

Dementia Support for Asian Communities

Understanding barriers and developing culturally appropriate services

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Executive Summary

Dementia is a progressive and debilitating disease of the brain which affects a known 43,396 people in New Zealand; with many more undiagnosed (Alzheimers New Zealand, 2010). With the ageing population of New Zealand, the rate of dementia is projected to increase dramatically in the coming years. This report has been written for Alzheimers Auckland Charitable Trust (AACT), a non-profit organisation which provides free support services for people with dementia and/or their carers. Of those AACT support, only 3% self-identify as Asian (Alzheimers New Zealand, 2013). This report details the Dementia Support for Asian Communities project which aimed to investigate the reasons behind this low utilisation rate. Insights gained from this project will hopefully contribute to improving current AACT services to better support the Asian population of Auckland. Recommendations are developed to guide improvement of current services and the relationship with the Asian population. Asians are the fastest growing ethnic category in New Zealand. It is predicted that the Asian population of Auckland will increase by 60% by 2026 (Mehta, 2012). Thus, it is imperative to recognise and overcome barriers to access experienced by the Asian population.

Methods

A comprehensive literature review was undertaken to explore current knowledge on barriers to accessing dementia support services for the Asian population. In addition, 12 experts in the fields of Asian health and/or dementia care from the Auckland region were consulted.

Literature Review

The literature review revealed a relative lack of studies exploring Asian dementia support service use in New Zealand. Studies used in the review were mostly from the United States and the United Kingdom. Two main themes emerged from the review. These were the relative lack of knowledge about dementia and the reluctance to seek help amongst Asian communities. Asian people recognize that memory loss occurs, but believe that it is a normal part of the ageing process. They do not understand that it is a disease of the brain. Misconceptions about dementia and its disease process were associated with stigmatisation of the disease. Thus, those with dementia and their carers/family felt reluctant to seek external support. Furthermore, adult children felt obligated to care for their parents. This further discouraged help-seeking behaviour.

Consultations

Expert consultations reinforced findings from the literature review. The lack of knowledge, stigma, family obligation and reluctance to seek help were discussed in the consultations. The consultations also provided new insight into barriers experienced specifically by the Asian population of Auckland. Challenges faced by Asians as refugees or migrants were

discussed as well as strategies to improve AACT services. Accessibility issues discussed by the experts are presented using Penchansky and Thomas's (1981) framework for access.

Implications

Expert consultations provided new insight into barriers experienced by Asian communities accessing dementia support services. Although the literature highlighted aspects of Asian culture that act to prevent help-seeking behaviour, it is important to recognise and understand factors external to Asian communities which may also act as barriers. The consultations emphasised the need for change in the way services are delivered by AACT. Collaboration with other health service providers and partnerships with the Asian community within Auckland are essential to improving utilisation of AACT services.

Recommendations

1. **Customise services to specific cultural needs** – Identify the specific Asian ethnic group(s) to support and work with.
2. **Reducing language barriers** – Ensure availability of educational resources in preferred languages and interpreters as needed.
3. **Increasing awareness of available services** – Clearly state the services provided and how people can be referred to AACT.
4. **Community activation** – Support advocates within Asian communities to reduce stigma associated with dementia.
5. **Collaborate with existing Asian health service providers and community groups** – Connect with existing groups to develop support programmes.
6. **Educating the Asian community** – Be creative in promoting services. Use ethnic media such as Radio Tarana and the Chinese Herald.
7. **Building workforce capability** – Encourage staff to undertake cultural competency training and to reflect on service delivery.
8. **Leadership and commitment to change from AACT** – A champion from within AACT is required to drive the change needed.

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Introduction

Dementia is a debilitating disease of the brain that is not part of the normal ageing process. Alzheimers Auckland Charitable Trust (AACT) is a non-governmental organisation that provides free support services for people with dementia and their carers in the Auckland region. At present, there are approximately 15,000 Aucklanders diagnosed with dementia and many more undiagnosed. Alzheimers New Zealand highlights that the prevalence of dementia will increase dramatically in coming years in response to New Zealand's (NZ) ageing population (Alzheimers New Zealand, 2013).

AACT currently supports 10% of those diagnosed with dementia in the Auckland region with most of their clients being above the age of 65 years. Of those with dementia whom AACT is currently supporting across the three Auckland District Health Boards (DHB), only 3% self-identify as Asian. The utilisation rate of AACT services by the Asian ethnic group is less than that of European (78.6%), Maori (4.2%) and Pacific Islander (6.4%) ethnic groups (Alzheimers Auckland Charitable Trust, 2013). Hence, this research aimed to investigate why this disparity exists and identify necessary changes to the current service delivery model of AACT to improve services, relationship and outreach toward the Asian community of Auckland.

In order to achieve these aims, the researchers undertook a comprehensive literature review and consulted experts in Asian health and/or dementia care. The literature review explored patterns of dementia support service use by Asian communities and barriers faced in accessing the dementia services both in NZ and internationally. The consultations with experts in Auckland provided a unique NZ, and more specifically an Auckland perspective to answering the research question. Utilising Penchansky and Thomas's (1981) framework of access (i.e. availability, affordability, physical accessibility, acceptability and accommodation) the results section of this report highlights the different dimensions of access required for a service to be accessible as identified by the experts. The literature review and consultations together allowed the development of recommendations for AACT on best practice when serving the Asian community in Auckland. It is hoped that the findings from this research will help overcome the above mentioned disparity and improve AACT service utilisation by the Asian population of Auckland.

The Asian population of Auckland, currently 22% of the total Auckland population, has grown significantly more than any other ethnic group in the last few decades. Predictions are that the Asian population will increase by more than 60% by 2026. Hence, it is vital that health services such as AACT are able to provide culturally appropriate and accessible services to the Asian population (Mehta, 2012).

