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Observational Study

Association between recognizing dementia as a mental illness and dementia knowledge among elderly Chinese Americans

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Abstract

AIM: To investigate whether older Chinese Americans perceive dementia as a mental illness and the relationship between such perception and their general understanding of dementia remains unclear. Our study aims to understand this relationship and its future implication on improving dementia literacy among ethnic minorities.

METHODS: Elderly Chinese American participants from the Greater Los Angeles were asked to complete an 11-item dementia questionnaire, following a community health seminar. Cross-sectional survey data was analyzed using standard statistical methods.

RESULTS: The questionnaire received an 88.3% response rate. Among 316 responders, only 28.8% ($n = 91$) of elderly Chinese Americans identified dementia as a mental illness, and 71.2% ($n = 225$) did not recognize its mental disease origin. Furthermore, in comparison between these two groups, the first group demonstrated significantly higher level of baseline knowledge of the disease.

CONCLUSION: This study reveals that only approximately 1 out of 4 older Chinese Americans recognized dementia as a mental illness, consistent with previous studies on Asian Americans. Our study however showed that when dementia was being perceived as a mental illness, such perception was associated with a higher level of baseline dementia understanding. The current study suggested the potential of improving older Chinese Americans dementia literacy by increasing awareness of its mental illness origin.

Key words: Dementia literacy; Mental illness; Chinese Americans; Stigma

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Core tip: This study reveals that only approximately 1 out of every 4 elderly Chinese Americans recognized dementia as a mental illness. Our study however demonstrates that when dementia was being perceived as a mental illness, such perception was associated with a higher level of baseline dementia understanding. Further research is necessary to identify any causative relationship between viewing dementia as a mental illness and improved dementia knowledge, with the ultimate goal of improving dementia management outcomes in elderly Chinese American ethnic population.

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INTRODUCTION

According to the United States Census, an estimated 20% of the total United States population will be reaching age 65 or above by the year 2030^[1]. With more elders living longer, age-dependent conditions like dementia have become increasingly important topics. Asians are the fastest growing ethnicity in the United States, with a 46% increase between 2000 and 2010^[2]. Because Chinese Americans constitute the largest subgroup amongst Asian Americans reaching a population of 4 million in 2010, this ethnic group is particularly important when studying various conditions, including dementia^[1,2].

Older Chinese Americans demonstrate profound stigma towards the term "mental illness". According to Yang *et al*^[3], mental illness stigma has been described as especially pervasive and severe among Chinese population. Elderly Chinese individuals often equate "mental illness" with schizophrenia, a severe form of mental illness in which patients are generally ostracized by the Chinese society^[4]. Chinese patients with mental illnesses are quite commonly unable to regain social

acceptance and thus are isolated from the society. The label of a "mental illness" may serve as cues to stereotype these patients with negative characteristics such as "crazy" or "dangerous". Several previous studies show that older Chinese Americans have a very limited level of general knowledge about mental illness, and this has further contributed to social exclusion and discrimination toward diagnosed individuals with mental illness^[5-7]. Therefore, measuring whether the perception of "mental illness" will affect knowledge is particularly important.

Previous research has demonstrated that elderly Chinese American ethnic group has low baseline knowledge of dementia^[8]. Studies have shown that lack of dementia knowledge in Chinese community is associated with higher care-giver burnout rate, lower overall medical resource utilization rate and reduced quality of life for dementia patients^[8,9]. Unlike the western community which individualism is highly valued and appreciated, traditional values such as homogeneity forms the basis of Chinese American community. Individuals with mental illness such as dementia are perceived as outliers and thus explained the social isolation and discrimination towards those patients. As a result, Chinese Americans suffering from dementia receive less overall medical resources. Moreover, the delay in medical care exacerbates the disease progression leading to increased healthcare cost. In order to ensure a better delivery of dementia care to this ethnic group, the priority lies in the effort to increase elderly Chinese American's baseline dementia knowledge at the population level.

