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Title: Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers

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Help seeking in Asian people with dementia

Abstract

The prevalence of dementia is increasing in Australia. Limited research is available on access to Cognitive Dementia and Memory Services (CDAMS) for people with dementia from Culturally and Linguistically Diverse (CALD) communities. This study aimed to determine the barriers and enablers to accessing CDAMS for people with dementia and their families of Chinese and Vietnamese backgrounds. Consultations with community members, community workers and health professionals were conducted using the “Cultural Exchange Model” framework. For carers, barriers to accessing services included the complexity of the health system, lack of time, travel required to get to services, language barriers, interpreters and lack of knowledge of services. Similarly, community workers and health professionals identified language, interpreters, and community perceptions as key barriers to service access. Strategies to increase knowledge included providing information via radio, printed material and education in community group settings. The “Cultural Exchange Model” enabled engagement with and modification of the approaches to meet the needs of the targeted CALD communities.

Key words

Aged

Barriers

CALD

Dementia

Early Diagnosis

The Cultural Exchange Model

Main text

Introduction

Prevalence of dementia is expected to increase dramatically worldwide as the population ages. In Australia, the prevalence of dementia is projected to increase from 245,400 in 2009 to around 1.13 million people by 2050 (Access Economics 2009). Along with the dramatic increase in the number of people with dementia, population projections indicate rapid increases in the numbers of older people born overseas. In 2008, among the estimated 21.4 million Australians, one quarter were born overseas (5.5 million people) (Australian Bureau of Statistics 2009). Of this group, the percentage of people above the age of 65 (18%) is higher than that of the Australia-born population (11%), accounting for 36% of the total older Australian population (Australian Bureau of Statistics 2009). It is estimated that the prevalence of dementia in people from culturally and linguistically diverse (CALD) backgrounds in 2009 was 35,000 people; this figure is projected to increase to 120,000 in 2050 (Access Economics 2006).

Early diagnosis for people with dementia is important for both the person with dementia and their family. A timely diagnosis allows the person and their family to plan ahead and gain early access to support services and subsidised medication (Alzheimer's Australia 2007; Ashford et al. 2006; Derksen et al. 2006). A timely diagnosis also means the person with dementia is more likely to be able to participate in the future planning process to ensure their wishes are considered (Iliffe et al. 2009). Furthermore, there is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given early in the disease process (Perry et al. 2008).

There is evidence that dementia is probably under-diagnosed and diagnosed at a later stage in people from CALD backgrounds than in the general population. In 2003, a review found

about half of older people met the criteria for dementia without General Practitioner (GP) awareness or dementia documentation in their medical record (Boustani, Peterson, Hanson, Harris, & Lohr 2003). The issue of late diagnosis is particularly true for people from CALD backgrounds. It is well documented that this group of older people often presents to health professionals at a much later stage to seek help for diagnosis, and when family and the person with dementia do present for assistance, it is often in crisis mode (Cheng et al. 2009; Cooper, Tandy, Balamurali, & Livingston 2010; Lee et al. 2011; LoGiudice, Hassett, Cook, Flicker, & Ames 2001 ; Mukadam, Cooper, Basit, & Livingston 2011; The Cultural and Indigenous Research Centre Australia 2008). Many factors contribute to these issues including GPs' lack of skill and training, clinical inertia, time pressures and lack of culturally appropriate diagnostic tools and services as well as families' beliefs and the stigma associated with dementia (Lee et al. 2011; Mukadam et al. 2011). However, even when diagnosis is made, access to medications and healthcare by people from CALD background is also limited (Cooper et al. 2010). A recent systematic review indicated that little research is currently available on dementia service use among people from CALD backgrounds (Cooper et al. 2010).

Use of Chinese (Mandarin and Cantonese) and Vietnamese languages is projected to grow, and by 2026 Mandarin and Vietnamese will be the first and fourth most frequently used languages spoken by older people from CALD backgrounds in Australia, accounting for 10.5% and 4.5% respectively of this population (Gibson, Braun, Benham, & Mason 2001). This trend is also evident in the state of Victoria, a region of high levels of migration in Australia. In 1996, neither of these two languages was among the top ten languages spoken by people from CALD backgrounds (Gibson et al. 2001). However, between 2006 and 2011, Chinese and Vietnamese speaking populations have grown by 70% and 20%, respectively and these are now among the

top four languages spoken in Melbourne, Victoria (Victorian Multicultural Commission 2011). By 2026, Chinese and Vietnamese will be ranked as the third and fourth languages for older Victorians from CALD backgrounds, respectively (Gibson et al. 2001). Migration trends have contributed to this population growth.