The Health Needs Assessment of Asian people living in the Auckland region conducted in 2012 highlight that in 2010 around 310,000 Asian people were living in the Auckland region.

This population consisted of 127,000 Chinese, 100,000 Indians and 84,000 Other Asian people. The Asian ethnic group is the second largest ethnic group in the Auckland District Health Board (ADHB) and Waitemata District Health Board (WDHB) and the third largest in Counties Manukau District Health Board (CMDHB). Geographically, the Chinese population is most dense in Auckland Central, Epsom, New Lynn and Dannemore. The Indian population is most dense in Auckland Central, Sandringham, Mount Roskill, New Lynn, Otahuhu, Mangere, Papatoetoe, Manukau Central and Dannemora. Other Asians are most dense in Browns Bay, Wairau Valley, Auckland Central and Dannemora (Mehta, 2012).

The Chinese and Indian ethnic groups are well-established groups in Auckland. The Other Asian group consists of a diverse range of ethnic groups with the largest of these groups including Korean, Sri Lankan, Filipino and Japanese. The Asian population of Auckland affiliate with a diverse range of religions and their age structures reflect a younger population than that of Europeans (Mehta, 2012).

The use of the term 'Asian' in this research refers to those identifying as having origins in the Asian continent. This includes people from East Asia (such as China), South-East Asia (such as Indonesia, Thailand, Cambodia and Burma) and South Asia (such as Bangladesh, India, Sri Lanka and Pakistan). The definition used is that used by Statistics New Zealand who also includes Afghanistan (Rasanathan, Craig, & Perkins, 2006). Where possible, grouping of all the different ethnic groups together under the one 'Asian' category was avoided in this research to acknowledge the differing needs of the different ethnic groups and to prevent the averaging of findings across all ethnic groups.

Description of the Organisation

Alzheimers Auckland Charitable Trust is a not-for-profit non-governmental organisation that is part of the wider Alzheimers New Zealand network. AACT aims to support people with dementia, their carers, family and whanau throughout the whole disease process, from before diagnosis until the end of their journey. The main services offered by the organisation are the dementia keyworker service, carer support groups, home-based dementia support services, a socialisation service and carer education courses. Patients can be referred to the service by health practitioners in the primary and secondary health sectors or via self-referral. AACT is funded primarily through DHB contracts and fundraising.

Literature Review

This section presents existing knowledge on barriers to dementia service utilisation for Asian populations. How cultural norms and values and differences in caregiving practices may act as barriers to help-seeking behaviour is discussed. Finally, some promising interventions for increasing dementia service use from overseas are examined.

Methods

Searches were conducted in Scopus, Medline, Google Scholar and Web of Knowledge. Articles were limited to those published in English, as the researchers were most fluent in this language. These were also limited to those published after 1999 to identify the most relevant discussions in this topic area. The search terms entered include 'dementia', 'support', 'Alzheimer's', 'Asian', 'service models', 'health services', 'utilization', 'New Zealand', 'care-giving' and 'barriers'. These terms were used in conjunction and independently.

Of the 37 articles reviewed, most were from the US, followed by the UK, Australia, Singapore, Hong Kong and Thailand. The literature search revealed a lack of published material from NZ on the topic area.

Use of the Term 'Asian'

Although widely used, the term 'Asian' is socially constructed, with multiple meanings to different people. It is important to note that the people included under this category are extremely heterogeneous (Leong & Lau, 2001; Rasanathan, Craig, & Perkins, 2006; Sayegh & Knight, 2013). Statistics New Zealand's definition of the term 'Asian' (refer to introduction) is the one used predominantly in NZ. There is no standard definition recognised internationally (Rasanathan, Craig, & Perkins, 2006). Ethnic groups contained under the 'Asian' category differ between countries and studies. In addition, the term 'Asian' is not always explicitly stated in articles. Instead, other terms such as 'South Asian,' 'minority ethnic,' 'ethnic elders,' and specific ethnic group names (e.g. Chinese, Indian, Filipino, Korean) were also often named (Bowes & Wilkinson, 2003; Daker-White et al., 2002; Dilworth-Anderson & Gibson, 2002). Several articles explicitly stated the ethnic groups included while others did not. In the US, Pacific peoples were frequently grouped with East, South, and Southeast Asians (Arnsberger, 2005; Sayegh & Knight, 2013). In reviewing the US literature, careful attention was given to identifying the ethnic groups included under the Asian category (Ayalon & Arean, 2004; Chow et al., 2000; Chung, 2001; Wu, Lombardo & Chang, 2010). There were fewer studies from the UK. However, the majority of articles reviewed from the UK explicitly stated the ethnic groups included. There are risks to using

the term 'Asian' as there is a wide diversity of culture and practices within this broad grouping. Ethnicity and culture are complex concepts and there is a risk of inappropriate generalisations whenever used. It is essential that researchers recognise the influence of ethnicity and culture in answering research questions as well as ensuring individual characteristics are not ignored. Ethnic labels should be applied sensitively.

Cultural Norms and Values

Cultural perspectives and values can affect knowledge about health issues such as dementia (Jones et al., 2006). These beliefs about health and illness also have a strong influence on how older people attach meaning to dementia and consequently, their decisions in seeking help (Dilworth-Anderson & Gibson, 2002). Research has highlighted that within Asian communities cultural beliefs about dementia are related to stigma. This in turn acts as a barrier to accessing dementia services (Hinton et al, 2005; Sayegh & Knight, 2013).

