23(4): 453–75.
- Jonnalagadda, Satya S., and Sadhna Diwan. 2005. "Health Behaviors, Chronic Disease Prevalence and Self-Rated Health of Older Asian Indian Immigrants in the U.S." *Journal of Immigrant Health* 7(2): 75–83.
- Kleinman, Arthur. 1980. *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry*. Berkeley: University of California Press.
- Landrine, Hope, and Elizabeth A. Klonoff. 2001. "Cultural Diversity and Health Psychology." Pp. 851–892 in *Handbook of Health Psychology*, ed. Andrew S. Baum, Tracey A. Revenson, and Jerome E. Singer. Mahwah, NJ: Lawrence Erlbaum Associates.
- Lawton, Julia. 2003. "Lay Experiences of Health and Illness: Past Research and Future Agendas." *Sociology of Health and Illness* 25(3): 23–40.
- McBride, Melen R., and Heide Parreno. 2006. "Filipino American Families and Caregiving." Pp. 123–135 in *Ethnicity and the Dementias*, ed. Gwen Yeo and Dolores Gallagher-Thompson. New York: Routledge.
- Miles, Matthew B., and Michael Huberman. 1994. *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, CA: Sage Publications.
- Panganamala, Deborah R., and Deborah L. Plummer. 1998. "Attitudes toward Counseling among Asian Indians in the United States." *Cultural Diversity and Mental Health* 4(1): 55–63.
- Parekh, Bina R. 2000. "Culture and Health in Asian Indians." Ph.D. diss., Loma Linda University.
- Patel, Vikram, and Martin Prince. 2001. "Ageing and Mental Health in a Developing Country: Who Cares?" *Psychological Medicine* 31(1): 29–38.
- Periyakoil, Vyjeyanthi S. 2006. "Working with Asian Indian American Families." Pp. 165–172 in *Ethnicity and the Dementias*, ed. Gwen Yeo and Dolores Gallagher-Thompson. New York: Routledge.
- Ramakrishna, Jayashree, and Mitchell G. Weiss. 1992. "Health, Illness, and Immigration: East Indians in the United States." *Western Journal of Medicine* 157(3): 265–70.

- Roberts, J. Scott, Cathleen M. Connell, Dawn Cisewski, Yvonne G. Hipps, Serkalem Demissie, and Robert C. Green. 2003. Differences between African Americans and Whites in their Perceptions of Alzheimer Disease. *Alzheimer Disease and Associated Disorders* 17(1): 19–26.
- Roberts, J. Scott. “Boston University Medical Center Alzheimer’s Disease Treatment and Illness Perceptions Survey” (unpublished survey).
- Sarkisian, Catherine A., Ron D. Hays, Carol M. Mangione. 2002. “Do Older Adults Expect to Age Successfully? The Association between Expectations Regarding Aging and Beliefs Regarding Healthcare Seeking among Older Adults.” *Journal of the American Geriatrics Society* 50(11): 1837–43.
- Srinivasan, Shobha, and Tessie Guillermo. 2000. “Towards Improving Health: Disaggregating Asian American and Native Hawaiian/Pacific Islander Data.” *American Journal of Public Health* 90(11): 1731–34.
- Statistical Analysis Software 9.0. 2002. Cary, NC: SAS Institute Inc.
- Stewart, Rob, Martin Prince, and Anthony Mann. 1999. “Vascular Risk Factors and Alzheimer’s Disease.” *Australian New Zealand Journal of Psychiatry* 33(6): 809–13.
- Sue, Stanley, Derald W. Sue, Leslie Sue, and David T. Takeuchi. 1995. “Psychopathology among Asian Americans: A Model Minority?” *Cultural Diversity and Mental Health* 1(1): 39–51.
- Tempo, Phyllis M., and Ann Saito. 2006. “Techniques of Working with Japanese American Families.” Pp. 109–122 in *Ethnicity and the Dementias*, ed. Gwen Yeo and Dolores Gallagher-Thompson. New York: Routledge.
- U.S. Bureau of the Census. 2000a. “The Asian and Pacific Islander Population in the United States: March 1999.”
- _____. 2000b. “The Asian Population: Census 2000 Brief.”
- _____. 2000c. “We the People: Asians in the United States.”
- _____. 2000d. Census 2000 Summary File 1, Matrices P1, P3, P4, P8, P9, P12, P13, P17, P18, P19, P20, P23, P27, P33, PCT5, P8, P11, P15, H1, H3, H4, H5, H11, and H12.

POORNI G. OTILINGAM, M.P.H., M.A., is a doctoral student in the Clinical Science Program, Aging Track housed in the Department of Psychology at the University of Southern California. Her research focuses on reducing cognitive health disparities in underserved populations.

MARGARET GATZ, Ph.D. is a Professor in the departments of Psychology, Gerontology and Preventive Medicine at the University of Southern California and a foreign adjunct professor at The Karolinska Institute in Sweden. She is also the current Chair for the Department of Psychology. Her research interests encompass age-related change in depressive symptoms, risk and protective factors for Alzheimer's disease, and evaluation of the effects of interventions.

Check Out AASC PRESS' ONLINE BOOKSTORE!

Order UCLA Asian American Studies Center Press (AASC PRESS) Publications Online!

www.aasc.ucla.edu/aascpress/comersus/store/comersus

The screenshot shows the website interface for UCLA Asian American Studies Center Press. On the left is a navigation menu with sections for 'NAVIGATION' (Home, About, Contact Us, Products, Top Sellers, Clearance, Last Chance, News, Register, My Account, Log Out) and 'CATEGORIES' (AAPI Nexus, Amerasia Journal, Asian American Firsts, Bibliographies, Literature, Media, Arts, Public Policy). Below the menu is a 'QUICK SEARCH' box with a 'SEARCH' button and 'Advanced Search' link. The main content area displays a grid of book listings. Each listing includes a book cover, title, price, stock, popularity, and an 'Add to cart' button. The top of the page features a header with the UCLA logo, 'Asian American Studies Center Press' text, and a shopping cart icon showing a total of \$0.00.

Check out our new online bookstore featuring all of the Press' available publications. Now you can view the bookcovers and the Table of Contents of all UCLA Asian American Studies Center Press' titles. You will find the Press titles organized by category to help you find what you are looking for. It is easy to use and a secure site for credit card transactions, if you need a book in a hurry. Be on the lookout for special online sales and discounts!

We still have the regular ordering options, by phone, fax, or email.

INQUIRIES: (310) 825-2968, (310) 825-2974 FAX (310) 206-9844

EMAIL: aascpress@aasc.ucla.edu

WEBSITE: www.aasc.ucla.edu/aascpress/comersus/

PROMOTIONAL DISCOUNT!

When you order, enter this Discount Code on the shipping page and receive 20% off your entire order: AAAS20