# Attitudes towards dementia among Chinese adults aged 50 years and older: a comparative study of immigrants living in Melbourne and nonimmigrants living in Beijing

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#### **ABSTRACT**

**Objectives:** This study investigated attitudes towards dementia among Chinese immigrants aged 50 years and over living in Australia and compares these attitudes with those of individuals living in mainland China. It aimed to better understand what older Chinese adults think about dementia and to inform the development of tailored dementia-related services for this group of people.

Design: A qualitative design involving individual interviews was employed in this study.

**Participants:** Forty-six participants were recruited: 21 in Melbourne and 25 in Beijing. All interviewees were born in mainland China, were community-dwelling, and did not have a dementia diagnosis.

**Measurements:** The tripartite model of attitudes was used to guide the semi-structured interview design and report the results. Thematic qualitative analysis was employed.

**Results:** In both groups, most participants held negative feelings, stigmatized views and negative stereotypes of dementia. However, most participants expressed a willingness to help individuals living with dementia. Regarding dementia care, nearly all participants preferred home care but thought formal care would become the mainstream form of care in the future. Fewer Melbourne participants expressed concerns regarding developing dementia, were interested in dementia, or perceived a need for dementia-related educational activities. Melbourne participants also reported more avoidant responses to dementia or individuals living with dementia.

**Conclusion:** This study carefully compares attitudes towards dementia between older Chinese immigrants in Melbourne and older Chinese adults in Beijing. Similarities and differences were observed between these two groups. Dementia-related service providers should consider the sociocultural changes and migration-related barriers experienced by Chinese immigrants.

Key words cross-national, migration experience, dementia attitudes, the tripartite model of attitudes

### Introduction

In 2021, an estimated 472,000 Australians are living with dementia; moreover, almost 1.6 million Australians are involved in the care of people living with dementia (Dementia Australia, 2021). Hence, in

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line with the World Health Organization's statement, it is essential to create an inclusive and accessible environment for people living with dementia (PLWD) and their carers and families (World Health Organization, 2017). To create such dementia-friendly communities, a reduction in the stigmatization, discrimination, and misunderstandings of dementia is a key aspect. In addition, positive attitudes towards dementia and PLWD are critical to encourage the public to actively engage in dementia health promotion, including risk reduction and timely detection (Devoy and Simpson, 2017; Phillipson *et al.*, 2015).

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Modern Australia is a multicultural country. One in five PLWD in Australia are from culturally and linguistically diverse (CALD) backgrounds (Brown et al., 2016). With the anticipation of a substantial increase in the number of immigrants aged 65 years and over in the coming decades, it is expected that the number of dementia patients with CALD backgrounds in Australia will also increase (Wilson et al., 2020). However, CALD populations, including Chinese immigrants, are greatly unrepresented in Australian dementia research (Low et al., 2019). In Australia, Chinese immigrants have been the second-largest migrant group since 2017 (Australian Bureau of Statistics, 2020). It is therefore reasonable to anticipate that Chinese immigrants will make up a sizeable portion of PLWD in the future.

Considering the migrant background of CALD populations, their traditional values and cultural beliefs might affect how they think about dementia and PLWD (Dilworth-Anderson and Gibson, 2002; Sayegh and Knight, 2013). In a study on Hispanic, African, Asian, and Pacific Islander Americans, researchers summarized and discussed four culturally associated beliefs and values about memory loss and dementia (Sayegh and Knight, 2013). These beliefs/values included as follows: viewing mild symptoms of early dementia as a normal part of aging; attributing dementia to insanity rather than a neurodegenerative disease; the fatalism of dementia causes, such as labeling dementia as "evil," "an act of God," or "bad feng shui"; and feeling shame and concealing the patients. In addition, given their experience of migrating to and resettling in a new country, sociocultural changes might also impact on how they respond to dementia, such as seeking diagnosis and care support. For example, language difficulties were often reported as a barrier to social and health service access in CALD populations (Batalova, 2012; You et al., 2021).

Most recent studies on dementia attitudes among CALD populations were conducted in the United States or Europe, and their findings suggested that negative attitudes and stigma towards dementia might be very prevalent. Herrmann et al. reviewed dementia-related stigma studies and found that stigma might be more common among America's ethnic and immigrant minorities (Herrmann et al., 2018). Another study in the United States indicated that African Americans often use negative words and phrases to describe PLWD, such as "fear," "crazy," and "damned" (Epps et al., 2021). In Denmark, Nielsen et al. compared three immigrant groups, Polish, Pakistani and Turkish, with native Danish people regarding their attitude towards dementia (Nielsen and Waldemar, 2016). They found that the proportions of misunderstandings and stigmatizing concepts in relation to dementia were much higher in CALD participants than the native population.

However, studies targeting older Chinese immigrants are very limited in the literature, including in Australia. Most of these studies were conducted in the United States and used quantitative methods. Their results focused on perceived threats of or stigma towards dementia. Therefore, more studies are needed to obtain a preliminary and detailed description of their attitudes towards dementia. In this study, a qualitative methodology was employed.