Perspectives on Health, Ageing and Dementia

In the literature, one of the most commonly described barriers to accessing dementia services for Asian people was the lack of knowledge about the disease (Ayalon & Arean, 2004; Bowes & Wilkinson, 2003; Burnard, Naiyapatana & Lloyd, 2006; Lawrence et al., 2011). This often stems from the underlying cultural perceptions of health and ageing. Many Asian cultures view this stage in life as a negative time riddled with physical and emotional problems for the individual (Liu et al., 2008; La Fontaine et al, 2007; Milne & Chryssanthopoulou, 2005). For instance, general decline in health, difficult changes in behaviour and increasing dependence on others are viewed as normal in the traditional Chinese belief. A common view still held today is that people regress to a child-like state in old age as part of the cyclical life course (Chiu, et al., 2009; Mok et al, 2007). For Sikh and Hindu Indians living in the UK, regardless of participant's age, ageing was viewed as a mainly negative process (La Fontaine et al., 2007). Elders are seen to become angrier, intolerant, worrying and isolated by choice. In addition, while physical and emotional problems were recognised as characteristics of ageing, cognitive impairment was rarely mentioned (La Fontaine et al., 2007). Family members of older people may not perceive physical and cognitive dilemmas as serious problems, as health problems in old age are normalised (Hinton et al., 2000).

The normalisation of dementia has repeatedly been found to be prevalent in many Asian groups including Chinese, Japanese, and Korean Americans (Jones et al., 2006), South Asian British (Lawrence, et al., 2011), Vietnamese (Liu et al., 2008) and Singaporean (Lim et al, 2012). Normalisation is the understanding of memory loss and other behavioural and psychological symptoms of dementia as being an ordinary aspect of old age (Sayegh &

Knight, 2013). The general lack of knowledge and misconceptions about dementia perpetuate the reluctance to seek help, as symptoms of dementia are not viewed as being problematic. However, when these progress and become more severe, dementia is also often viewed as form of insanity.

As the literature highlighted, there are many misconceptions surrounding dementia. Asian people are likely to believe that dementia symptoms such as abnormal behaviour are due to mental disorders and insanity (Ayalon & Arean, 2004; Sayegh & Knight, 2013). A common term used to describe such behaviours is 'craziness' (Ayalon & Arean, 2004). There were also implications of blame. For example, the idea that dementia results from a lack of effort from the person in staying active, or due to a lack of care from the family were identified (Lawrence et al., 2011).

Another theme is religion and spirituality, as these may also shape the way that some individuals perceive symptoms. Spiritual explanations for the disease further contribute to misconceptions of dementia. In one study of Chinese people from Hong Kong, patients explained their disease as "[a way for] heaven to slow them down" because they were overworked (Mok et al., 2007). For Thai Buddhists, causes of mental illness include the effects of ghosts, spirits, and karma (Burnard, et al., 2006). The concept of Karma or retribution for wrongdoing in the past is also a belief shared by many Chinese (Mok, et al., 2007). As the problem is not perceived to be due to physiological ailments, help seeking may not be in the form of formal dementia services (Dilworth-Anderson & Gibson, 2002).

Furthermore, a majority of studies found that Asian people had poor knowledge about dementia (Bowes & Wilkinson, 2003; Lawrence et al., 2011; La Fontaine et al., 2007). Patients did not recognise 'dementia' and 'Alzheimer's disease' as words that described their condition (La Fontaine et al., 2007). Many misconceptions about the prevalence, cause, diagnosis and treatment of dementia were also found to exist (Dilworth-Anderson & Gibson, 2002).

Stigma

Misconceptions and the lack of knowledge about the disease lead to stigmatisation of those with dementia (Ayalon & Arean, 2004). This theme was described in most of the articles, and is one of the biggest barriers in utilising dementia services (Ayalon & Arean, 2004; Burnard et al., 2006; Chow et al., 2000; Katbamna et al., 2004; Liu et al., 2008; Mok et al., 2007; Wynaden et al, 2005). Stigma surrounds mental illness in Asian communities, so much so that people fear the possibility of being diagnosed with one. However, understanding stigma in these communities is also quite complex. Stigma exists at many different levels for those with dementia. For instance, some Chinese and Vietnamese people with dementia face a double burden of stigma. This includes first, in having a mental condition and second for old age (Liu et al., 2008). Thus, Asian people quite often feel ashamed about their

condition and may hide it from their family. Or, family may feel ashamed and hide the person with dementia away from the community to 'save face' (Leong & Lau, 20001). This is the concept of maintaining a good self-image or dignity in the presence of others (Mok et al., 2007). Stigma stemming from a lack of knowledge may also further prevent people from seeking information (La Fontaine et al., 2007). It can lead to blaming the individual with dementia, who is seen to be weak and responsible for their mental illness. Thus, those with dementia are perceived to be responsible for supporting themselves (Bowes & Wilkinson, 2003; La Fontaine et al., 2007; Lawrence et al., 2011).

Caregiving in Asian Communities

There is evidence to suggest that the impact of caregiving for a person with dementia varies among different ethnic groups (Arnsberger, 2005; Boughtwood et al, 2011; Burnard et al., 2006; Ho et al., 2000; Katbamna et al., 2004, Sun et al., 2012). Cultural norms and values have a significant impact on how dementia is understood. These have a powerful influence on the caregiver's experience with care giving and their help-seeking behaviour (Sun et al., 2012).

Family Obligation

Family play a very important role in the support of Asian people with dementia, it is seen as an obligation or duty of an adult child to care for an elderly and sick parent (Boughtwood et al., 2011; Katbamna et al., 2004). For example, in the Chinese communities, the family is viewed as a basic unit of life and the main support for one's problems in life (Mok et al., 2007). The relationship between parent and child is interdependent. The views of South Asian people with dementia echoed similar values. They are more likely than white British to always have at least one family carer caring for the person with dementia (Purandare et al., 2007). As a duty, relinquishing the role as a carer is perceived to be a disloyalty to the person with dementia (Sayegh & Knight, 2013). Often, there are mixed views even within the family whether it is appropriate to seek help, due to the widespread cultural norms in caregiving (Sun et al, 2012). This in turn further contributes to the complexity of stigma. As a result, family members caring for those with dementia are often reluctant to reveal to those outside the family that their elderly relative has dementia (Boughtwood et al., 2011).

