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Title

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Journal

Geriatrics and Gerontology International, 17(5)

ISSN

1444-1586

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Publication Date

2017-05-01

DOI

10.1111/ggi.12782

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Peer reviewed

ORIGINAL ARTICLE: EPIDEMIOLOGY,
CLINICAL PRACTICE AND HEALTH

Examining the differences in the stigma of dementia and diabetes among Chinese Americans

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Aim: One of the major barriers in making a diagnosis and managing dementia in the Chinese American population is the stigma surrounding the disease. The goal of the present study was to examine differences in the stigma and perceptions of dementia and diabetes among Chinese Americans.

Methods: A total of 449 Chinese Americans answered one survey with two self-administered, true/false questionnaires assessing stigma and perceptions toward dementia and diabetes. Higher total scores were associated with increased stigma and negative perceptions. The results of the two questionnaires were compared to assess for any differences in attitudes.

Results: For the dementia questionnaire, the mean score was 5.58 (95% CI 5.37–5.79) with a standard deviation of 2.31. For the diabetes questionnaire, the mean score was 2.01 (95% CI 1.85–2.18) with a standard deviation of 1.76. Statistical analysis showed that Chinese Americans were more likely to hold stigmatized views toward dementia than diabetes ($t = 33.9$, $d.f. = 448$, $P < 0.01$).

Conclusions: The higher average score in the dementia questionnaire shows that there are greater stigma and negative perceptions of dementia in comparison with diabetes among Chinese Americans. Considering that stigma delays access to healthcare for dementia-related symptoms, efforts should be taken to minimize negative attitudes associated with dementia. *Geriatr Gerontol Int* 2016; ●●: ●●–●●.

Keywords: Chinese Americans, dementia, diabetes, mental illness, stigma.

Introduction

With an aging population, the prevalence of dementia is on the rise and estimated to triple by 2050.¹ Symptoms of dementia impact quality of life by disempowering patients and affecting their sense of independence. One of the major barriers in making a diagnosis and managing dementia is the public stigma surrounding the disease.² Stigma refers to the negative stereotypes of certain groups resulting from perceptions held by the community. These perceptions can result in prejudice and discriminatory practices against stigmatized groups.² Stigma varies among different cultures, and prior qualitative research has shown that stigma of dementia is highly prevalent in the Chinese American community.³

Studies of Chinese populations have shown that negative perceptions of dementia often delay patients from

accessing medical care.^{4,5} One reason for delayed dementia diagnosis in Chinese Americans is that signs of cognitive decline are associated with normal aging.^{4,6} As a result, patients attribute symptoms to normal physiological changes of aging, and do not seek care until symptoms significantly impair a patient's executive functioning.^{7,8} Negative health outcomes that can result from untreated dementia include increased rates of depression and anxiety, loss of personal control, physical health deterioration, social withdrawal, decreased self-esteem, and loss of social support.⁹

Understanding the role of stigma in Chinese culture is important, as the prevalence of dementia in Chinese Americans is estimated to increase 300% between 2000 and 2050.³ A major theme in Chinese culture is the Confucian principle known as filial piety, which emphasizes the obligations that children have to take care of their aging parents. Thus, although a single member in a family might be diagnosed with dementia, the disease burden often extends to the entire family. Because of a belief that dementia is the result of retribution for past sins committed by the family, both patients and their families often express feelings of shame if diagnosed with the disease.^{3,4,10} In order to minimize the delay in accessing care so that

Accepted for publication 22 February 2016.

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Institutional review board approval was obtained through the University of California, Los Angeles.

appropriate treatment and care plans can be initiated as early as possible, negative perceptions of the disease must be minimized among Chinese Americans.

Existing research has provided limited insight into the relationships between mental illnesses, dementia and stigma in Chinese Americans. A prior study found that stigma of depression was more severe in Chinese Americans than Caucasian Americans, using diabetes mellitus as a comparison.¹¹ Another study also showed that among Chinese American immigrants, there was social challenge of stigmatized views toward diabetes.¹² Chinese Americans suffering from diabetes were distressed and varied in their willingness to disclose the condition. Although individuals with a family history of dementia have an increased risk of dementia themselves, research however showed that having a familial risk factor for dementia would not reduce the stigma of dementia among Chinese Americans.¹³ However, no study has been carried out so far to understand the stigma and negative perceptions of dementia among Chinese Americans in comparison with another disease. The current cross-sectional study aimed to examine the differences in the stigma of dementia and diabetes among older Chinese Americans, using a quantitative approach. Topics examined include attitudes and perceptions toward social status, occupational and social impairments, executive functioning levels, and societal responsibilities associated with each disease.