In addition, a conceptual framework is needed to structure and guide this investigation while considering their migration experience, sociocultural changes, and traditional health beliefs. In the literature, the conceptual frameworks, such as the Self-Regulation Model or Common Sense Model of Illness Representation, and related measures were used to explore or evaluate people's attitudes towards dementia (Clare *et al.*, 2016; Quinn *et al.*, 2018). Usually, these studies mainly targeted people's beliefs about dementia, which might ignore other perspectives on how people perceive dementia or PLWD.

Hence, in this study, the tripartite model of attitudes was selected as the conceptualized structure of dementia attitudes to gain a comprehensive understanding of how people think about dementia or PLWD (Rosenberg et al., 1960). This model, developed by Rosenberg et al., is widely used to understand attitudes towards various diseases and palliative care and guided the development of the Dementia Attitude Scales (O'Connor et al., 2019; O'Connor and McFadden, 2010). In this model, attitude consists of three measurable components: affective, cognitive, and behavioral. In the context of attitudes towards dementia, the affective component could refer to people's evaluations of and feelings about dementia or PLWD. The cognitive component could refer to people's knowledge of and thoughts about dementia or PLWD. The behavioral component could refer to people's intentions or actual behaviors towards dementia or PLWD.

With regard to the affective component of dementia attitudes, among a group of 207 older Chinese Americans aged 55 years and above, Shi et al. reported that 55% of them worried about their own memory problems, 11% even indicated that they were too worried to fall asleep, and 87% thought their family members would be very stressed if they had dementia (Shi et al., 2018). With regard to the conceptive component, in Shi et al.'s study mentioned above, 32% of older Chinese Americans thought they would develop dementia someday. In another study, researchers interviewed 36 older Chinese Americans about their perceptions of the symptoms and causes of dementia (Laditka et al.,

2013). They reported that participants commonly thought genetics or heredity, anxiety or stress, and "having a lot on the mind" were causes of dementia, and the core symptom was memory loss, from minor forgetfulness to a very severe condition. Woo et al. studied stigma towards dementia among older Chinese Americans aged 55 years and over and found that 32% of the 449 participants thought that PLWD were dangerous to others, and 73.1% also thought that PLWD were impulsive and unpredictable (Woo and Mehta, 2017). With regard to the behavioral component, in Shi et al.'s study, 56% of older Chinese Americans wanted to know their risk of developing dementia someday, and 22% would seek dementia-related information about prevention from doctors and others. In Woo et al.'s study, 40% of the participants would not want to be friends with PLWD, and 49% thought PLWD should be institutionalized. In Laditka et al.'s study, older Chinese Americans rarely used the term "dementia"; instead, they used the term "Alzheimer's disease" or euphemisms, such as "senior moment."

To the best of our knowledge, only one study on dementia attitudes was conducted in Australia, which included Chinese immigrants aged 18 years and over. Low *et al.* assessed 437 Chinese Australians' attitudes towards dementia with seven "yes" or "no" questions (Low *et al.*, 2010). The study observed that Chinese immigrants expressed more negative attitudes than third-generation Australians. Fifty-one percent of them agreed with the statement that dementia was a normal part of aging, 84% thought PLWD could have done something to avoid dementia, 83% thought PLWD should be cared for like young children, and 7% thought they would feel embarrassed if a family member developed dementia.

In previous studies, older Chinese immigrants are not well represented, especially in Australian studies, and current evidence indicates that they have many misunderstandings of or negative attitudes towards dementia. However, there is not enough current evidence to generate a comprehensive understanding of the attitudes of older Chinese immigrants towards dementia. Little is known regarding the impact of the migration experience and sociocultural environment on dementia attitudes. Therefore, this study aimed to explore attitudes towards dementia in two groups of Chinese adults aged 50 years and over: immigrants living in Melbourne, Australia, and nonimmigrants living in Beijing, China. By comparing the similarities and differences in dementia attitudes between these two groups, an improved understanding of the role of the migration experience and sociocultural

changes in older Chinese immigrants' attitudes towards dementia can be gained.

### **Methods**

### Study design

A qualitative research design was employed in this study. The data were collected through in-depth semi-structured interviews.

### **Participants**

Two convenience samples were recruited from the metropolitan areas of Melbourne, Australia, and Beijing, China. Participants were recruited using the following inclusion criteria: 1) aged 50 years or above; 2) born in mainland China and self-identified as ethnic Chinese; 3) community-dwelling; 4) not diagnosed with dementia, mild cognitive impairment, or any neurocognitive disorders; and 5) for participants recruited from Melbourne, first-generation Chinese immigrants.

This study was approved by the Medicine and Dentistry Human Ethics Sub-Committee of The University of Melbourne and the Ethics Review Board of Peking University Institute of Mental Health (Sixth Hospital). All participants provided written (before COVID-19 pandemic) or oral consent (during COVID-19 pandemic).