Reluctance to Seek Help

Asian carers of people with dementia often have strong beliefs about the role of adult children in caregiving. For a number of reasons, carers are often reluctant to seek help. For example, they may not be accustomed to or identify with, terms such as 'carer', 'care-giver' or 'respite' (Moriarty, 2011). The issues do not relate to a misunderstanding of the terms.

Instead, carers may face challenges in recognising differences between tasks arising from an illness or disability and tasks which come under their duty as a family member (Boughtwood et al., 2011; Moriarty, 2011).

The likelihood of carers accessing support services also depends on the condition of the person with dementia. Often, Asian people will not seek support until symptoms are severe (Leong & Lau, 2001; Mukadam et al., 2011; Sayegh & Knight, 2013). Those with higher levels of informal assistance are less likely to use services (Botsford et al., 2011).

Other Associations

Even though most barriers to utilisation of services identified related to culture, other factors have also been noted throughout the literature. In the US and UK, Asian people with higher socioeconomic status, education, and level of acculturation were more likely to seek dementia support services (La Fontaine et al, 2007; Sayegh & Knight, 2013). However, support for these factors was not as strong in the literature.

In addition, studies highlighted numerous barriers resulting from the way services are designed and delivered (Chow et al., 2000; Leong & Lau, 2001; Li, 2004; Mukadam et al., 2011). Due to differing contexts of these studies, not all findings may be applicable to the NZ setting. However, as there is a lack of NZ literature, findings from overseas studies will be used to facilitate discussion. These findings should be applied with caution due to differences in health system organisation and structure. Without NZ's own research, it may be difficult to pinpoint the barriers originating from the system here. To truly understand issues faced by Asian people in this situation, more research should be conducted to address the gaps in knowledge.

Service Barriers to Access

One of the biggest barriers in accessing services for Asian people was found to be language. Additionally, there were concerns with the cultural appropriateness of services provided (Leong & Lau, 2001, Mok et al., 2007, Moriarty et al., 2007). If Asian people with dementia and their carers feel that services lack the confidence and competence to manage language and cultural differences then they are less likely to access these services. There is evidence to suggest that if organisations and practitioners have preconceived ideas about Asian people with dementia, such as beliefs about the extent of family support or preferences for treatment, Asian people with dementia and their families are more likely to feel discouraged from using services (Boughtwood et al., 2011).

In spite of cultural influences in help-seeking behaviour, it has been noted that diagnostic tools used to identify dementia may be culturally biased (Daker-White et al., 2002). Thus, this may also contribute to the late diagnosis of disease as if dementia is not detected

earlier with the current diagnostic tools. However, others argue that it is not due to the inappropriateness of tools, but rather the language ability of the person with dementia to communicate with the health professional. This also highlights the need for further research into diagnosis of dementia (Daker-White et al., 2002). Additionally, Asian people often do not feel that services meet the standards they require or are not culturally appropriate (Leong & Lau, 2001; Li, 2004; Moriarty, 2011).

Evidence for Interventions

Improving Available Information About Dementia

As the lack of knowledge about dementia is one of the driving factors of low service utilisation, initiatives to increase understanding were implemented overseas. It has suggested that using local radio stations to publicise information has a positive impact (Woo, 2012). As radio is specific in the Asian language and has the possibility of reaching a large proportion of the Asian population. Pamphlets are a common form of spreading information about health. A study found that information pamphlets were more effective if neutral language was used. For example, using the term 'memory-loss' in place of 'dementia' and 'looking after' over 'carer'. Also, multi-purpose pamphlets with a variety of vital information about dementia (such as where to get help and what it is), is more effective than many individual pamphlets (Moriarty et al., 2011).

Improving Services that are Available

A few initiatives in the UK have worked to improve existing services, and have shown to have some positive results with the Asian population. Involving the community and creating links with religious groups have shown some of the best results (Wu et al., 2012). However, it should be noted that different approaches will be needed to meet the needs of different ethnic groups. Chui et al. (2009) implemented an internet-based caregiver support for Chinese Canadians in caring for a family member with dementia. This initiative was found to be effective in reducing care-giver burden.

Training and Workforce Development

Service barriers and stigma experienced marginalise those affected by dementia within their community. Hence, it is important for Asian people to be supported through the process of seeking care. Evidence suggests that appointing a keyworker to local communities for caregiver support is a successful approach to combating some of these issues (Chow et al., 2009).

In the UK, while they have found that many practitioners feel they may require additional training for supporting Asian people with dementia, access to this sort of training is variable (Moriarty et al., 2011). In New Zealand, some resources and training courses have been developed by Waitamata District Health Board in the form of cultural competency training for working with Culturally and Linguistically Diverse (CALD) people (Waitemata DHB, 2010).

Staff can adopt several approaches to improving the uptake of services, such as developing different information resources and appointing workers with responsibility for outreach. Dementia workplaces may also provide staff with more training on how to give culturally acceptable care and support to Asian people with dementia.

Summary and Implications

It is well recognised that Asian people are likely to delay seeking formal help for dementia until conditions are very severe. Studies have identified that this may be related to familial beliefs about the duty to care for elders. Relinquishing the role as a carer is perceived to be a disloyalty to the person with dementia. In addition, strong cultural norms and values contribute to the stigma and shame faced in revealing existence of the condition. Evidence from interventions aimed to tackle barriers in accessing dementia support services, indicated that successful interventions can be implemented at many different levels. From the literature review, two overarching themes that contribute to low service use were identified. These were the lack of knowledge about dementia and the reluctance to seek help in Asian communities. The lack of knowledge about dementia creates barriers to service use through promotion of stigma and shame. Further, cultural caregiving practices and perceptions of obligation contribute to the reluctance to seek help. The combination of factors under these themes adds to the barriers faced in accessing support.