Dementia, widely categorized as a mental illness in the western culture, is highly stigmatized by older Chinese Americans^[1,10]. Cultural beliefs, such as the view that dementia brings shame and embarrassment to the family, also play an important role in stigmatizing dementia^[5,6]. Recently, DSM-5 has reclassified dementia and related disorders as neurocognitive disorders to highlight their separation from other mental illnesses and to disconnect neurocognitive disorder from the mental illness stigma associated with the term "dementia". Nonetheless, whether elderly Chinese Americans perceive dementia as a mental illness, and the association between this perception and their general baseline dementia knowledge is poorly understood. Thus in this current study, we aim to understand this relationship and its implications to improve dementia literacy among ethnic minorities.

MATERIALS AND METHODS

Design and procedure

This cross-sectional study enrolled a total of 358 participants from local Chinese American communities. Participants were recruited to attend dementia seminars hosted in the Greater Los Angeles area by means of radio, newspaper, posters, and word of mouth. Inclusion criteria included literacy in Chinese, the ability to

complete a survey questionnaire written in Chinese, and aged 55 and above in an attempt to capture the group of people entering into the age of developing cognitive impairments. Before the seminars, participants completed the questionnaire that identified their opinion on whether dementia was a mental illness, obtained their sociodemographic characteristics, and evaluated their general dementia knowledge. Sociodemographic variables included age, gender, education level, duration of residency in the United States and family history of dementia. The dementia knowledge was assessed by 11 questions that consisted of true (T) or false (F) statements regarding dementia causes, symptoms, treatment and prognosis as described in a previous study^[8]. Based on the questionnaire design, the total number of correct items, ranging from a score of 0-11, was positively associated with general dementia knowledge. A higher total score indicated a better understanding of dementia and thus higher baseline dementia knowledge.

Statistical analysis

Based on self-reported yes/no response to the statement "Dementia is a chronic mental illness", participants were separated into two study groups. Sociodemographic variables such as age, gender, education level, length of residency in the United States, as well as family history of dementia between the two groups were compared. Descriptive statistical analysis was performed using SPSS v13; two-tailed *t* test and χ^2 test were used to compare continuous variables and categorical variables respectively. Results with a *P* value < 0.05 are defined to be significant. The statistical review of the study was performed by a biomedical statistician.

RESULTS

Three hundred and sixteen of the 358 enrolled participants returned valid questionnaire answers, resulting in a response rate of 88.3%. Of the 316 valid responses, 28.8% (*n* = 91) elderly Chinese Americans identified dementia as a mental illness similar to western culture, and 71.2% (*n* = 225) did not recognize its mental disease origin. The group that recognizes dementia as a mental illness had 34% (*n* = 31) males, 53% (*n* = 48) high school graduates, 47% (*n* = 43) had lived in the United States for less than 20 year, 26% (*n* = 24) with a family history of dementia and had an average age of 64. On the other hand, the group that did not identify dementia as a mental disease had 32% (*n* = 73) males, 58% (*n* = 131) graduated high school, 54% (*n* = 122) had resided in the United States for less than 20 years, 20% (*n* = 46) with a family history of dementia and had an average age of 63. No statistical significance was found when comparing these two groups based on socio-demographic variables, such as gender (*P* = 0.781), age (*P* = 0.094), education level (*P* = 0.374), duration of residence in the United States (*P* = 0.261)

and family history of dementia (*P* = 0.250).

We identified statistical significant difference, however, in the total score of correct items from the questionnaire, which was used to gauge participant's baseline dementia knowledge. Table 1 shows the responses to the questionnaire based on perception of dementia as a mental illness. According to the 11-item questionnaire results, the group that recognized dementia as a mental illness (*n* = 91) has total scores ranging from 3 to 10, while the group that failed to see dementia as a mental illness (*n* = 225) has total scores between 3 and 11. However, the first group has a mean total score significantly better than the latter group (6.7 ± 1.6 vs 6.2 ± 1.7 , $t(314) = 2.39$, *P* = 0.018), indicating that the group which identifies dementia as a mental illness has higher level of baseline dementia knowledge.