### Data collection

Twenty-one interviews were conducted in Melbourne between September and December 2019, and 25 interviews were conducted in Beijing between March and June 2020.

In Melbourne, participants were given the option of either an in-person interview at their preferred locations or a phone interview. In Beijing, all interviews were conducted via telephone owing to the coronavirus (COVID-19) pandemic.

All interviews were conducted in Mandarin and audio-recorded with the consent of the participants. The duration ranged from 30 to 60 minutes per interview.

### Interview schedule

A semi-structured interview schedule was developed based on the tripartite model of attitudes and structured with three sets of open-ended questions regarding affective, cognitive, and behavioral components. At the beginning of the interview, several demographic questions were asked, including questions on age, sex, education, marital status, employment status, self-rated health condition, family

history of dementia, exposure to dementia, and migration experience. Additional explorative questions were asked if more detailed descriptions or information were sought from the participant.

### Data analysis

Descriptive analyses of the demographic information were conducted. Data for continuous variables are presented as means and standard deviation (SD), and data for categorical variables are presented as numbers and percentages. The Mann–Whitney U test and chi-square test were selected to compare the continuous and categorical variables between the two groups, respectively.

Interview recordings were transcribed verbatim by professional transcriptionists, and then MZ double-checked the accuracy of all transcripts. The transcripts from Melbourne and Beijing were analyzed separately using the thematic analysis method by Braun and Clarke (2006).

Firstly, an initial coding framework was generated. In each group, 20% of the transcripts were randomly selected and coded by MZ to derive this framework. Then, the second coder (HFZ) reviewed this framework using a randomly selected transcripts sample. Disagreements of the code framework were then addressed through group discussion within the research team. With this code framework, the remaining 80% of transcripts were coded. When more disagreements appeared, MZ and HFZ discussed and reached a consensus. Themes were initially defined and named by MZ and then were discussed within the research team until a consensus was reached. QRS NVivo 12 was used to store and manage data files and facilitate the data analysis.

#### Results

A total of 46 Chinese adults were interviewed in this study, including 21 from the Melbourne group and 25 from the Beijing group. There were no significant differences between these two groups regarding demographic characteristics, except for current employment status (Table 1). In the Beijing group, more participants volunteered or participated in part-time or full-time work (p < 0.05).

In the Melbourne group, the mean age when participants migrated to Australia was slightly over 55 years (SD = 10.5), and the average number of years living in Australia was nearly 12 years (SD = 8.9). All participants rated their English proficiency as "poor" (55%) or "fair" (45%).

Themes and subthemes are described in Table 2. There were four themes generated in

the affective component, five in the cognitive component and seven in the behavioral component. Of these, seven themes were present in both groups, five were present in only one group, and four were present differently between the two groups. More details on each theme are provided below and sample quotations are shown in Tables 3, 4 and 5.

### The affective component

A SCARY AND HOPELESS CONDITION

Both groups (14 out of 25 in the Beijing group and 18 out of 21 in the Melbourne group) reported feeling scared at the thought of dementia. Many participants characterized dementia as foolishness and a loss of dignity, self-control, and independence. Several participants mentioned that PLWD were so impaired that they even lost the ability to commit suicide.

### AN UNPLEASANT TOPIC

In the Melbourne group, many participants (7 out of 21) reported that older adults were not interested in or joined in the discussion if others mentioned dementia. The reason was that dementia was an unpleasant topic. Some words they used to describe their feelings were "boring," "annoyed," or "disgusted."

A TRAGEDY FOR THE WHOLE FAMILY, ESPECIALLY FOR ADULT CHILDREN

Participants in both groups expressed sympathy not only for PLWD but also for their carers and family members (12 out of 25 in the Beijing group and 16 out of 21 in the Melbourne group). They described having PLWD in the family as a tragedy that could destroy the lives of the entire family. Care burden was commonly mentioned by participants, who thought that the care burden was heavier for dementia than for other diseases and that caring for PLWD would place a physical, mental, and financial burden on their families, particularly their adult children.

Being worried about developing dementia in the future, the majority of participants in the Beijing group reported worries (15 out of 25). Moreover, they worried more if they had risk factors for dementia, such as a family history of dementia or stroke. In contrast, more participants in the Melbourne group (14 out of 21) reported no worries about developing dementia, and the most commonly mentioned reason was that they did not have a positive family history of dementia.