While a body of knowledge exists about Asian cultural beliefs on dementia and caregiving behaviours, the literature review has also revealed that there is still much to be learned. More research into interventions for overcoming barriers to help seeking for Asian people is needed for improving equity of access to dementia support services. The general cultural factors identified in overseas literature are applicable to current and potential Asian dementia service users in NZ, as they share common cultural origins and beliefs. However, as there is currently a lack of literature from NZ on this issue, it is unknown whether service barriers faced overseas are also shared here. It is likely that barriers such as language and transport are also issues for Asians in NZ. Nonetheless, it is difficult to confidently establish this without relevant studies. Therefore, further research into barriers faced by Asian people in accessing dementia support services, specific to the NZ and Auckland contexts is also needed.

Expert Consultations

Method

Participants

Participants consulted for this study were 12 experts in the fields of Asian health and/or dementia care. Many experts recommend other experts who they thought would provide important perspectives. The experts consulted self-identified as Korean, Chinese, Sri Lankan, Fiji-Indian, European/Other and Pacific. They were health professionals and social service providers working across a number of non-governmental organisations (NGOs) and DHBs (i.e. ADHB, CMDHB and WDHB) and included a general practitioner, Asian health researchers/academics, Asian health advocates, mainstream dementia health service providers, Asian specific health service providers in Auckland, a gerontology nurse specialist, a psychiatrist, an occupational therapist, a psychologist, a representative from the Ministry of Social Development and NGOs providing mental health services either for mainstream or the Asian community specifically in the Auckland region.

Data Collection Method

All experts were sent an invitation via electronic mail to participate in the project and were consulted once by the researchers at a time and place convenient for the expert. An unstructured consultation process took place where after a brief introduction to the study aims and information about the researchers the experts were given the opportunity to contribute any thoughts and ideas regarding the project topic. A formal set of questions was not used. However, the researchers had prepared discussion topics to stimulate conversation if needed. These topics were Asian utilisation of dementia support services in NZ, cultural barriers, service barriers, AACT and their services, how to improve access to dementia support services for Asian communities and service delivery models from elsewhere recommended for AACT. The consultations were between 30 to 60 minutes and were not recorded. Notes were taken on paper by each researcher. Post-consultation these notes were summarised.

Data Analysis Method

Following the consultation, the notes taken were summarised onto an electronic word document by both researchers. Following this, one researcher read all the summaries and systematically identified reoccurring themes throughout the different consultations by recognising similar comments and ideas expressed by the experts. Highlighters were used to thematically analyse the data. Different highlighter colours were used to mark the different ideas which appeared within the consultation notes. For instance, the colour green was used to highlight an expert's discussion of cultural barriers. This allowed the researchers to

look at all the consultation notes of the different experts and recognise similar topics of discussion. Emerged themes in this way were used to develop six category headings under which the results would be placed. These category headings were reviewed by the second researcher. The original consultation notes were consulted by the second researcher to validate the themes identified. Following this, one researcher wrote the findings section of the report which was validated by the second researcher. Changes were made to the written content after discussion and review of the original consultation notes.

Results

Six themes emerged from the thematic analysis of the consultation notes. Almost all experts discussed issues under all six themes. The six themes can be classified further as either a Barrier or Recommendation for Alzheimers Auckland Charitable Trust. The themes which emerged under Barriers were Cultural Barriers, Migrant and Refugee Status and Accessibility of Alzheimers Auckland Charitable Trust Services. Those which emerged under Recommendations for Alzheimers Auckland Charitable Trust were Building Capability and Capacity of Workforce, Collaboration with Other Players in the Health Sector and Culturally Appropriate Education for and Engagement with the Asian Community.

Barriers

Cultural Barriers

Experts emphasised that in many Asian cultures a stigma is attached to mental illness. Mental illness is hidden from society and is seen to bring shame upon families upon disclosure. Hence, diseases such as dementia which signal an abnormality of an individual is denied and/or ignored and concealed in some cases even from family. Asian communities worry about the consequences of outsiders discovering they have dementia. For example, one participant said:

Our communities are worried about ‘who is going to marry my daughter if they find out I have dementia?’

Hence, seeking support from those other than immediately close family members can be a terrifying experience for both those with dementia and family members who are carers of dementia patients. This fear of marginalisation within one’s own community prevents help seeking behaviour.

Experts suggested that the collectivist culture, the strong insider/outsider beliefs and power hierarchies within families also prevent help seeking behaviour among Asians. Asian families are very family-oriented and interdependent within their families but hesitant to let outsiders in to their lives. Parents are seen to be the head of the house that the children must respect. Seeking external support for the care of parents is seen as being disloyal and disrespectful by the children of elderly Asians. As most experts highlighted children see caring for their parents as a duty and an obligation rather than a burden. On the other hand, Asian parents can sometimes feel as if they are a burden on their children if they ask for support with their illness. One expert provided a very different view, that is, Korean elderly are so fully taken care of sometimes by their children that symptoms of dementia are unrecognised as elderly have no opportunity to engage and be active in activities which expose symptoms of dementia.

There was unanimous agreement among the experts that there is a lack of understanding among the Asian population about what dementia is, disease causation and treatment and management options. For example:

Dementia is seen as a normal part of ageing and is not recognised as a disease. Memory loss is normalised.

Experts who have worked with Asian dementia patients stated that where dementia was acknowledged to be a disease, disease causation was often informed by spiritual beliefs such as black magic and spirits in the body. Dementia viewed in this way prevents help seeking behaviour as the treatment and care required for dementia is seen to be of a spiritual and non-clinical nature.

Migrant and Refugee Status

Many experts discussed a number of characteristics of migrant and refugee Asian groups that influence access to dementia support services and health and social welfare services more broadly. Of these, language barriers were emphasised as important by all experts. South East Asians and East Asians, especially Chinese and Koreans are seen to have bigger language barriers than South Asians. All experts identified the need for interpreters to overcome language barriers faced by migrant and refugee Asian communities in Auckland. It was emphasised that a large proportion of the migrants and refugees in Auckland cannot speak, read or understand English.