The Chinese population in Australia is well-established and there is great diversity within this group, both in languages spoken (Cantonese, Mandarin, Hokkien, Shanghai and other Chinese dialects) and country of origin (mainland China, Hong Kong, Taiwan, Singapore, and other South Asian countries) (Guo 2005). The great diversity can be explained by the diversity within the Chinese culture itself, but is also related to the history of migration of this group. The Chinese population came to Australia during two main periods: the gold rush time (the latter half of the 19th century) and the years after 1973 (Guo 2005). The people who came during the gold rush time were mostly from impoverished areas in southern China, particularly the Guangdong province, and most of them spoke Cantonese (Museum of Chinese Australian History Inc.). The Chinese population decreased gradually after the gold rush period due to the restriction on Chinese immigration. It was not until 1973 when restrictions were lifted that the Chinese population began to expand (Department of Immigration and Multicultural Affairs 2001). Most of the Chinese immigrants arriving in the 1970s and early 1980s were from Cambodia, Hong Kong, Malaysia, Singapore and Vietnam (Department of Immigration and Multicultural Affairs 2001) and spoke Cantonese. It was in the mid-1980s that the number of people from mainland China, most of whom speak Mandarin, increased rapidly. In contrast, Vietnamese immigration has a relatively short history (Department of Immigration and Multicultural Affairs 2001). Most of the Vietnamese migrants came as refugees after the Vietnam War, with the first boat arrivals in 1976, and then through family reunion in the 1980s (Department of Immigration and

Multicultural Affairs 2001). It is important to know there is a mix of Vietnamese and Chinese ethnicities among the Vietnamese immigrants (Museum Victoria Australia) and a wide range of religious beliefs and practices. While many are not affiliated with any religion, the two main affiliated groups are Buddhist and Catholic. Health literacy in people of Vietnamese background is likely to correspond to their levels of education. Traditional beliefs regarding shame and guilt are particularly relevant in the diagnosis, discussion and treatment of dementia, since any mental illness or disorder is likely to be considered shameful.

Immigration patterns can be associated with hardship and trauma of refugee camps (Sims, Nguyen, LoGiudice, & Smith 1999). It has been reported that there is an increased incidence of depressive syndromes among refugees (Garcis-Peltoneiemi 1987); this includes our current Vietnamese older people (Sims et al. 1999).

Despite the different cultural influences which Chinese speaking groups from different countries might have experienced, their common linguistic and cultural heritage largely shapes their attitudes towards elder care. Similarly, Vietnamese speaking people in Australia are not a homogeneous group, either in ethnicity or in religious belief or practice, but there is also a level of commonality in their health beliefs and practices. Both groups are likely to combine traditional medical practices with Australian medical treatments. Other factors, such as different kinds of migration experience and exposure to different health systems might have influenced the health literacy of both groups, including their knowledge about dementia, and help-seeking behaviour (Queensland Health Multicultural Services 2013).

Confucianism has had a strong influence on the beliefs of both Chinese and Vietnamese speaking people, and largely influences attitudes to care of older family members. Filial piety, under which obedience, devotion and care towards one's parents and older family members are

grouped, is still seen as a central pillar of moral behaviour. Older Chinese and Vietnamese people often live with and receive care from their children, whose loyalty and care might compensate for early loss of function. This contrasts with the situation of an older person living independently, whose losses in function or cognition or changes in behaviour are more likely to be noticed. The protective behaviour of adult children towards parents from Chinese and Vietnamese backgrounds can result in a delay in the diagnosis of dementia (Iliffe et al. 2009; Lee et al. 2011).

This study targeted people of Chinese and Vietnamese speaking backgrounds living in Melbourne, Victoria, and aimed to determine the barriers and enablers for people with dementia and their families from these backgrounds to accessing Cognitive Dementia and Memory Services (CDAMS). The state of Victoria, Australia, is unique in providing Government funded regional multidisciplinary CDAMS that offer early diagnosis, advice, support and referral for people with cognitive difficulties and for those who support them. Referrals are received predominantly from GPs and local aged care services. Best practice guidelines include the need for cultural and linguistic sensitivity, and appropriate use of interpreters is paramount (Miletic et al. 2006). Part of the CDAMS role is to provide education on dementia to community services and health professionals.

The consultations for data collection reported in this paper were part of a larger study that developed and implemented two education programs (one for the community and one for health professionals) to improve detection of cognitive impairment and dementia at an earlier stage in the Vietnamese and Chinese speaking communities in Melbourne.