Table 1. Comparison of the participants' demographic characteristics between two groups

	MELBOU	IRNE	BEIJIN	NG		
	N=2	21	N=2	25	TEST VALUE	p-Value
Age (Mean (SD), range)	67.0 (6.4)	57–80	63.2 (7.9)	53–83	Z = -1.886	0.059
Gender $(N, \%)$						
Female	15	71.4	16	64	$\chi^2 = 0.287$	0.592
Present marital status (N, %)						
Married	19	90.5	22	91.7	$\chi^2 = 1.359$	0.507
Widowed	1	4.8	2	8.3		
Divorced	1	4.8	-	_		
Years of education (Mean (SD), range) Current employment status (N, %)	12.8 (3.0)	5–18	13.0 (2.2)	7–16	Z = -0.257	0.797
Retired	20	95.2	10	40	$\chi^2 = 15.603$	0.001
Volunteer	1	4.8	7	28		
Part-time	_	_	6	24		
Full-time	_	_	2	8		
Number of diseases (Mean (SD), range)	0.9(0.9)	0-3	1.20 (1.2)	0-4	Z = -0.802	0.423
Self-rated health condition $(N, \%)$						
Bad	_	_	1	4	$\chi^2 = 6.221$	0.101
Neutral	10	50	6	24		
Good	9	45	11	44		
Very good	1	5	7	28		
Family history of dementia (N, %)						
Positive	6	30	8	32	$\chi^2 = 0.021$	0.885
Contact with a people living with dementia						
Yes	10	50	17	68	$\chi^2 = 1.500$	0.221
Caring for a people living with dementia						
Yes	4	20	5	20	$\chi^2 = 0.000$	1.000
Age when arrived Australia (Mean, SD)	55.2	10.5	_	_		
Years living in Australia (Mean, SD)	11.8	8.9	_	_		
Self-rated English proficiency (N, %)			_	_		
Poor	11	55	-	_		
Neutral	9	45	_	_		

Note: N = number; SD = standard deviation.

### The cognitive component

Stigma still present for some people

When asked a broad question about Chinese adults' attitudes towards dementia, the majority of participants in both groups believed that some older Chinese adults still held stigmatizing thoughts about dementia and that, if diagnosed with dementia, some people might have self-stigma and be ashamed of their diagnosis (10 out of 25 in the Beijing group and 14 out of 21 in the Melbourne group). Younger age, a lack of exposure to PLWD, and a higher education level were mentioned as possible reasons for such stigma towards dementia.

### STEREOTYPES INFORM INITIAL IDEAS ABOUT DEMENTIA

When exploring the general view of dementia or PLWD in both groups, most participants' description of PLWD was usually related to severe cognitive or behavioral problems, such as getting lost and

having incontinence (16 out of 25 in the Beijing group and 14 out of 21 in the Melbourne group). Some also reported that developing dementia meant a loss of independence and even a loss of meaning in life.

### A disease that did not affect me

When asked about their primary thoughts on dementia, participants living in Melbourne (7 out of 21) usually thought dementia had nothing to do with them. Their reasons varied, ranging from a younger age to a positive personality. They denied the possibility that themselves might develop dementia in the future.

A COMMON CHRONIC DISEASE IN LATER LIFE In the Beijing group, many participants (16 out of 25) regarded dementia as a common disease later in life. They believed that very mild memory loss is a common problem for most older adults but that it can worsen and become an early symptom of dementia.

**Table 2.** Attitudes towards dementia among Chinese adults in the Melbourne and Beijing groups based on the tripartite model of attitude

			THEMES REPORTED (YES/No)  MELBOURNE BEIJING	
COMPONENT	THEMES	SUBTHEMES		
Affective	1. A scary and hopeless condition		Yes	Yes
component	2. An unpleasant topic		Yes	No
	3. A tragedy for the whole family, especially for adult children		Yes	Yes
	4. Being worried about developing dementia	Great worries	No	Yes
		No worries	Yes	No
Cognitive	1. Stigma still present for some people		Yes	Yes
component	2. Stereotypes inform initial ideas about dementia		Yes	Yes
_	3. A disease that did not affect me		Yes	No
	4. A common chronic disease in later life		No	Yes
	5. Home care is preferred for people living with dementia, but formal care is the mainstream form of care in the future		Yes	Yes
Behavioural	1. Joking about their own forgetfulness		Yes	Yes
component	2. Being willing to help people living with dementia		Yes	Yes
	3. Avoiding the topic of dementia and people living with dementia		Yes	No
	4. Getting more support from communities, the government, and society regarding dementia		No	Yes
	5. Being interested in dementia educational activities	Great interests	No	Yes
	-	Lack of interests	Yes	No
	6. Decision-making process of participation in dementia educational activities	Following adult children's advice	Yes	No
		Be able to decide for oneself	No	Yes
	7. Barriers to participation in dementia educational activities	Family issues	Yes	No
	•	Inconvenient transportation	Yes	No
		Language difficulties	Yes	No

HOME CARE IS PREFERRED FOR PEOPLE LIVING WITH DEMENTIA, BUT FORMAL CARE IS THE MAINSTREAM FORM OF CARE IN THE FUTURE Home care, particularly provided by spouses or adult children, was still the first choice for most older adults regarding dementia care in both groups (11 out of 25 in the Beijing group and 16 out of 21 in the Melbourne group). Home care could provide a familiar and convenient living environment for the patient. Participants particularly highlighted the psychological support patients could receive from their loved ones. Home care is also aligned with the traditional Chinese values of caring for older family members.