Upon arrival, migrants are overwhelmed by new environments and commitments whereby health becomes less of an immediate priority. Migrants are also concerned about jeopardising their chances of obtaining New Zealand citizenship through presentation of an illness. Hence, many do not seek help for medical conditions which they perceive will diminish their opportunity of obtaining New Zealand citizenship. As one expert said:

When migrant elderly first move to New Zealand they do not have citizenship, therefore, will not get free healthcare. However, they do not know that the Mental Health Act entitles them to care.

This above comment highlights another area of concern that was raised. Information regarding the New Zealand health system, laws and regulations is foreign to the migrant and refugee Asian population. Understanding these new ways of doing things is much harder for the Asian ethnic group than for migrants from countries with similar health systems and where English is used more frequently.

It is difficult to gain knowledge of available services let alone access them within an unknown complex system. Many experts were concerned that a lack of understanding about support available for dementia patients and their carers has disadvantaged the Asian

community. For instance, experts were concerned that Asian dementia patients do not understand the role of an enduring power of attorney and the benefits of planning ahead while still being competent to do so. Experts agreed that this was a lost opportunity for Asian dementia patients and families.

Experts also highlighted that many elderly migrants joining their children in New Zealand often live with their children helping care for their grandchildren and attending to housework. These groups are isolated at home with little to no social networking opportunities outside their immediate family. Elderly caring for children at home cannot leave the children if under the age of 14 to attend services. Elder abuse among the Asian population in NZ was presented as a barrier to accessing services. Experts discussed situations in which elderly parents are often brought to NZ to work for their children. These elderly often were seen by experts to have poor living conditions and social environments. They often experience emotional and financial abuse as children seize the dole and/or benefit of their parents. In such environments symptoms of dementia will not be noticed and action will not be taken to treat or care for these elderly. Experts argued that in cases where abuse and neglect occur, the quality of life of the elderly is not prioritised by their children.

Accessibility of Alzheimers Auckland Charitable Trust Services

During the consultations, experts highlighted specific concerns with regard to the dementia support services provided by AACT. These concerns emphasised that the way in which services are delivered at present might decrease access to dementia support services for the Asian population of Auckland. In order to present these findings clearly Penchansky and Thomas's (1981) framework of access will be used to highlight five aspects of access required for a service to be accessible.

Availability:

Most experts consulted were confused as to what services AACT provided. The lack of information about the types of services available and how they can be accessed prevented dementia patients and their carers accessing services. Community health service providers such as general practitioners and Asian health and social service providers were also not able to refer their patients/clients to AACT for this reason.

Some experts stated that the referral pathway itself is not clear. For example:

Who refers carers and patients? Carer only services? There has been a lack of consistency in services provided overtime - doing different things at different times.

Affordability:

Many Asian dementia patients and carers might be unaware that the services provided are free of charge. Furthermore, transport costs to attend services such as group socialisations both in terms of time and money may impede access to services. As stated previously under Migrant and Refugee Status, experts highlighted that elderly at home will have to rely on their children to transport them to and from the service. If minding children or grandchildren then finding alternative care can be expensive and impact family relationships.

Accessibility:

Where services are geographically placed is important as it can either increase or decrease access to services. Ensuring services are placed in areas where Asians live and work in increases physical access to the services. Transport distance, costs and time to and from the services might prevent utilisation of services.

Acceptability:

All experts emphasised that services provided need to be culturally, religiously and spiritually acceptable to the diverse Asian ethnic groups. Population-wide strategies and generic Western models of care were deemed unsuccessful. Asian ethnic groups will only access services if delivered in a way which respects their culture and values. Often, Asian patients and carers prefer that Asian staff provide the service. According to some experts a service provider from one's own cultural background is seen to be more welcoming and understanding of certain cultural concepts and ways of living. However, one expert highlighted how Asian staff can act as a barrier to services provided with ethnic groups with small populations emphasising that not all ethnic groups under the Asian category have similar needs. For example:

For Koreans, it's better to come from outside than from within the community. Don't want someone they know in the community to know they have dementia. They also prefer to receive services in an individual setting rather than group setting.

Many experts inquired as to whether the services of AACT were provided in a variety of different languages to cater for the different language needs of different Asian ethnic groups. Experts were concerned that services delivered over the telephone would be ineffective for non-English speakers.

One expert did not know that a brochure for AACT existed in the Korean language stating that it was never seen in primary health care settings accessed by Koreans. After viewing brochures currently in circulation within Auckland many experts were concerned about the

wording/terminology of the translated brochures. The Chinese brochure written in Traditional Chinese will not be readable by all Chinese as there are many dialects within the Chinese language. One expert highlighted that in Korean, dementia translates to 'ageing-related madness'. Hence, recommended investigation into alternative ways of naming services that do not further stigmatise and deter help-seeking behaviour of Asian groups.

Moreover, experts emphasised that the Asian community must be educated in a way which does not direct attention to specific individuals with dementia and their carers. Dementia education should not point fingers at and marginalise dementia patients and their carers as emphasised by many Asian health service providers. Broader educational approaches targeting whole communities instead of individuals will provide a safer, more comfortable environment which promotes help-seeking behaviour and help destigmatise dementia within Asian communities. One expert looking at the English brochure stated that most services offered require the dementia patient and their carer to acknowledge the presence of a mental illness which is difficult to do given the stigmatisation of the disease within Asian communities. This expert said:

. . . people are required to come out and accept the disease and talk about it openly. For example, the socialisation service for dementia patients and the group support for carers.

Accommodation:

Concerns were raised regarding the times at which AACT services were available. Experts discussed child minding, work and educational commitments during the day time which may prevent utilisation of available services. After-hours services might be a hassle for carers who must look after young children, cook and do housework after returning from work.