Upon further analysis of individual items of the questionnaire, five (item numbers 3, 4, 5, 9 and 11) out of the 11 items were found to be significantly different between the two groups. Participants who perceived dementia as a mental illness were more likely to correctly identify "Risk of dementia increases with age" (93.4% vs 84.4%, *P* = 0.032). Among this group, 96.7% of the participants agreed that "dementia is defined as a reduction of cognitive abilities including understanding and judgment, as well as memory loss"; however, only 83.6% in the other group recognized this true statement (96.7% vs 83.6%, *P* = 0.002).

Similarly, more participants in the group that recognized dementia as a chronic mental illness correctly identify that "some types of dementia are caused by cerebrovascular diseases" (45.1% vs 28.0%, *P* = 0.004). In addition, 46.2% of participants in this group agreed that "dementia shortens the life expectancy after onset", which was significantly more than the 32.0% in the other group (46.2% vs 32.0%, *P* = 0.018).

Interestingly, more participants in the "dementia is not a mental illness" group correctly identified "senescence forgetfulness progresses with advancing age, resulting in patients being unable to recognize their families" as a false statement (81.8% vs 71.4%, *P* = 0.042). However, this one exception did not seem to change the fact that this group had a lower total score in this questionnaire.

DISCUSSION

This study reveals that only approximately 1 out of every 4 elderly Chinese Americans recognized dementia as a mental illness. This is consistent with previous study which demonstrated that Asian Americans are less likely to recognize dementia as a mental illness^[9]. Our study however identifies that when dementia was being perceived as a mental illness, such perception was associated with a higher level of baseline dementia understanding.

When stigmatization of mental illness is prevalent in the society, it may further impede an individual from taking the initiative to learn more about dementia

Table 1 Association between dementia knowledge questionnaire items and perception of dementia as a mental illness

Knowledge category	Questions	True/false	Answered yes to "dementia is a chronic mental illness" (n = 91)	Answered no to "dementia is a chronic mental illness" (n = 225)	P	χ^2
General	1 Dementia is forgetfulness due to aging. Everyone will have dementia with advancing age	F	29 (31.9)	92 (40.9)	0.135	2.231
General	2 Dementia is a disease affecting the brain. Not everyone will suffer from dementia	T	88 (96.7)	207 (92.0)	0.129	2.310
General	3 Risk of dementia increases with age	T	85 (93.4)	190 (84.4)	0.032	4.609
General	4 Senescence forgetfulness progresses with advancing age, resulting in patients being unable to recognize their families	F	65 (71.4)	184 (81.8)	0.042	4.154
Symptoms	5 Dementia is defined as a reduction of cognitive abilities including understanding and judgment, as well as memory loss	T	88 (96.7)	188 (83.6)	0.002	10.131
Treatment	6 Some types of dementia are treatable	T	56 (61.5)	114 (50.7)	0.079	3.081
Symptoms	7 People suffering dementia become unable to perform familiar tasks at once	F	36 (39.6)	87 (38.7)	0.883	0.022
Symptoms	8 People suffering from dementia become unable to recognize time, place, and person at once	F	25 (27.5)	68 (30.2)	0.627	0.236
Cause	9 Some types of dementia are caused by cerebrovascular diseases	T	41 (45.1)	63 (28.0)	0.004	8.536
Cause	10 Some types of dementia are hereditary	T	57 (62.6)	136 (60.4)	0.717	0.131
Prognosis	11 Dementia shortens life expectancy after onset	T	42 (46.2)	72 (32.0)	0.018	5.629
Total score			6.7 ± 1.61	6.2 ± 1.71	0.018	t = 2.39