On the other hand, many participants (6 out of 25 in the Beijing group and 7 out of 21 in the Melbourne group) argued that aged care facilities would become an inevitable and mainstream form of care in the future. Considering the care burden for adult children and the advantages of formal care, such as having healthcare professionals, participants from both groups indicated they could accept formal care if they had dementia in the future. However,

the risk of ignoring the psychological well-being and abuse of older adults in aged care facilities were also mentioned as serious worries about formal care.

### The behavioural component

JOKING ABOUT THEIR OWN FORGETFULNESS

When asked whether they talked about memory problems or dementia in their daily lives, some participants in both groups (6 out of 25 in the Beijing group and 5 out of 21 in the Melbourne group) mentioned making jokes about their own memory loss or the possibility of getting dementia. In other words, they thought developing dementia was a joke which would never happen to themselves.

BEING WILLING TO HELP PEOPLE LIVING WITH DEMENTIA

Most participants (11 out of 25 in the Beijing group and 13 out of 21 in the Melbourne group) in both groups expressed compassion towards PLWD and their families and a willingness to help PLWD with mild symptoms in the community. In particular,

Table 3. Sample quotat	tions of each theme	from the affective	component
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THEMES	SAMPLE QUOTATIONS
1. A scary and hopeless condition	If I got dementia, I think that I could not even end my own life because of losing the ability to do so. This is scary, a terrible diseaseAW09, Melbourne
	This (dementia) is a severe problem. I think it is worse than cancer. Cancer just ends your life, but this (dementia) doesn't. (When getting dementia), you bring great trouble to the entire family, and you are suffering. What can you do? You can do nothing.  _MM01, Beijing
2. An unpleasant topic	If you talk about dementia with older adults, they might say, "I am fine, why are you talking to me about this? Do you think I will get this disease in the future?" They will have such thoughts and feel disgustedBT07, Melbourne
3. A tragedy for the whole family, especially for adult children	Dementia patients significantly impact family members. First, there will be great psychological stress. If there is a patient in the family, the family members will have both physical and psychological breakdownsMX02, Beijing
	My mum always told me that "No matter what disease I might get, at least it must not be dementia. I would rather choose to die quickly than bring troubles to my children who have to take care of me." _AB06, Melbourne
4. Being worried about developing dementia	I don't feel very worried because I don't have a family history (of dementia), and I am open and like talking with others, so I think I may be less likely to get dementia.  _MX02, Beijing
	I never worry about it. Why? First, if my family members develop dementia, I think I can take care of them. Second, I think that genetics is significantly related to dementia. My parents do not have dementia; they are long-lived and have not developed this diseaseAB06, Melbourne

when their friends developed dementia, some participants believed that it was their responsibility to help them when needed.

Avoiding the topic of dementia and people living with dementia

When asked about the topic of dementia in the Chinese community in Melbourne, participants (8 out of 21) commonly reported that Chinese adults usually avoid this topic. They did not actively mention it in daily conversation, denying the possibility of developing dementia or even avoiding PLWD.

In addition, when asked about people's possible reactions to a dementia diagnosis or a person with dementia in the Chinese community in Melbourne, many participants (12 out of 21) mentioned avoidance. For example, people might deny this diagnosis, try their best to pretend to be cognitively normal, conceal their diagnosis, and even actively withdraw from others.

GETTING MORE SUPPORT FROM COMMUNITIES, THE GOVERNMENT, AND SOCIETY REGARDING DEMENTIA

In the Beijing group, many participants (9 out of 25) mentioned the community, government, and society's role in disseminating dementia-related information, care services, and other support

resources for PLWD and their families. They thought more policies or programs were needed to raise public awareness and to support PLWD and their families.

Being interested in dementia educational activities

Many immigrants in the Melbourne group (8 out of 21) reported they did not want to know or felt they did not need to know dementia-related information. The most frequently mentioned reason was that they did not have a family history of or any risk factors for dementia. However, most of them did not share their reasons. In contrast, for the Beijing group, participants (16 out of 25) expressed great interest in dementia educational activities, especially in risk reduction.

### DECISION-MAKING PROCESS OF PARTICIPATION IN DEMENTIA EDUCATIONAL ACTIVITIES

When discussing whether they decided to participate in dementia educational activities, Melbourne participants (10 out of 21) first considered their adult children's advice as they were not familiar with the local environment, including the sociocultural environment. In contrast, Beijing participants (12 out of 25) reported that they could make the decision based on their needs and interests.