The “Cultural Exchange Model”

The project used the “Cultural Exchange Model” (see Figure 1), a framework for understanding knowledge development as an iterative process of exchange between researchers and stakeholders including service providers and people in the community. An important element of the model was action research which covered planning, taking action, evaluation and reflection (Andrews et al. 2009). Participants were involved and contributed to all stages of the process. The action research approach has been successfully implemented in our previous research and enabled engagement of staff, clients and their families in improvement in clinical practice (Lea et al. 2012). Action research is a form of participatory research and recognises that change is built into the research process through engaging with participants (Wadsworth 1984). The “Cultural Exchange Model” also drew upon aspects of the knowledge-to-action process by Graham and Tetroe (2007) whereby researchers and service providers work collaboratively to translate an evidence base into a community setting, through adaptation of both the content and process according to the knowledge gained from that community (Straus, Tetroe, & Graham 2011). We adapted the Knowledge Translation framework by Graham and Tetroe (2007) to gain better understanding of how each community operated (Straus et al. 2011) and to meet the needs of each community when translating knowledge into practice (Graham & Tetroe 2007). The model enabled the researchers to engage the stakeholders early and to refine the implementation process based on their feedback.

[Figure 1]

Methods

Ethics approval was obtained from the Melbourne Health Human Research Ethics Committee (HREC E91/0910), the Eastern Health Research and Ethics Committee (E91-0910) and the Melbourne East GP Network and it conforms to the provisions of the Declaration of Helsinki (as revised in Edinburgh 2000).

Consultations were undertaken with carers, health professionals and community workers through focus groups, face-to face interviews or telephone interviews. Carer interviews ranged from 30 minutes to one hour. The Chinese community worker focus group ran for 57 minutes and the Vietnamese community worker focus group ran for 1 hour and 20 minutes. Data is only available for one of the three Chinese community worker interviews and this ran for approximately one hour. Chinese health professional interviews ranged from 15 minutes to one and a half hours and the Vietnamese health professional interviews ranged from 30 minutes to one hour.

Carers

Carers of people with dementia from Chinese and Vietnamese backgrounds were identified through current service providers including CDAMS clinics, Aged Care Assessment Services (ACAS) and community workers as well as members of the advisory group. The ACAS is a service provided across Australia where clinicians provide assessment of frail older people to determine their overall care needs and to assist them to gain access to the most appropriate services, including referrals for further formal/comprehensive assessments to memory clinics. Staff in these services were asked to display invitations to participate in the study in a prominent position, to hand them out, or distribute them by mail to carers who might be interested in

participating. Additionally, a formal partnership was established with a Chinese ethno-specific organisation which assisted with recruitment via their Chinese community worker. The Chinese community worker's role included assisting with the recruitment of carers and community workers, providing space for a focus group and promoting the project amongst the community and community workers. This included facilitating the involvement of the research team in a dementia information session for the Chinese community. Interviews with carers included questions about their understanding and knowledge of dementia, access to information and services, their feelings about seeking a diagnosis, the diagnosis process and experiences of caring for someone with dementia.

All carers participated in face-to-face interviews and completed demographic surveys either in English or their own language, as required. Information asked of carers in the survey included their date and country of birth, gender, preferred language, and their relationship to the person they were caring for. Interpreters/bilingual staff were used in all of the consultations if required/requested.

Seven carers of Vietnamese people with dementia were interviewed from the Western region of Melbourne; two interviews were with carers caring for the same individual (sharing the caring role), resulting in five interviews. Six carers of Chinese people with dementia were interviewed from the Eastern region of Melbourne. All carers from the Vietnamese community were family members; six were children of the person they were caring for and one was a wife. In the Chinese community, five of the six carers were family members, all children of the care recipient, and the other was a friend with whom the care recipient lived.

Eleven carers were female. There was one male carer from the Vietnamese community. The mean age of the Chinese carers was 54 years (SD: 14.35) and 62 years (SD: 11.10) for

Vietnamese carers; 71.4% of Vietnamese carers and 66.67% of Chinese carers were 50 years or older (see Figure 2).

[Figure 2]

Vietnamese participants were all born in Vietnam; however, Chinese participants were from five different countries, including one person born in Vietnam, one in Hong Kong, one in Malaysia, one in East Timor and two born in China.

Community Workers

Community workers were identified through current service provider contacts as well as advice from advisory group members. A community worker is a person who, through professional training and field education, has the knowledge, skills and values to work in a social welfare agency or program intended to promote or restore the social functioning of individuals, families, social groups or larger communities (The Australian Community Workers Association 2012). Community workers provide services, support, activities, information and referral for those in need of assistance. They do this by linking people with appropriate services, government departments, groups, communities and each other (The Australian Community Workers Association 2012). A formal partnership was also established with a Chinese ethno-specific organisation, and recruitment in the Chinese community was conducted via the organisation's community worker. The Vietnamese community workers were recruited from community organisations, workers involved with Vietnamese older people in the Western region of Melbourne and by word of mouth.