T: True; F: False.

and improve level of knowledge. In fact, a previous qualitative research has highlighted that for Chinese family dementia caregivers, stigma was a common theme. They found that significantly more Asian Americans (53%) than Anglos (16%) endorsed that "Alzheimer's is a form of insanity", demonstrating a lack of dementia knowledge among Asian Americans^[11]. However, our current study, surprisingly, shows quite the opposite - individuals who see dementia as a mental illness is associated with better understanding of the disease. This could be explained by a relatively non-aggressive nature of dementia compare to other mental illnesses. Indeed, Lam *et al.*^[12] reports that while there are different stereotypes for various mental illnesses, patients with anxiety or dementia were much better accepted than those with psychosis in Chinese communities. The term "mental illness", when associated with dementia, may not be as stigmatizing, as evidenced by higher dementia knowledge from the current study. In addition, a more recent quantitative research examining 89 Chinese American general public revealed that over three-quarter participants supported further research on dementia, suggesting their interest in learning more about this disease^[13].

In general, as evidenced by questionnaire items 3, 5, 9 and 11, viewing dementia as a mental illness is associated with better understanding of dementia in the following categories: General knowledge (risk increased with advanced age), symptoms (dementia reduced cognitive ability), cause (some dementia are caused by cerebrovascular disease), and prognosis (dementia

shortens life expectancy). These specific knowledge categories are consistent with the knowledge categories found insufficient among Asian American ethnic groups in Hawaii based on a previous study^[11]. Nevertheless, item 4 shows that the group who recognizes dementia as a mental illness is more likely to mistaken that senescence forgetfulness progresses with advancing age. Similarly, a number of studies have highlighted the strong tendency of Asian Americans, particularly elderly Chinese, to view dementia as a normal part of aging process in order to "buffer" the stigmatization of dementia from other aggressive mental illnesses^[14,15]. Such "normalization" carries with it a soft stigma that was distinct from that of severe mental illnesses. Future intervention would be necessary to address this fundamental misbelief of dementia in this ethnic population.

Chinese Americans who do perceive dementia as a chronic mental illness generally describe dementia as a disease of the brain. In a survey of 22 Chinese Americans, all Chinese Americans (100%) tend to view dementia as an illness that affects the brain. For example, one participant stated in Chinese, "Playing mah-jongg can eliminate dementia because it activates my brain"^[16]. The above finding is similar to a pilot study conducted among Vietnamese American Immigrants. Eighty percent of the participants believe that dementia is a disease affecting the brain^[17]. Among 208 Chinese Americans, younger adults showed a significantly higher level of understanding that dementia could result from cardiovascular disease^[18]. However, Chinese Americans

continue to associate dementia with stigma and “loss of face”. In fact, family members were more likely to perceive patients with dementia to be incapable of feeling other people’s worries or concerns at once^[19].

Previous studies have found that older Chinese Americans with less than 20 years of residence in the United States were less likely to understand that dementia shortens life expectancy after onset^[20]. Our data adds that when elderly Chinese Americans do not identify dementia as a mental illness, they are more likely to misunderstand dementia prognosis. Therefore, it appears that there are multiple factors affecting older Chinese Americans in understanding dementia prognosis knowledge. As knowledge is necessary to change health-related behaviors, a necessary step in dementia promotion involves increasing the Chinese American public’s knowledge on dementia prognosis.

This study suggested the potential of improving elderly Chinese Americans dementia literacy by increasing awareness of its mental illness origin. Traditionally, programs aiming to deliver medical knowledge about dementia are done *via* classroom, pamphlets or other media outlets^[21]. Such programs often have low effectiveness secondary to stigmatization/lack of interest in the general public, however they still require a sizable amount of community resources. Interestingly, our current study may point to a new direction. Simply by delivering a concise message such as “dementia is not a normal part of aging. Let’s face this mental illness together”, we may have challenged the popular Chinese American perception and therefore, stimulate their interest in learning more about the disease. Moreover, previous study by Ho *et al.*^[22] suggested that Chinese Americans are eager to learn if resources are available, despite having low level of baseline dementia knowledge. Together with Chinese Americans’ willingness to seek information about this illness, future education programs that emphasize dementia’s mental illness origin may have improved effectiveness in delivering dementia knowledge to this ethnic group.