Recommendations for Alzheimers Auckland Charitable Trust

In discussing how AACT can improve its services, many experts argued that Asian health does not currently occupy a prioritised position on the political agenda of New Zealand. A few experts stated that DHB support and funding for Asian health is currently lacking. Experts highlighted how after much struggle and advocacy Maori health is finally been addressed now, emphasising that for the Asian ethnic groups the battle to gain recognition of health inequities has just begun. Many also agreed that Western models of care which primarily cater for the needs of European/Others will not enable access to dementia support services for the Asian community of Auckland.

Building Capability and Capacity of Workforce

With limited resources, staff and funding, experts emphasised that AACT needs to build on existing services and improve what is already available. The organisation needs to have a champion/leader from within the organisation that drives the changes required to increase utilisation of their services by the Asian population. Without commitment from the organisation to prioritise Asian dementia care and critically evaluate current service delivery, change will be highly unlikely.

Many experts inquired about the ethnic composition of AACT staff. After revealing that only one staff member identified as Asian the experts suggested the organisation should attempt to increase its Asian and bi-lingual workforce. However, experts acknowledged that it is unrealistic to have staff from all of the many different ethnic groups making up the Asian category as some groups are very small and individuals may not be qualified to provide the services. Interestingly, experts emphasised that having Asian staff will not necessarily lead to better service delivery. Being Asian alone is not enough; staff need to know best practice and how to engage with the Asian population appropriately.

Cultural competency training was recommended for AACT staff as a way to help develop capability and capacity to reflect on personal values and thinking. This was argued to improve interactions with various Asian ethnic groups. Some experts suggested that cultural competency training should be made compulsory for all health service providers across the sector. Just as it is important to understand the Treaty of Waitangi and the different needs of Maori compared to European/Other, it is also important to understand the Asian paradigm.

AACT should not generalise all Asian ethnic groups under one category. Not everyone will want to see someone from their own ethnicity; others will not see anyone but someone from their own ethnicity. Being culturally competent is much more than just knowing what to do and what not to do with different ethnic groups as experts argued. AACT as an organisation needs to understand how its values and processes may impact on their interaction with the Asian population.

Collaboration with Other Players in the Health Sector

Experts recommended collaboration with other health and social service providers within the Auckland region to share limited resources and gain access to the Asian population benefiting both AACT and the collaborative partners.

Experts from a non-governmental Asian health service for Chinese stated that they would like to connect with AACT and arrange visits to educate and raise awareness among their community. These experts have access to over 200 Chinese elderly in their service. Hence, identifying, introducing and connecting with existing services which have already accessed

the various Asian ethnic groups will enable culturally appropriate services to be delivered in a culturally preferred format.

One expert suggested that AACT can work with services like Shanti Niwas (who at present do not have the capacity to run a dementia support service themselves) to implement a dementia support network for its users.

Another expert suggested teaming up with primary healthcare organisations (PHO) instead of individual general practitioners alone to educate practitioners on available services for dementia support in the Auckland region. This would help overcome the problem of general practitioners not knowing about the services provided. This expert argued that through implementation at a PHO level more general practitioners would be informed of available services.

Culturally Appropriate Engagement with and Education for the Asian Community

Experts emphasised that current approaches used to reach out to the Asian community of Auckland need to change if AACT is to successfully engage with, educate and support the Asian community. It is important to ensure that the Asian community is actively engaged in reducing the stigma associated with dementia within their community. AACT must work in partnership with the Asian community and not impose change. It was emphasised by experts that the community itself needs to direct and lead change.

To enable communities to direct change themselves it is important to empower the Asian community, to facilitate ownership of the problem and development of the appropriate solutions themselves. Decreasing stigma and increasing dementia support services use is dependent on developing positive relationships with the Asian community.

Supporting advocates of dementia support services within the community and community champions acting to reduce stigma about dementia creates a volunteer workforce which is aware of the unique needs of its community. Experts emphasised that there are many untapped markets like Korean volunteers in churches and shops, those accessing Asian supermarkets, and already existing groups like Chinese Taichi and painting groups. It is important to identify which Asian community AACT wants to connect with and where they can be found.

Using key Asian community leaders like religious leaders can increase the likelihood that AACT messages are listened to by the community. Faith-based interventions in temples, churches and mosques can change perceptions about dementia in an acceptable manner.

One expert suggested that AACT can attract funding for its services from the Asian communities by showing them what AACT can offer their community through partnership.

This mutual benefit will increase funding for AACT which can then be used to provide services for the Asian population.

Finally, experts were concerned that the AACT advertisements on television were not relatable to the Asian community. In order to engage with and educate the various different ethnic groups under the Asian category experts suggested utilising forms of media that Asians interact with daily. Partnering with Hindi radio stations like Planet FM and Radio Tarana, Korean radio, newspapers and magazines and Chinese newspapers and radio was suggested by many experts. A few suggested the creation of a DVD for Asian communities to watch at home with subtitles, visualisation and dubbing in order to deliver the AACT messages in a non-stigmatising and less shameful way.

Discussion

This project aimed to investigate the reasons behind the underutilisation of AACT services by the Asian population of Auckland. Even though dementia affects all ethnic groups, not all can access support services available. As the second largest ethnic category in Auckland, and increasing still, it is imperative that Asians affected by dementia receive appropriate support (Mehta, 2012).

In order to explore barriers experienced by the Asian community in accessing dementia support services, a comprehensive literature review and expert consultations were undertaken. The literature review identified cultural factors which may prevent access to support services. The expert consultations reinforced these cultural factors, but also highlighted barriers specific to the Auckland and New Zealand context.