Focus groups or interviews were conducted with community workers to explore questions about their knowledge of dementia, barriers for clients and families to seek an early diagnosis, unmet needs and ways of improving the first crucial step to diagnosis. Focus groups were selected as an appropriate tool because they provide a rich source of data on people's experiences, values and beliefs (May 1993). For those who did not feel comfortable about participating in a group, or who were not available to attend the focus group on the specified date, individual interviews were offered as an option. All community workers completed a demographic survey. Information asked of community workers in the survey included a description of their role, the community they serviced, the number of years they had been servicing this community, and organisations they represented.

Demographic data was collected from eight Vietnamese and four Chinese community workers. Four Chinese community workers did not complete a survey.

Five Vietnamese community worker participants were from mainstream organisations while three were from Ethno-Specific organisations. Of the Chinese community worker participants one was from a mainstream organisation, five were from Ethno-Specific organisations and two were from community-based organisations.

The number of years community workers ($n=11$) had provided services to the Chinese or Vietnamese community ranged from 1-28 years. The mean number of years was 8.89 years (SD: 8.04 years) (see figure 3). Vietnamese community workers had provided services to the Vietnamese community for an average of 11.29 years (SD: 9.34, $n=7$) while the Chinese community had provided services to the Chinese community for an average of 4.7 years (SD: 1.99, $n=4$).

[Figure 3]

Two focus groups were conducted with community workers; one with community workers involved with the Vietnamese community and one with those working with the Chinese community. Eight participants attended the Vietnamese focus group and four the Chinese focus group. Individual telephone interviews were conducted with two members of the Chinese community and a group phone interview was conducted with two other members of the Chinese community; in total, eight Chinese speaking workers were consulted.

Health Professionals

Health professionals who worked with people who spoke Vietnamese or one of the Chinese languages in the designated regions were contacted to be part of the study. Face to face or telephone interviews were conducted with health professionals either individually or in a group setting. Health professionals, identified through the internet, general practitioner networks, interviews with carers and community workers, word of mouth, and advice from our advisory panel, were contacted to see if they worked with the designated community. If they did, they were invited to participate in the study. There were many challenges to the recruitment of health professional participants in this study, including locating bilingual professionals in the respective areas, engaging their interest in participating, and finding a suitable time to speak to them. In some cases, there was greater potential for participation if the research team provided education at the same time as the data collection process (refer to Table 1).

A total of eight health professionals who worked with the Vietnamese community and 31 health professionals who worked with the Chinese community were consulted. Health

professionals consulted included practice nurses, GPs, a geriatrician, a pharmacist, a herbalist, residential care facility staff and other allied health professionals. Many of the health professionals interviewed were bilingual in Vietnamese or one or more Chinese dialects. Table 1 provides a profile of participants and method of data collection.

[Table 1]

Data recording and analysis

Methods used for recording data from the focus groups or interviews included meeting facilitation, note taking and audio recording with permission from participants. Each interview included an interviewer and note taker. Each session was audio taped. A series of standard questions was used for each of the groups consulted. Each set included specific questions relevant to each group. However, information about barriers and enablers to help seeking was sought from each of the three groups. These questions were developed following the completion of the literature review for the study (Lee et al. 2011).

Sessions were conducted in English with carers and, where required, an interpreter or bilingual worker was used. Interpreters were required for two of the sessions conducted with Vietnamese carers. For all the sessions conducted with Chinese carers, bilingual researchers attached to the project team attended with the interviewer. Several of the carers spoke good English so that was the language used for most of the interview, but they were able to use the bilingual researcher as a resource person for clarification of any questions or answers. In other cases, they relied more heavily on the assistance of the bilingual researcher. The questions were

asked in English, and interpreted as required. Interpreters or bilingual staff were not required for the sessions with community workers and health professionals.

Focus groups and interviews were transcribed; the transcripts were thematically analysed by three project staff who each reviewed the individual transcripts and drew out the major themes. Thematic analysis is a method of identifying, analysing and reporting patterns (themes) within data (Braun & Clarke 2006). The themes extracted by the three researchers were then compared for any differences and consensus reached.

Results

Carers

Thematic analysis yielded five main categories to explain carers' experiences of barriers and enablers to help seeking: 1) carer distress; 2) misunderstanding of dementia, believing it is a normal part of ageing; 3) seeking a diagnosis following a specific event or crisis; 4) carers needing more knowledge about dementia; and 5) both negative and positive experiences of the service system.

