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Journal

Geriatrics and Gerontology International, 17(1)

ISSN

1444-1586

Author

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Publication Date

2017

DOI

10.1111/ggi.12686

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Peer reviewed

ORIGINAL ARTICLE: EPIDEMIOLOGY,
CLINICAL PRACTICE AND HEALTH

Family history and its relationship with dementia stigma beliefs among Chinese Americans

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Aim: It is known that Chinese Americans associate dementia with stigma and “loss of face.” However, further research is required to provide a more complete picture of the extent and nature of stigma in Chinese Americans with family histories of dementia (FHD). The present study examined whether FHD are associated with quantitative measures of stigma in Chinese Americans.

Methods: A total of 300 Chinese Americans in two health seminars answered a 15-item, true/false questionnaire to assess their beliefs toward dementia. Two groups were dichotomized and compared based on FHD.

Results: Both groups subscribed to moderately stigmatizing views about dementia. Our findings showed that the group with FHD was more likely to disclose having relatives with dementia. However, this group was also more likely to perceive patients with dementia to be incapable of feeling other people’s worries or concerns at once.

Conclusions: Strategies to decrease stigma toward dementia are required. Cultural interventions must also extend into the Chinese American general public to reduce stigma of dementia. **Geriatr Gerontol Int 2015; ●●: ●●–●●.**

Keywords: Chinese Americans, dementia, family history of dementia, mental illness, stigma.

Introduction

Dementia is a broad category of brain diseases that causes profound cognitive and functional disability. As the global population continues to age, it is estimated that the number of people affected by dementia will triple between 2010 and 2050 worldwide.¹ Increasing public awareness of this debilitating disease is important to promote early intervention and diagnosis of dementia.² There is also convincing evidence that increased contact with persons with mental illnesses correlates with less stigma.³

Over the past decade, Asian Americans have been the fastest growing ethnic group in the USA. Research has highlighted that, in comparison with Caucasians, Asians are significantly less knowledgeable about dementia, and underutilize its treatment services.^{4,5} Although Chinese Americans are the largest Asian immigrant group, there has been little research to establish the extent or nature of stigma associated

with dementia in Chinese immigrants.⁶ Nevertheless, this research has uncovered the presence of stigma in the Chinese American community, as 85% of the general public surveyed found it difficult to talk to people with dementia. Also, 63% of the general public found patients with dementia to be impulsive and unpredictable.

There are barriers and challenges to managing dementia among Chinese American older adults, particularly among immigrants. Because of their language and cultural barriers, Chinese-speaking only patients might underutilize mental health services.⁷ In a study of 288 first-generation Chinese American immigrants from the public, approximately 60% misunderstood dementia as normal aging and believed that everyone would develop forgetfulness as a result of aging. Furthermore, over 60% of respondents failed to recognize that dementia can shorten life expectancy after onset.⁸ In order to target stigma, ethnic media in the form of radio⁹ and short film¹⁰ could be important means of educating and informing Chinese immigrants. Existing research has provided some insight into the relationships between dementia, stigma and family history of dementia. There is strong evidence to suggest that individuals with a family history of dementia have an increased risk of dementia themselves.¹¹ Research has

Accepted for publication 15 October 2015.

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also shown that family history risk might influence health behaviors and cognitive perceptions about the disease.¹² However, familial risk factor for dementia might also be perceived as unavoidable and even shameful in the Chinese culture. It is known that Chinese Americans often associated family history of dementia with stigma, fear of aging and “loss of face.”¹³ Therefore, further research is required to provide a more complete picture of the extent and nature of dementia stigma in Chinese Americans. The current cross-sectional study aimed to investigate whether family histories of dementia are associated with quantitative measures of stigma in Chinese Americans.

Methods

A total of 300 Chinese Americans living in Los Angeles, California, USA, were recruited from two health seminars. Attendees who met the following criteria were recruited: (i) the person was literate in written Chinese and gave informed consent; and (ii) the person was aged at least 18 years. The current study was approved by University of California, Los Angeles, Institutional Review Board. The questionnaire was distributed before the seminars. A 15-item stigma self-assessment written in Chinese was utilized to assess beliefs about discrimination against individuals with dementia.⁶ The questionnaire was scored from 0 to 15, with higher scores indicating a greater severity of stigma toward dementia. Data collected also included sociodemographic variables, such as age, sex, highest level of education, duration of residence and family history of dementia (FHD) among first-degree relatives (i.e. parents and siblings). Family history of dementia was assessed through self-report. Descriptive statistical analysis was carried out using SPSS version 17 (SPSS, Chicago, IL, USA). The *t*-test and χ^2 -test were carried out for continuous and nominal data, respectively.