Methods

In the study, Chinese American immigrants were recruited to complete two self-administered 15-item stigma questionnaires simultaneously. The questionnaires were written in Chinese, and intended to gather information regarding perceptions and attitudes toward dementia (dementia questionnaire) and diabetes (diabetes questionnaire). The dementia questionnaire included the 15-item stigma self-assessment to assess beliefs about discrimination against individuals with dementia.¹⁴ The diabetes questionnaire, by substituting diabetes as the medical illness, adapted the 15 questions to assess stigma and perceptions toward individuals with diabetes. Both questionnaires were scored from 0 to 15, with higher scores indicating a greater severity of stigma toward the medical conditions. This was a convenience sample with participants recruited from the general public residing in Los Angeles, California, USA. Eligibility criteria for participation included: (i) the person was literate in written Chinese and gave informed consent; and (ii) the person was at aged least 55 years. The current study was approved by the University of California, Los Angeles.

Analysis of the data was used to test for differences between stigma and negative perceptions toward dementia and diabetes. All questions were true/false format. Scores were calculated based on how many answers were marked "true," and higher scores were associated with increase

negative attitudes. Univariate analysis included χ^2 -tests for categorical variables, and the *t*-test for continuous variables. A *t*-test was used to compare the overall average score for the Dementia Questionnaire with the Diabetes Questionnaire. A χ^2 analysis was used to compare differences between the two surveys in responses for each individual question.

Results

Of the 485 individuals invited to participate, 449 participants (92.6% participation rate) completed both questionnaires. Among the 449 participating respondents, 302 (67.3%) were women and 147 (32.7%) were men. A total of 290 (64.6%) respondents completed high school. The duration of residence in the USA included 88 (19.6%) participants residing there less than 10 years, 210 (46.8%) participants residing there 10–19 years and 151 (33.6%) participants residing there for at least 20 years. Of the 449 respondents, 77 (17.1%) and 202 (45.0%) reported a family history of dementia and diabetes, respectively. The mean score in the dementia questionnaire was 5.58 (95% CI 5.37–5.79) with a standard deviation of 2.31. The mean score in the diabetes questionnaire was 2.01 (95% CI 1.85–2.18) with a standard deviation of 1.76. The higher average score in the dementia questionnaire shows that Chinese Americans were more likely to hold stigmatized views toward dementia than diabetes ($t = 33.9$, d.f. = 448, $P < 0.01$).

Significant differences in the attitudes and perceptions of dementia and diabetes among Chinese Americans were found for 12 of the 15 stigma items. Our findings show that in comparison with stigma toward diabetes, Chinese Americans were more likely to report negative attitudes and perceptions toward dementia. Table 1 shows the results of the dementia stigma questionnaire and diabetes stigma questionnaire in Chinese American participants.

Discussion

Although prior studies have aimed to better understand the impact of attitudes and stigma surrounding dementia in Chinese American populations, none have compared dementia with other diseases that are more prevalent, better understood and more accepted in the community. Thus, the current study benefits from comparing stigma and negative perceptions of dementia and diabetes in Chinese American immigrants. On the 15-item stigma questionnaires, higher scores are associated with increased stigma and negative perceptions. On average, respondents in the present study scored 3.6 points higher on the dementia questionnaire than on the diabetes questionnaire. The current study results show that among Chinese Americans, attitudes toward dementia are more negative than attitudes toward diabetes. One of the reasons for increased negative perceptions toward dementia might be

Table 1 Results of the dementia survey and diabetes survey in Chinese American participants ($n = 449$)

Question	Dementia survey true responses n (%)	Diabetes survey responses n (%)	χ^2 Difference P -value ^{†,‡}
1 Most employers will fire a 65-year old employee with this illness.	349 (77.7%)	93 (20.7%)	<0.01
2 This illness is different from other physical illnesses. (e.g. high blood pressure)	210 (46.8%)	177 (39.4%)	0.03
3 Research on this illness is nothing, but is a good way for pharmaceutical companies to make profits.	113 (25.2%)	51 (11.4%)	<0.01
4 Increasing government spending to care for patient with this illness is a waste of money.	24 (5.35%)	17 (3.79%)	0.26
5 Most people will not want to be friends with people suffering from this illness.	179 (39.9%)	29 (6.46%)	<0.01
6 It is difficult to communicate with people with this illness.	323 (71.9%)	33 (7.35%)	<0.01
7 Only those with a low educational level would develop this illness.	33 (7.35%)	15 (3.34%)	0.01
8 I would avoid disclosing the truth if my relatives have this illness.	49 (10.9%)	29 (6.45%)	0.02
9 Patients with this illness would not understand other people's concern or worry.	262 (58.4%)	96 (21.4%)	<0.01
10 A patient with this illness is dangerous to self.	179 (39.9%)	47 (10.5%)	<0.01
11 A patient with this illness is dangerous to others.	142 (31.6%)	24 (5.24%)	<0.01
12 A patient with this illness is impulsive and unpredictable.	328 (73.1%)	128 (28.5%)	<0.01
13 Patients with this illness should be institutionalized.	221 (49.2%)	71 (15.8%)	<0.01
14 Health insurance policies should not cover any costs of this illness.	62 (13.8%)	67 (14.9%)	0.63
15 Society should not treat patients with this illness with more tolerance.	32 (7.12%)	27 (6.01%)	0.50