### Table 4. Sample quotes of each theme from the cognitive component

THEMES	SAMPLE QUOTATIONS
1. Stigma still present for some people	People are scared (about dementia). I think if I got dementia, others will isolate me, abuse me, and criticize meAB01, Melbourne I think, for example, if an acquaintance, such as a workmate or neighbor, gets dementia, when people see him/her in the distance, they will start to discuss this person, such as "he/she is insane, you should not talk to him/her." Usually, others will gradually isolate the patientLH03, Beijing  Younger people might have some stigma towards dementia. People who have a family member with dementia or older people can understand (dementia). But for younger people, they do not have
2. Stereotypes inform initial ideas about dementia	the sense of it (dementia)BT07, Melbourne  If someone gets this disease (dementia), their whole life (patient) is ruined. (The patient) cannot understand their surroundings, just like a dead bodyAW06, Melbourne
	When thinking about the dementia patient, I would think the patient cannot recognize me anymore, have incontinence and have a low quality of lifeMX01, Beijing
3. A disease that did not affect me	I fear it. But it will not happen to me. Because I am positive, optimistic and I laugh every dayAW05, Melbourne  Honestly, when you talk about dementia with people who are around my age (56 years old), I think it has nothing to do with meAB04, Melbourne
4. A common chronic disease in later life	People I know all think this disease is normal, especially for us at this age, and they prefer to do many puzzles (to use their brain to reduce their risk) rather than do nothing and just wait for the risk of getting dementia to increase with ageLH04, Beijing.
5. Home care is preferred for people living with dementia, but formal care is the mainstream for of care in the future	Of course, if there are family members available or I am available, it

### Barriers to participation in dementia educational activities

Melbourne participants (11 out of 21) mentioned many migration-related barriers when considering whether to participate in dementia educational activities. These barriers included family responsibilities, such as taking care of their grandchildren and helping with the housework, transportation problems, such as an inability to drive and

inconvenient public transportation, and low English proficiency.

### **Discussion**

This study provides an in-depth description of older Chinese Australians' attitudes towards dementia and compares them to those of older

Table 5. Sample quotes of each theme from the behavioral component

THEMES	SAMPLE QUOTATIONS
1. Joking about their own forgetfulness	Usually, people don't talk about dementia, don't mention it in daily life.  However, it is ok to make a joke about dementia themselves. The conversation usually looks like this: A says, "My memory is becoming poor. I must have dementia" And B replies, "You are joking. Your brain is bright, and it is impossible for you to develop dementia!" _AB02, Melbourne
	Sometimes, people say, "maybe I will get dementia in the next several years."  It is joking, in fact, these people do not take it as an important disease  LH02, Beijing
2. Be willing to help people living with dementia	I think if my friends get dementia, I will still be willing to treat them as usual.  Because they are my friends, if they get dementia, I should help them.  _AB06, Melbourne
3. Avoiding of the topic of dementia and people living with dementia	There are (people who might stay away from patients). This percentage might be more than 20 or 30% in the community. Why? It might not be a stigma against dementia. People might think, "It is better to save trouble," and "I just need to interact less with him/her (People with dementia)." _AW08, Melbourne
	Honestly, I know many (people living with dementia in the community).  Some of them migrated to Australia in the same year as I did. They don't tell others what diseases they getAB04, Melbourne
4. Getting more support from communities, the government, and society regarding dementia	I think current attempts to raise public awareness of dementia are inadequate. The government should accept this responsibility to disseminate dementia-related information to the public. As raising public awareness takes time, people's knowledge about dementia will gradually increase from a very low level to a very high levelMM04, Beijing
5. Be interested in dementia educational activities	I think I do not like learning about such things because there are no patients in my family. I think If there is a specific activity for dementia education, few people will participateAB06, Melbourne
	I will take part in it (dementia educational activities). Because of population aging, older adults should at least have a general knowledge about dementia. If you tell them how to prevent dementia, I think they might be interestedMX01, Beijing
6. Decision-making process of participation in dementia educational activities	I follow her (daughter) advice because I am not familiar with the local environment here and do not know English. Even though the decision is not related to language, I will also listen to her because she has lived here longer than usAW04, Melbourne
	No need to ask others for their suggestions. For us, we are still independent and responsible for our decisions. JML02, Beijing
7. Barriers to participation in dementia educational activities	For me, there is an essential precondition for participation (no family responsibilities) because our work is looking after the home, not hanging out. The grandchildren are still very young, and my children need to work. We are here to help them. So they are the priority in our livesAW09, Melbourne
	Transportation (is a problem). Here, if the event is in the daytime, time is a problem. Sometimes there is bus/tram/train, but sometimes there is not or the waiting time is very longBT02, Melbourne

Chinese adults living in China. Guided by the tripartite model of attitudes, several similarities and differences were found in the aspects of affective, cognitive, and behavioral components. In general, although these two groups of older Chinese adults shared many common feelings, perceptions and actions related to dementia or people living with dementia, Melbourne participants were more likely to negatively perceive or respond

to dementia or people living with dementia than Beijing participants.

# Similarities between the Melbourne and Beijing groups

There were common results for each attitude component between Melbourne and Beijing participants. To some extent, these similarities are related and compose a relatively negative view of how older Chinese adults think about dementia. From the cognitive perspective, participants held stigmatizing views of people living with dementia and negative stereotypes of dementia symptoms. Thus, such perceptions might lead to negativity regarding dementia and people living with dementia, including "a scary and hopeless condition" and "a tragedy for the whole family." Hence, from the behavioral perspective, most participants expressed an intention to help patients with dementia and their families.