Results

Of the 300 participating respondents, 201 (67%) were female, 194 (65%) had completed high school, 193 (64%) were aged ≥ 50 years and 105 (35%) had a duration of residence in the USA for ≥ 20 years. Respondents were divided into two comparison groups based on FHD, with 245 (82%) without familial risk factor for dementia and 55 (18%) having FHD. Table 1 summarizes the main sociodemographic characteristics of the study respondents based on FHD. No statistical difference was found in demographic factors between participants with FHD versus participants without FHD. The two groups did not differ in sex ($\chi^2 = 0.13$, d.f. = 1, $P = 0.715$), education ($\chi^2 = 2.88$, d.f. = 1, $P = 0.090$), age group ($\chi^2 = 1.86$, d.f. = 1, $P = 0.172$) or duration of residence ($\chi^2 = 0.15$, d.f. = 1, $P = 0.696$).

Little variability was seen in average stigma questionnaire score for respondents without FHD versus with FHD (mean [SD] 5.6 [2.3] vs 5.8 [2.3]; $t = 0.58$, d.f. = 298, $P = 0.561$). Table 2 presents the comparison between the two groups in terms of their responses to the stigma scale. Significant differences in responses between the two groups were found for two of the 15 stigma items. Our findings show that the group with FHD was more likely to disclose having relatives with dementia (13% vs 4%; $\chi^2 = 3.97$, d.f. = 1, $P = 0.046$). However, the group with FHD was also more likely to perceive patients with dementia to be completely incapable of feeling other people's worries or concerns at once (75% vs 56%; $\chi^2 = 6.20$, d.f. = 1, $P = 0.013$).

Discussion

To our knowledge, this is the first study to date that has examined the relationship between FHD and stigma related to dementia in Chinese Americans. Our findings suggest that negative attitudes towards dementia are not

Table 1 Distribution of sociodemographic variables of the study respondents based on family history of dementia status

Variable		Total		Positive FHD (<i>n</i> = 55)		Negative FHD (<i>n</i> = 245)		χ^2	<i>P</i> -value
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%		
Age group	<50 years	107	35.7	24	43.6	83	33.9	1.86	0.172
	≥ 50 years	193	64.3	31	56.4	162	66.1		
Sex	Male	99	33.0	17	30.9	82	33.5	0.13	0.715
	Female	201	67.0	38	69.1	163	66.5		
Education	Completed high school	194	64.7	41	74.5	153	62.4	2.88	0.090
	Did not complete	106	35.3	14	25.5	92	37.6		
Duration of residence in the USA	<20 years	195	65.0	37	67.3	158	64.5	0.15	0.696
	≥ 20 years	105	35.0	18	32.7	87	35.5		

FHD, family history of dementia.

Table 2 Results of dementia stigma survey in Chinese American participants by family history of dementia status

Question		Respondents with FHD (<i>n</i> = 55) <i>n</i> (%)	Respondents without FHD (<i>n</i> = 245) <i>n</i> (%)	χ^2	<i>P</i> -value
1. Most employers will fire an employee with dementia.	Yes	47 (85.5%)	191 (78.0%)	1.54	0.215
	No	8 (14.5%)	54 (22.0%)		
2. Dementia is different from other physical illnesses.	Yes	21 (38.2%)	119 (48.6%)	1.95	0.163
	No	34 (61.8%)	126 (51.4%)		
3. Research on dementia is a good way for pharmaceutical companies to make profits.	Yes	17 (30.9%)	61 (24.9%)	0.84	0.358
	No	38 (69.1%)	184 (75.1%)		
4. Increasing government spending for dementia is a waste of money.	Yes	0 (0.0%)	13 (5.3%)	3.05	0.081
	No	55 (100.0%)	232 (94.7%)		
5. Most people will not want to be friends with people suffering from dementia.	Yes	27 (49.1%)	100 (40.8%)	1.26	0.262
	No	28 (50.9%)	145 (59.2%)		
6. It is difficult to communicate with people with dementia.	Yes	44 (80.0%)	173 (70.6%)	1.98	0.160
	No	11 (20.0%)	72 (29.4%)		
7. Only those with a low educational level will develop dementia.	Yes	4 (7.3%)	19 (7.8%)	0.01	0.903
	No	51 (92.7%)	226 (92.2%)		
8. I would avoid disclosing the truth if my relatives have dementia.	Yes	2 (3.6%)	32 (13.1%)	3.97	0.046
	No	53 (96.4%)	213 (86.9%)		
9. Patients with dementia would be completely incapable of feeling other people's worries or concerns at once.	Yes	41 (74.5%)	138 (56.3%)	6.20	0.013
	No	14 (25.5%)	107 (43.7%)		
10. A patient with dementia is dangerous to self.	Yes	22 (40.0%)	99 (40.4%)	0.00	0.956
	No	33 (60.0%)	146 (59.6%)		
11. A patient with dementia is dangerous to others.	Yes	15 (27.3%)	80 (32.7%)	0.60	0.438
	No	40 (72.7%)	165 (67.3%)		
12. A patient with dementia is impulsive and unpredictable.	Yes	42 (76.4%)	178 (72.7%)	0.32	0.574
	No	13 (23.6%)	67 (27.3%)		
13. Patients with dementia should be institutionalized.	Yes	25 (45.5%)	126 (51.4%)	0.64	0.423
	No	30 (54.5%)	119 (48.6%)		
14. Health insurance policies should not cover any costs of dementia.	Yes	10 (18.2%)	33 (13.5%)	0.81	0.367
	No	45 (81.8%)	212 (86.5%)		
15. Society should not treat patients with dementia with more tolerance.	Yes	2 (3.6%)	20 (8.2%)	1.35	0.245
	No	53 (96.4%)	225 (91.8%)		