[†]Using χ^2 analysis, we analyzed the difference between the two surveys in responses for each question. The degrees of freedom for each is 1; [‡] χ^2 analysis for all questions (except for questions 4, 14, 15) were statistically significant (P -value <0.05).

the result of a lack of awareness that dementia is indeed a medical condition and the symptoms of dementia are in fact related to a neurocognitive disorder.¹⁵

The χ^2 analysis of each individual question showed a significant difference in attitudes toward social status, occupational and social impairments, executive functioning levels, and societal responsibilities toward dementia in comparison with diabetes among Chinese Americans. It is known that stigma causes distress, rejection and discrimination. The present findings showed that in comparison with diabetic patients, patients with dementia are more likely to have greater difficulty in maintaining friends. Not only that, the Chinese American general public might find it difficult to communicate with dementia patients. Furthermore, Chinese American immigrants are more likely to avoid disclosing having family members with dementia. This is consistent with previous research studies, which have shown that Chinese dementia caregivers would avoid the dementia label due to fear of "losing face."^{3,4,6} The present study adds that the stigma of dementia extends into the general Chinese American population. As negative attitudes can lead to a delay in seeking treatment for dementia, more effective campaigns targeting the general public are required to reduce the stigma towards dementia in Chinese Americans.^{16,17}

Stigma surrounding dementia contributes to shame felt by patients and their families in the Chinese American community, which can affect both quality and access to care. Because of the negative impact stigma might have on a patient's social support and care, minimizing stigma is crucial in the treatment of this disease. The present study confirms that members in the Chinese American community hold stigmatizing views about dementia, especially on its impairment on executive functioning. Educational programs will be essential in correcting such misconceptions about dementia, and helpful in minimizing negative connotations associated with this medical condition. Previous research has shown that dementia educational seminars can increase public awareness of this debilitating disease, and are important for promoting early intervention and diagnosis of dementia in the general public.¹⁸

Some of the limitations of the present study include the use of true/false questions to assess personal beliefs regarding two different disease processes. Our study was also susceptible to a selection bias. The present study also did not include further social variables, such as family structure, economic state, experience of living with individuals suffering from dementia and so on. Future studies should include these social variables and an array of other medical and psychiatric conditions (such as hypertension, stroke, depression and traumatic brain injury) to systematically assess the level of dementia stigma in Chinese Americans. As the study used a convenient sample consisting of only a Chinese population located in Los Angeles, our findings might not reflect the view of the

overall Chinese American general population. The present study also did not compare Chinese Americans with other Asian Americans to further characterize the level of stigma toward dementia. Future studies should utilize a cross-ethnic comparison approach to capture such disparities. Furthermore, our study did not assess whether factors, such as dementia knowledge, prior experience of dementia or family history, might have influenced the findings. Another limitation that should be noted is its cross-sectional design limited causal conclusions. Future studies are indicated toward further exploring the stigma of dementia, and its impact on help-seeking behaviors in Chinese Americans.

Using a quantitative scale, the present study has shown that there are significant increased negative attitudes towards dementia in comparison with diabetes. Although dementia is a debilitating disease, accessing healthcare early will help slow the disease progression, and will set up a care plan to benefit both the patient and the caretaker. Efforts to reduce the general public stigma and negative perceptions toward the disease are crucial in order to reduce feelings of isolation and to coordinate care for dementia patients in the community.¹⁹ Ultimately, a better understanding of dementia and strategies to decrease stigma among the Chinese American population will be necessary to improve the quality of care for dementia patients.

Acknowledgments

The authors are thankful to the participants in the study. The authors received no financial support for the research, authorship and/or publication of this article.

Disclosure statement

The authors declare no conflict of interest.

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