These findings of stigma and negative stereotypes are largely consistent with the findings of previous studies on Chinese immigrants and Chinese adults living in China (Low et al., 2010; Wang et al., 2013; Woo and Chung, 2013; Woo and Mehta, 2017; Yang et al., 2021). These findings indicate that Chinese adults' understandings of dementia might relate more to folklore knowledge, cultural beliefs, or self-experience than to scientific evidence. Our previous study also found that older Chinese adults living in Melbourne and Beijing had insufficient knowledge of dementia, with a mean score of approximately 17.5 out of 30, which was consistent with other studies in the United States and mainland China (Sun et al., 2014; Yang et al., 2021; Zhao et al., 2021). Therefore, future research should focus on increasing the public's evidence-based knowledge about dementia. After increasing their acquaintance with such knowledge, older Chinese adults might be more likely to reduce their negative perceptions towards dementia and individuals living with dementia (Yin et al., 2020).

The fear and hopelessness of dementia and the willingness to help dementia patients both reflect people's most direct affective responses to the symptoms and impacts of dementia. These responses might be due to a common response to health threats as well as Chinese culture and traditional values. In this study, participants were cognitively healthy and socially active. Hence, it is unthinkable for them that they would behave like people living with dementia in the future. Additionally, self-sacrifice and filial piety are two core features of Confucianism. The gradually decreasing independence of people living with dementia in daily life would place a heavy burden on their families, including financial burden, carer burden, social stress, and psychological stress (Chen et al., 2017; Wang et al., 2017; Zhang et al., 2020). Consequently, instead of making a contribution, older adults with dementia would place significant burdens on the family and challenge filial piety, which might lead to the fear among such individuals of developing this disease and increased compassion for family members of dementia patients.

Another expected finding is the preference for home care among Chinese adults, which supports findings reported in the literature (Alexandra and Joanna, 2017; Low et al., 2010). However, surprisingly, participants also admitted that formal care, such as aged care facilities, would become the mainstream form of care in the future. Although concerns regarding the quality of care and risk of abuse were also reported, our results showed an increasing acceptance of formal care among older Chinese adults. Therefore, in line with the recommendations in the literature, more formal care services, such as community-based supportive care or aged care facilities, could be designed and implemented for Chinese communities.

## Differences between the Melbourne and Beijing groups

Worries about developing dementia

One notable difference between the study groups was identified for the affective component: worries about developing dementia in the future. On the one hand, most Beijing participants expressed significant worries about getting dementia, while only a small proportion of the Melbourne group expressed this concern. This result is consistent with those of many previous studies conducted in mainland China (Calia et al., 2019; Zeng et al., 2015). The reasons for the worries might be various. From previous studies, concern about developing dementia might be attributed to many factors, such as age, education, exposure to dementia, income, knowledge about dementia, perceived care burden, and traditional cultural beliefs (Gao et al., 2020; Jang et al., 2018; Sun et al., 2013). Moreover, in the present study, participants' negative perceptions of dementia and people living with dementia might also contribute to their worries. In particular, in the Beijing group, a higher proportion of participants were volunteers or employees with better selfrated health conditions than in the Melbourne group. Hence, one possible reason for more worries in the Beijing group is that dementia would disturb their current active social life or even lead to social isolation.

On the other hand, a higher proportion of Melbourne participants did not report worries, and this result is inconsistent with those of previous studies. Shi *et al.* evaluated 207 Chinese Americans (mean age 75.37 years) and found that more than half were worried about memory loss (Shi *et al.*, 2020). In contrast, Jang *et al.* found a very low percentage (11.5%) of Chinese Americans (aged between 18 and 98 years) who were concerned about developing Alzheimer's disease (Jang *et al.*, 2018). Considering the age difference in participants in these studies, worries of developing dementia might be more prevalent in older adults. One possible explanation

might be that Melbourne participants were uneasy about expressing their worries about memory problems. First, the Western sociocultural environment might make them feel unsafe and uneasy; thus, they might try to hide their perceived weaknesses. For example, most of them did not understand English and the local lifestyle. In particular, they were not familiar with the services and support that they could seek for help. Second, in line with the finding of "following adult children's advice," older Chinese immigrants become the more vulnerable member in the parent-child relationship and lose their financial independence and social status after migrating to a new country (Jetten et al., 2018; Montayre et al., 2019; Shuang et al., 2019). Hence, they might avoid complaining about memory loss, which might trouble their children and make them impatient.