Participants from both groups reported similar experiences of distress associated with caring for someone with cognitive impairment. They mentioned distress at seeing the deterioration of the person they cared for; how they had to think about their own behaviour towards the person they cared for; and noted that getting enough sleep was an issue for them.

“You need to be patient looking after her and listen.” [Chinese relative 4]

“Over and over I’ve got to stretch myself.” [Chinese relative 3]

“All of a sudden, she just decided she wanted to boil some water, so that was when we thought, ‘It’s definitely time for her to get professional help in a safe environment’.”

[Chinese relative 1]

“You should not leave people like this [with dementia] alone for a long period.”

[Vietnamese relative 4]

In terms of sleep, carers mentioned that they had difficulty sleeping at night, or being woken up by the person they cared for. One carer described sleeping as one of the most difficult things about being a carer. Carers were woken by the person they cared for wandering around the house, visiting the bathroom, or screaming out to them at night time. A carer noted that lack of sleep and being so tired prevented them from attending social groups.

“I can’t sleep at night and I am very exhausted so I don’t want to go.” [Vietnamese relative 5]

When carers were asked to comment on their understanding of dementia, many described it as a disease, saying it involved forgetting or forgetfulness, and was related to age or ageing. Both Vietnamese and Chinese carers reported that in the past they thought that signs of dementia were part of normal ageing. They also felt that this was the general perception of others in their communities.

Although these themes were common, there were differences between the two language groups. Vietnamese carers stated that dementia was inherited, and when discussing their own understanding of dementia, they listed symptoms such as paranoia or the person imagining things. Participants emphasised the care requirements of people with dementia, with one participant saying that the person with dementia “*needs some caring, looking after*”.

In contrast, Chinese carers focused their discussion on the pathology of the disease. Comments included: a “*chemical imbalance in the brain*”; “*it can’t be cured and it gets worse, basically*”; it has “*stages*”; “*it comes in various degrees – it depends on the person*”: and that it can affect people of different ages differently.

Protective behaviour of children and spouses was reflected by both Vietnamese and Chinese speaking carers in our study sample, though was expressed more explicitly by Vietnamese speakers.

“So far as I understand it the best thing is for my mother to share with the family members not with the doctor.” [Vietnamese relative 4]

This person did not want her mother told of the diagnosis because it might have upset her and did not want respite carers to come to the house.

“In my experience that is not a good idea because those people don’t like strangers”.

[Vietnamese relative 4]

In both the Chinese and Vietnamese speaking groups, there was a very strong sense of obligation for children to look after their parents.

“That is the culture, children had to pay back their parents by looking after them when they’re getting older. We don’t get ahead to send my parents to the nursing home”.
[Vietnamese relative 2].

“It’s not only language, it’s like the person you care, the behaviour, they don’t want it, they don’t want a stranger, they just only want you. Like a very good friend of mine and she’s the same as me, looking after her mum, the mother living with her and the mother only want her, nobody else.” [Chinese relative 3]

While Chinese carers we spoke to had generally been able to access information about dementia, and understood it as a disease rather than a natural part of ageing, most in the Vietnamese sample had assumed that the forgetfulness and confusion were a normal part of ageing. Some had been able to access information through observant GPs and other professionals, but others owed their knowledge more to friends or community groups such as the Vietnamese Women’s Association. Some felt they did not need information because they knew that they needed to meet the behaviour and needs of the person they cared for.

“It’s sometimes difficult to look after an old person and mum has been very attached to me and when I’m not around she’s not happy”. [Vietnamese relative 1].

Both Chinese and Vietnamese carers obtained information about dementia or got assistance from service providers, media, friends and family and information sessions. Most participants were prompted to seek a diagnosis following specific events, such as sudden behavior changes, or problems after a stroke, fall or car accident.

“I don’t know why he got lost and drove my car nonstop into the next day, nearly 22 hours nonstop ... didn’t drink, didn’t eat, didn’t sleep, only stopped three times for the petrol.” [Chinese relative 2]

Participants across both groups emphasised that knowledge could be enhanced via education and information about the first signs of dementia, symptoms, progression, early diagnosis, where to seek help and details about services.

“I don’t think we have enough information, because the information they sent me is mostly in English, very little ... in Chinese.” [Chinese relative 4]

Participants also spoke about negative and positive experiences they had once they entered the service system.

Most comments from Chinese participants focused on the concern that mainstream workers or services did not always understand the diversity of the Chinese cultures.

“I am happy my mother has someone to look after her, but I am a bit upset because the Australian nursing homes are all for looking after English speaking patients, of course,

our cultures are different, sometimes my mother wants to talk, sometimes she wants to solve her problem, but she can't speak English." [Chinese relative 4]

It was suggested by Chinese carers that doctors be provided with information about the disease via seminars or lectures to increase their knowledge.