This study has several limitations. First, data were based on a cross-sectional survey that relied on self-reported data, so our findings are subject to report biases inherent in these approaches. Second, the survey was brief and excluded some specific topics on dementia. It also did not directly assess the stigma of dementia. Third, due to the true/false response format, there may be lower variance among the items. Future studies should utilize scales with established psychometric properties and cut-off scores. Fourth, the sample included only participants aged 55 and older, in an attempt to capture people entering into the age group of developing cognitive impairments. Although this age group corresponds to the majority of participants who may eventually develop neurocognitive disorders, it does raise the question of whether our data are generalizable to all age groups. Fifth, the goal of our study was to explore whether viewing dementia

as a mental illness is associated with overall dementia knowledge among elderly Chinese Americans. There were no differences on sociodemographic factors between the two groups. As such, we did not perform logistic regression to examine predictors. Future studies may focus on identifying additional sociodemographic characteristics with significant test of interaction and use logistic regression to examine whether perception of mental illness may be a useful predictor for high baseline dementia knowledge. Sixth, this study would benefit from using Likert scale on the question “Is dementia a chronic mental illness” to provide a way of measuring attitudes. Seventh, with the possibility that people with bias about dementia may have less interest in attending dementia seminar, this study may underestimate the bias by collecting data from seminar attendees. Lastly, we recognized that the term, “chronic mental illness”, carries significant stigma as well. Future studies may consider using the term, “severe mental illness” to prevent potential confounding bias.

This study reveals that only approximately 1 out of every 4 elderly Chinese Americans recognized dementia as a mental illness. Our study however demonstrates that when dementia was being perceived as a mental illness, such perception was associated with a higher level of baseline dementia understanding. Further research is necessary to identify any causative relationship between viewing dementia as a mental illness and improved dementia knowledge, with the ultimate goal of improving dementia management outcomes in elderly Chinese American ethnic population.

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COMMENTS

Background

As one of the fastest growing ethnic groups in the United States population, elderly Chinese Americans are known to have a profound cultural stigma towards mental illnesses and poor knowledge about these diseases. Dementia, widely categorized as a mental illness based on a biomedical model in the Western World, is highly stigmatized in this ethnic group. Nonetheless, whether older Chinese Americans perceive dementia as a mental illness and the relationship between such perception and their general understanding of dementia remains unclear. This study aims to understand this relationship and its future implication on improving dementia literacy among ethnic minorities.

Research frontiers

Research focusing on the Chinese American population has been scarce in general, especially in the field of mental illness. The research hotspot is to gain more understanding in this topic *via* a variety of research modalities and approaches.

Innovations and breakthroughs

Since people’s perception of mental illness is a very subjective opinion, a few of research studies have tried to detour from investigating this subject. The study, however, confronted this perception of dementia as a mental illness, and attempted to find its association with dementia knowledge.

Applications

As knowledge is necessary to change health-related behaviors, a necessary step in dementia promotion involves increasing the Chinese American public's knowledge on dementia. Together with Chinese Americans' willingness to seek information about this illness, future education programs that emphasize dementia's mental illness origin may have improved effectiveness in delivering dementia knowledge to this ethnic group.

Terminology

Dementia is a broad category of disease that causes a long term and often gradual decrease in the ability to think and remember that is great enough to affect a person's daily functioning.

Peer-review

The work is interesting and it has a significant degree of originality since it focuses on dementia as a mental illness among elderly Chinese Americans, which represents a rapidly growing population in the United States.

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