A COMMON/NORMAL CONDITION IN LATER LIFE Another difference was found in the cognitive component: Beijing participants in this study clearly stated that dementia was an abnormal condition that usually develops later in life, whereas previous studies have found that Chinese participants generally considered dementia to be a normal part of aging. Yang et al. assessed older Chinese adults in Shanghai, China, and reported that comparatively large proportions of the participants (44.6%) agreed that "dementia is not a disease. It is forgetfulness due to aging" (Yang et al., 2021). Similarly, Zeng et al. also found that approximately 38.1% of Chinese participants thought that "It is normal to get Alzheimer's disease during aging" (Zeng et al., 2015). This inconsistency may be caused by misunderstandings of the word of "normal" in Chinese. As aging or old age is seen as an essential cause of or risk factor for dementia in Chinese culture, many people regard developing dementia as common in later life. In quantitative studies, this view could be mistakenly presented as "dementia is a normal condition with aging." Furthermore, in the current qualitative study, participants were recruited from community centers or groups who had high education levels and actively participated in local community activities. Therefore, with a high literacy level and good communication skills, participants in this qualitative study could better understand the questions, clearly express their ideas, and give more details about "normal aging" and dementia.

### AVOIDANT RESPONSES TO DEMENTIA

From all three components of attitudes, there were more avoidant responses to dementia in Chinese immigrants living in Melbourne than in Chinese individuals living in Beijing. Such attitudes include becoming uncomfortable regarding the topic of dementia, denying the possibility of developing dementia, and avoiding thinking or talking about dementia or even engaging with people living with dementia. Only one common avoidant response was found in both groups: joking about one's own forgetfulness. All these behaviors might be barriers to seeking help for potential symptoms of dementia (Nielsen *et al.*, 2020; Vernooij-Dassen *et al.*, 2005). Therefore, these avoidant thoughts and behaviors might delay dementia diagnosis and treatment and reduce these individuals' interactions with people living with dementia, in turn deepening their fear of dementia and causing more stigma about dementia in the community.

### Interest in, need for, and barriers to dementia educational activities

This study found more interest in and need for dementia educational activities in the Beijing group and more barriers against these activities in the Melbourne group. As discussed above, resettling in a new sociocultural environment might make older Chinese immigrants uneasy and rely more on their adult children. Other factors also prevented them from engaging in local community activities, such as seeking dementia-related information, attending dementia-related activities, and communicating with people living with dementia. For example, Melbourne participants often faced language difficulties, were unfamiliar with public transportation, were unable to drive, and had limited social connections (Ester et al., 2019; Haralambous et al., 2014; Lee et al., 2011; Xiao et al., 2013).

In contrast, increasing dementia-related information was available to the general public in mainland China, including information on risk reduction, early symptoms, and care services. This information could be easily accessed on the internet, mobile phone, and TV. With the development and promotion of these dementia-related resources, the general public would feel more encouraged to talk about dementia, seek help for memory problems, and gain support from the community.

### Limitations

Several limitations of this study need to be noted. First, the method we used is a qualitative comparative study in nature and is usually considered as part of the mixed research methodologies (Rihoux and Lobe, 2009; Rihoux, 2006). The findings might partly complement our previous survey findings on the different levels of dementia knowledge between older adults living in Beijing and Melbourne (Zhao *et al.*, 2021). However, the qualitative comparative analysis is case-sensitive and may limit the generalizability of our findings from a statistical viewpoint. Second, all

older Chinese immigrants in this study were born in mainland China. Therefore, the generalization of the results to Chinese immigrant groups born out of mainland China, such as Taiwan, Hong Kong, and Macau, may not be appropriate. Third, this qualitative study was exploratory in nature and therefore might not sufficiently explain the underlying factors and mechanisms contributing to the development of dementia attitudes in the studied groups. Future studies should focus on exploring further underlying factors of dementia attitudes. Fourth, anon-CALD comparison group or immigrant groups from other CALD backgrounds might be needed to further explore the impact of migration experience and sociocultural environment on Chinese immigrants' attitudes.

### **Conclusion**

To our knowledge, this study is the first to explore differences in attitudes towards dementia between older Chinese immigrants in Australia and their nonimmigrant counterparts in mainland China. Our findings might provide policymakers, healthcare professionals, and other service providers with a better understanding of the attitudes towards dementia of Chinese immigrants living in Australia. In this study, older Chinese immigrants expressed diverse avoidant responses to dementia and barriers to engaging in local dementia services. Special training or information about Western culture, local lifestyles, the English language, and other practical skills should be offered to older immigrants in culturally appropriate ways. Considering the change in the parent-child relationship, family responsibilities and relationships must be considered when implementing health services or other activities for older Chinese immigrants.

### **Conflict of interest**

None.

### Description of authors' roles

M. Zhao, N. Lautenschlager, H. Wang, and X. Lin formulated the research questions. M. Zhao, N. Lautenschlager, H. Wang, and X. Lin designed this study. M. Zhao conducted all the semistructured interviews. N. Lautenschlager and H. Wang supervised the data collection. M. Zhao and H. Zhang carried out the thematic analysis. N. Lautenschlager, H. Wang, and X. Lin reviewed

and discussed the themes. All authors contributed substantially to the study conduct and interpretation of the data. M. Zhao wrote the manuscript. N. Lautenschlager, H. Wang, X. Lin, E. You, and H. Zhang provided critical review and comments on the manuscript.

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