For Chinese carers, barriers to accessing services included the complexity of the system; services were too far away or not specific enough for carers of people with dementia; waiting lists for Chinese residential aged care facilities were too long (residential aged care facilities are services to provide residential care for older people when they can no longer continue to remain in their own homes). Other barriers were that a person could line up for hours waiting for services; and a person might not receive a call back if they had an inquiry about a service.

For Chinese carers, positive experiences when trying to access help from services included: GPs or residential aged care staff being "*caring*" or listening to instructions; getting enough information or knowing that there are services available for carers to access; and receiving quick referrals.

"To be honest with you, the memory system is really good. They referred me straight away." [Chinese relative 6]

Vietnamese participants emphasised that early education would make families aware of the service system and services. Family meetings could be helped at the point of diagnosis.

Vietnamese carers discussed language issues, and positive and negative experiences with the service system. Several carers saw language as a barrier to accessing services; however,

others did not see it as a barrier, either because some organisations provided interpreting services, or they had access to Vietnamese speaking doctors. In one case, two carers from the same family noted that applying for respite would have been hard for their father, but they did not see it as a problem because they spoke English and could apply for him. Carers also noted that it was important to have home help and respite provided in Vietnamese and that receiving information in their own language was a positive experience for them.

“Respite is really helpful because they can literally take over the role of the carer over twenty four (hours).” [Vietnamese relative 2]

Community workers

Thematic analysis yielded three main categories to explain community worker experiences of barriers and enablers to help seeking, including: 1) definition and understanding of dementia; 2) barriers to early diagnosis; and 3) information, knowledge and education as ways of overcoming barriers.

When asked to describe their understanding of dementia, participants across both groups stated that dementia was associated with memory loss, a disease of the brain, old age and forgetfulness.

“I think that this is a deterioration of the brain condition. ... ” [Vietnamese focus group participant]

“Well obviously it’s a condition where people’s cognitive cognition is impaired or impacted and they lose their cognition, cognitive capability including memories or judgment, perception, and sometimes it also affects their physical ability as well”.

[Vietnamese focus group participant]

“I can add some more, like that it’s a progressive disease and it’s a neurological disease, definitely, that especially affects older brains’ functioning, and dementia is a bigger battle for those people who may have dementia under Alzheimer’s disease or Parkinson’s disease. They have also dementia. It’s really broader, rather than people who just think about Alzheimer’s disease. It’s much broader a term”. [Chinese focus group participant]

“Dementia is something to do with the chemical in the brain, affecting the cell, degeneration for the brain cell, therefore the loss of memory”. [Chinese focus group participant]

Similar barriers to seeking an early diagnosis were mentioned across both groups. These included: community knowledge and perceptions about dementia, language and translation issues, and access to/lack of knowledge about CDAMS. General practitioners were also identified by both groups as a challenge in seeking early diagnosis.

Chinese workers stated that there was a lack of knowledge in the community about the impact of dementia, causes and treatment available. They believed that people were more aware of the value of prevention of physical problems like high blood pressure and heart disease.

Others accepted the myth that it is reasonable to be clumsy and forgetful and joke about the symptoms, regarding them as a normal part of ageing.

Vietnamese focus group participants reported a community perception that dementia is part of the ageing process. However, they felt that that people were slowly beginning to recognise that dementia is an illness. People understood dementia to be about loss of memory.

Like the Chinese group, Vietnamese community workers expressed frustrations with GPs, stating that GPs often fail to respond to concerns about memory and confusion, seeing the symptoms as part of old age. Similarly, in this community, the GP was the first point of contact for workers when there were concerns identified by workers or expressed by clients or carers.

Both communities named information provision, increasing knowledge and service access as enablers or ways of overcoming these barriers. It was suggested that the provision of professional development for community workers on dementia, dementia services and referral pathways should be considered. These participants described how they saw professional development as an enabler to help seeking. Chinese participants felt that education would assist people to get help early. This included education and knowledge for the community as well as for service providers. One Chinese participant commented that workers were generally not aware of dementia unless they did a mental health course. Another participant suggested the provision of professional development on dementia for community workers; more dementia services and better referral pathways.

Chinese participants said education for GPs should include information about making referrals and asking questions to screen for dementia. Most comments from Chinese participants focused on the importance of mainstream workers needing to understand the diversity of Chinese

cultures. It was suggested that doctors be provided with information about the disease via seminars or lectures.

For Vietnamese participants, the emphasis was on early education and how it could assist in making families aware of the service system and services. One participant from the Vietnamese group suggested holding information or education sessions on a regular basis for the community in order to make an impact. Members from this community suggested that information could be provided regularly like a campaign. This could include a radio campaign with a series of sessions about Alzheimer's disease, dementia and memory problems.