limited to uninformed members in the community; even Chinese Americans with first-degree relatives with dementia subscribe to moderately stigmatizing views about the illness. This is consistent with a previous qualitative study on Chinese dementia caregivers, in which individuals often associated dementia with stigma and fear of aging.¹³ Our study adds that having first-degree relatives does not reduce the stigma of dementia. This is contrary to previous research, which suggests that increased contact with persons with mental illness is associated with less stigma.³

Approximately 96% of Chinese Americans with FHD were willing to disclose having relatives with dementia. This is in contrast with previous studies, which have shown that Chinese dementia caregivers would avoid the dementia label as a result of fear over "loss of face."^{4,13,14} This is encouraging, and suggests that the

social process of dementia-label avoidance among Chinese Americans can be eliminated. However, it is important to highlight that stigma of dementia remains prevalent, and goes beyond the stigma associated with "loss of face" in the Chinese American community.

Three of four Chinese Americans with familial risk factors believed persons with dementia to be completely incapable of feeling other people's worries or concerns at once. At a moderate-to-severe stage, patients with dementia might lack insight and misunderstand other people's worries or concerns. Thus, the respondents with FHD could simply be responding to the stigma item, "dementia patients are unable to understand other people's concerns," based on their own factual experience. However, in the Chinese culture, traditionally, first-degree family members will become caregivers for their loved ones with dementia.^{13,14} It is known that

stigma causes distress, rejection and discrimination. The present findings show that Chinese Americans with FHD are more likely to report complete “loss of interest” or apathy in patients with dementia, even at the early stage of the illness, which might further contribute to family members’ perception of burden and burnouts. It is likely that if we had recruited participants with family members recently diagnosed with mild cognitive impairment or early stage dementia, this association might have been more robust. Nevertheless, culturally appropriate and effective psychosocial interventions are necessary to address such issues.

There were some limitations to the generalizability of the study results. The present study was susceptible to a selection bias. The participants in our study were drawn from a self-selected group of individuals who wanted to attend health seminars. Our findings might not apply to the Chinese American general public, as the study used a convenience sample consisting of an immigrant Chinese population located in Los Angeles only. The second limitation is that no adjustment was made for multiple comparisons in the stigma scales. The third limitation is that a rigorous translation procedure was not followed in designing the questionnaire. Another limitation that should be noted is its cross-sectional design limits causal conclusions. Future studies are indicated toward further characterizing the relationships between family history of dementia and stigma. A longitudinal study using both quantitative and qualitative analyses might provide additional information regarding the nature and course of stigma in the general public with FHD. The group of Chinese American dementia patients has long been a marginalized study population. However, with this work, and the work that is left to be done, there is reason to believe that stigma will decrease in this minority group. In order to reduce health disparities, further culturally-sensitive education and group-support intervention for Chinese Americans with dementia should focus on increasing dementia literacy. A campaign to remove the stigma that patients with dementia would be completely incapable of feeling other people’s worries at once would be important to facilitate a rational discussion among Chinese American general public.

Acknowledgments

The author is indebted to Ruthie Tang of Black Mountain College for her generous assistance and support.

Disclosure statement

The author declares no conflict of interest.

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