The literature review and consultations highlighted that a lack of understanding about dementia in Asian communities contributed to low service use. Cultural beliefs about ageing which normalise dementia symptoms also act as barriers. Misconceptions of dementia lead to stigmatisation of the disease within Asian communities. Often help-seeking behaviour is avoided due to fear of being marginalised by the community. Furthermore, Asian families often feel a sense of duty and obligation to care for family members themselves rather than accessing external support. Together these cultural factors discourage Asian people from accessing dementia support services.

In addition to cultural factors, the expert consultations highlighted challenges faced by Asians as migrants or refugees. Experts also suggested barriers specific to AACT that may prevent service use. These included challenges with affordability, acceptability, availability, accommodation and physical accessibility. Strategies to improve service delivery in order to overcome these barriers were also discussed by the experts. These were building capability and capacity of workforce, collaborating with other players in the health sector, and culturally appropriate engagement with and education for the Asian community.

Although the literature highlights aspects of Asian culture that act to prevent help-seeking behaviour, it is important to recognise and understand factors external to Asian communities which may also act as barriers. The consultations emphasised a need for change in the way services are delivered by AACT. Collaboration with other health service providers and partnerships with the Asian community within Auckland are essential to improving utilisation of AACT services.

If AACT is to successfully increase utilisation of their services by the Asian population of Auckland, changes need to be made at both a community level and service level. At the community level, AACT should support efforts to reduce stigma surrounding dementia within Asian communities. Help-seeking behaviour should be normalised. At the service level, AACT should ensure that services provided meet the heterogenic needs of the Asian community.

Recommendations

In order to effectively provide dementia support to the Asian community AACT will need to be flexible and adapt current service delivery methods to reflect the needs of the Asian community. As this report has highlighted AACT needs to be committed to changing both the way their services are delivered and how they approach the Asian community. The following recommendations outline strategies for AACT to increase service utilisation by the Asian population of Auckland.

- **Customise services to specific cultural needs:** AACT needs to identify which Asian community group(s) they want to work with. As there are many Asian ethnic groups under the Asian category, a blanket approach to service delivery covering all Asian ethnic groups will not accommodate for the diverse needs. Thus, support services should cater for differing needs of individual ethnic groups. AACT will need to geographically locate where their target group is within Auckland.
- **Reducing language barriers:** Ensuring information resources such as pamphlets are designed in a way that will destigmatise and reduce myths about dementia. When translating resources AACT should consult with both a health professional and a translator to ensure the translation is clinically and culturally appropriate. With services such as the telephone consultation it is important to ensure availability of advice in alternative languages if required. The use of interpreters is also recommended to deliver AACT services in preferred languages.
- **Increasing awareness of available services:** AACT must improve awareness of services provided as currently there is confusion as to what is offered and for whom. Thus it is recommended that AACT clearly state what services they provide, for whom and how clients can be referred to AACT. This information must be up-to-date and consistent throughout AACT promotional material. Asian communities and health and social service providers within Auckland need to clearly understand this information in order to confidently refer their clients to AACT.
- **Community activation:** AACT needs to build partnerships with the many different Asian ethnic groups within Auckland. It is important to work with and not on the Asian community - a bottom-up approach where the community themselves are leading the change process. Community initiated dementia education and advocacy could help deliver the AACT message in a culturally appropriate way. To do this, AACT should identify, introduce and build relationships with Asian community leaders who can help connect AACT to Asian communities. A keyworker from AACT needs to work with specific Asian communities to build trust overtime and promote

their services. Volunteers from within the Asian community can advocate messages of destigmatisation.

- **Collaborate with existing Asian health service providers and community groups:** There are many small to medium size Asian groups formed within Auckland based on interests, religion and recreation as well as those accessing Asian-specific health services. AACT should identify these groups and make use of their connections to the Asian community. AACT can work with these groups to develop and implement dementia support services for members of these groups as required. A number of Asian health service providers have been identified and recorded by WDHB. These can be viewed on their website¹. AACT can also collaborate with other health and social service providers within Auckland to share limited resources and develop strategies for increasing service utilisation by Asian communities in Auckland.
- **Educating the Asian community:** In order to overcome cultural barriers and stigma AACT needs to help the Asian community understand the facts about dementia in a manner that is respectful of their beliefs and values. Dementia education needs to be delivered by AACT in a way which does not isolate the patient and/or carer and sets them out as different within their community. Approaches which help reduce stigma and normalise help-seeking behaviour of the whole community is recommended. For instance, the use of media such as videos, Chinese and Indian radio, Chinese and Korean newspapers and magazines can be used to deliver the AACT message.
- **Building workforce capability:** AACT needs to understand that the way in which current services are delivered is not culturally appropriate for the Asian community. In order to develop skills of reflection and understanding, AACT staff is encouraged to undertake cultural competency training. Such training is recommended as a way of helping staff understand strategies for working with diverse Asian communities. If and when possible AACT should employ staff of Asian background and/or bi-lingual staff.
- **Leadership and commitment to change from AACT:** A staff member(s) from within AACT needs to become the champion for driving change required to better cater for the needs of the Asian community. AACT needs to make policy commitments that prioritise development and implementation of Asian-specific dementia support services. A commitment from the AACT board to prioritise Asian dementia support is crucial to initiate the change process.

¹<http://www.caldresources.org.nz/info/cr/CALD%20Services/Asian,%20Migrant%20and%20Refugee%20Culture-Specific%20Services.htm>

Conclusion

This report has highlighted various barriers experienced by the Asian community of Auckland in accessing dementia support services provided by AACT. Whilst there is no 'one solution' to overcoming these barriers, it is hoped that the recommendations made will assist AACT in making the improvements needed. Indeed, the changes recommended will require a long-term commitment from AACT to allocate both time and resources necessary. We recognise that implementing changes suggested will be a challenge with the limited resources available. However, it is imperative that services like AACT understand that the way in which they design and deliver services as well as how they think about healthcare will need to change in order to accommodate the changing needs of our society.

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