“A detailed program that talks about memory problems, inviting people who have some memory problems, in the early stage, or have just been diagnosed”. [Vietnamese focus group participant]

“...it's important for the medical team to invite the family in, to have some kind of family meeting for a care plan for this person and ... these are the services that we recommend and stress the benefit for the carers in the long run”. [Vietnamese focus group participant]

Health professionals

Thematic analysis yielded five main categories to explain health professional experiences of barriers and enablers to help seeking. These categories included: 1) patients generally present late for diagnosis across these communities; 2) community barriers to early detection; 3) role of the family as a barrier; and 4) education and information can enhance help seeking.

Across both cultural groups there was a general belief that patients with dementia from these communities presented late for a diagnosis.

“Quite often if the family has accepted some sort of help from the council, the problem is bigger than you think.” [Vietnamese health professional]

Health professionals across both groups reported a range of community barriers to early detection of dementia: the community perception of dementia as a normal part of ageing, lack of awareness about dementia, acceptance, interpreter issues, language and limited knowledge of services.

“So it’s just interesting with memory loss. It’s a bit harder to pick up if there’s an interpreter there because I don’t notice those...or maybe saying the wrong words. With an interpreter it’s one of those diagnoses that can be missed with a Vietnamese interpreter there.” [Non-Vietnamese GP participant (working with Vietnamese community)]

A range of issues about families was raised. These included the difficulty of discussing dementia with families, particularly because of insufficient understanding in the past. Comments were made about family dynamics and conflict within the families about care decisions, such as when the older person is not well enough to continue to remain in their own home. Stigma was also mentioned in relation to dementia in the Vietnamese community. Lack of acceptance of signs of dementia was also identified as a barrier:

“People might not want to admit something is going wrong”. [Vietnamese participant]

Education and information provision were seen as enablers to improving help seeking for both these cultural groups. GPs were asked what information and resources about dementia they would like to receive. GPs who worked with the Vietnamese community tended to focus on specific aspects of dementia and of the service system. GPs who worked with the Chinese community provided a broad range of topics including the need for printed material and information about residential care facilities. Other health professionals made a range of comments, citing the need for information workshop sessions for families, information from the internet and resource kits.

Participants commented on content, type and method of education. Multiple methods and strategies were suggested including continuing professional development sessions, media and journal articles.

Discussion

This study explored carer, community worker and health professional perspectives about access to CDAMS, screening and detection of dementia, and education needs regarding dementia from two CALD communities in Melbourne. The consultations were part of a larger study of implementation of education about dementia to health professionals and members of the CALD communities. The “Cultural Exchange Model” piloted in this study enabled an exchange and development of knowledge and understanding about dementia in CALD communities between researchers and a range of stakeholders including service providers, carers and community workers. The consultation process described here was part of a process of continual project

iteration. This paper has focused on the barriers and enablers to help seeking in older Vietnamese and older Chinese people with dementia. The focus on help seeking was in relation to knowledge and access to CDAMS and early detection and screening.

Our literature review identified a range of GP, patient and family related barriers to early diagnosis of dementia (such as GPs' doubts about the benefits of early diagnosis; perceptions of dementia in these communities) and characteristics of successful education programs (including an interactive, problem-focused approach, with locally relevant materials) (Lee et al. 2011). The consultations confirmed these findings but provided more in-depth information from two specific cultural groups about their help seeking experiences.

For carers, some of the barriers to help seeking were: carer stress, limited understanding of dementia, seeking a diagnosis following a crisis rather than at the early stages, and needing more information about dementia. Carers talked about positive and negative experiences with the service system. These experiences included: the complexity of the service system, travel required to get to services, language barriers, and waiting lists. In other recent studies, carer beliefs, including the stigma associated with dementia and the belief that care for older people is a family responsibility, delayed timely access to dementia services (Mukadam et al. 2011). Access to care and medications was found to be lacking among the CALD communities despite receiving a diagnosis (Cooper et al. 2010). A recent study among CALD communities also reported similar barriers where carers of people with dementia had experienced difficulties navigating the health system, further exacerbating the issue (Shanley et al. 2012).

Confirming reports in published literature on stigma, one Vietnamese carer suggested that many people in her community would refuse information or services. *"Just a different culture. Yes, they want to keep them confidential from time to time, sometimes they don't want people to*

visit them as well” [Vietnamese relative 1]. This included refusing even Vietnamese helpers. *“I don’t know why, the people they have a sick person at home, they don’t want people to visit them, to know them”*. [Vietnamese relative 1]

In our study, carers identified negative experiences with the service system. However, despite the barriers identified, carers also mentioned positive experiences with the service system. These included caring staff, quick referrals, being provided with sufficient information, provision of interpreters and provision of information in one’s own language.

The community workers identified: level of community knowledge and perceptions of dementia; and delayed diagnosis as key barriers to help seeking. These beliefs included the myth that it is reasonable to be clumsy and forgetful and joke about the symptoms and a perception that dementia is a normal part of ageing. They also mentioned the role of the GP as a barrier to early diagnosis; for example, not always responding to symptoms when the patient is referred by the community worker. If a GP fails to respond, this can impact on whether a person persists in help seeking for their symptoms.

Information, knowledge and education were identified as enablers to help seeking. A multi-pronged approach was suggested, including information for community workers, GPs, mainstream workers and family members. Engaging the family, understanding the culture, and linking communities to services were found to be important among the bilingual/bicultural workers (Boughtwood et al. 2011).

Community worker participants in our study reported wanting information on referral pathways and dementia and dementia services. Suggestions about how to provide information to the community included information sessions and using media (such as ethnic radio). Dissemination of information on a regular basis was suggested.

Health professionals identified barriers as: late diagnosis; issues within the communities; and families. They identified education and information as factors that can enhance help seeking.

Health professionals from both these communities suggested that patients with dementia present late for a diagnosis. They also mentioned a range of perceptions within these communities that were seen as barriers to help seeking. These included viewing dementia as a normal part of ageing, lack of awareness about dementia and general acceptance of symptoms of cognitive decline. Families were mentioned separately as a barrier to help seeking for reasons such as family dynamics, stigma within families and denial or lack of acceptance.

Health professionals said they believed education and information could enhance help seeking. They believed this applied to community members as well as themselves as health professionals. Health professionals personally wanted information about services, the service system and different cultures. Multiple methods and strategies were suggested. Another recent study proposed a more coordinated approach to information provision with greater interpersonal aspects and cultural diversities to meet the needs of target CALD communities (Boughtwood et al. 2012).

The focus of the our study was on two emerging Asian communities. The mainly qualitative method used was the strength of this study; it provided a rich account of experiences of carers of people with dementia, community workers and health professionals. However, the limitation of this approach is that findings are specific to those two communities and cannot be generalised to other populations. Another limitation of the study was the small sample size of carers. In addition to this, the group consulted was a group of people who are already connected to services. The study was not able to ascertain barriers for people who are not accessing services.

This study aimed to determine the barriers and enablers to accessing CDAMS for people with dementia and their families of Chinese and Vietnamese backgrounds. Consultation with community members, community workers and health professionals were conducted using the “Cultural Exchange Model” framework. The “Cultural Exchange Model” enabled engagement with and modification of the approaches to meet the needs of the targeted CALD communities. It assisted in obtaining information about enablers and barriers to help seeking.

We learnt that multiple methods and strategies for providing information to these communities should be adopted to enhance help seeking. Service providers have an important role to play in increasing knowledge, but people with dementia and their families’ perceptions of dementia and the role of health professionals need to be taken into account in development and promotion of services. Methods of increasing knowledge identified as helpful in this study include ethnic radio, ethnic papers, and information via community groups.

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Figure 1. The “Cultural Exchange Model”

Figure 2. Number of carers in each age group

Figure 3. Number of years providing services to the Chinese/Vietnamese Community

Table 1. Profile of health professional participants and method of data collection

Professional group	N	Speaks Chinese		Speaks Vietnamese		N in each method	Method of data collection		
		Yes	No	Yes	No		Indiv/ Gp	FTF/ Tele	With education or not
GPs	17	6	5			9	G	FTF	Yes
						2	I	FTF	Yes
				2	4	2	G	FTF	Yes
						4	G	FTF	Yes
Geriatrician	1	1	0			1	I	T	No
Psychiatrist	1			1	0	1	I	T	No
Practice nurses	2	1	1			1	G	FTF	Yes (with GP)
						1	I	Tele	No
Herbalist	1	1	0			1	I	FTF	No
Residential aged care staff – physiotherapist, nurses	16	0	16			16	G	FTF	Yes

Professional group	N	Speaks Chinese		Speaks Vietnamese		N in each method	Method of data collection		
		Yes	No	Yes	No		Indiv/ Gp	FTF/ Tele	With education or not
and PCAS									
Pharmacist	1			1		1	I	FTF	No

Notes: GP = General Practitioner (physician), RACF = Residential aged care facility, FTF = Face-to-face, T = Telephone, PCAs = Personal care attendants (persons employed to provide care to someone either in or out of their homes), With education or not = whether or not an education session was provided at the time of data collection.