



Alzheimer's
Australia Vic
Living with dementia

Perceptions of dementia in ethnic communities



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Allens Arthur Robinson



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This report is also available on the Alzheimer's Australia website
alzheimers.org.au

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National Dementia Helpline 1800 100 500

An Australian Government Initiative

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Foreword

Australia is currently experiencing a major shift in its demographic profile. Decreasing birth-rates and increasing ethnic diversity have culminated to a time where we are about to witness a significant increase in the number of culturally and linguistically diverse (CALD) older Australians. In fact, by 2011, one in five people aged 80 or over will be from a CALD background, increasing to one in four people by 2026.

It is well known that the incidence of dementia increases as we age. As such, dementia care is fast becoming a major issue for both community and residential aged care service providers. Add to this the complexity of caring for a population that is increasingly culturally and linguistically diverse and it can be seen that there is much work to be done to ensure that our multicultural ageing population can access appropriate care.

There is currently very little research into perceptions of dementia across CALD communities. Developing a better understanding of perceptions of dementia within different cultures will play an important role in identifying the dementia care needs of many older Australians, their families and carers.

The Ethnic Communities Council of Victoria (ECCV) applauds Alzheimer's Australia Vic on this project which attempts to uncover the perceptions of dementia among 12 ethnic communities to inform the development of a practical resource to assist planners and service providers to better understand and respond to the varying support needs of older CALD Australians.

It is hoped that a great deal more research will be done to continue to ensure that our aged care services are committed to quality improvement and best practice when serving the care needs of our ageing multicultural population.



Marion Lau OAM JP

Chairperson
Ethnic Communities Council of Victoria Aged Care Committee

Introduction

Older people from culturally and linguistically diverse (CALD) backgrounds constitute a significant proportion of the older Australian population. Australia's CALD community swelled significantly from the 1950s through migration and, as this first generation ages, there will be a rapid increase in the proportion of people with dementia from non English-speaking backgrounds. Currently, one in eight Australians with dementia do not speak English at home, while in Victoria this proportion is even higher with one in six people with dementia not speaking English at home.

People from CALD backgrounds face numerous barriers when it comes to accessing services. These include difficulties with language and a lack of knowledge of the service systems. The lack of culturally and linguistically appropriate services and culturally appropriate assessment is a major impediment to the accurate diagnosis and treatment for dementia. Brain changes associated with dementia present unique challenges to people from non-English speaking backgrounds, often causing them to revert to their primary language and past experiences. Such changes not only have a significant impact on family relationships but also cause difficulties for service provision. Furthermore, there seems to be a lack of understanding of dementia by many people in some CALD communities.

There is currently very little research into perceptions of dementia across CALD communities in Australia. Alzheimer's Australia Vic received funding from Allens Arthur Robinson to develop a resource kit outlining dementia perceptions in Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Polish, Russian, Serbian, Spanish, Turkish and Vietnamese communities. This resource will assist organizations working with CALD clients to better understand the background of consumers they are supporting and develop appropriate services to assist their clients.

The resource kit consists of individual community profiles and the following information:

- Introduction – brief reference to migration history and language.
- Perceptions of dementia
- Diagnosis and treatment
- Role of the family
- Attitudes to community care
- Attitudes to residential care
- Attitudes to counselling
- Religion and its role in dementia care
- Key issues to consider
- Key community contacts
- Dementia-specific information

Information contained in these profiles is based on opinions of people who were consulted during this project. It is important to remember that each person is an individual and each individual within a specific ethnic group may not hold the same views or opinions about dementia or even have the same amount of knowledge about the condition. It is essential to consider the perceptions of ageing, memory changes and dementia and recognise the differences within and across cultures in order to engage CALD communities and provide culturally and linguistically appropriate services. The basic principles of 'person-centred care' need to be taken when working with people with dementia from CALD backgrounds.

It is important to acknowledge that some of the views expressed in this document about the term 'dementia' and about perceptions held about dementia are not confined to people from culturally and linguistically diverse backgrounds. It is also to be noted that some issues identified by people from particular communities may also exist in other communities. Looking across the twelve community profiles, it is often the commonality of perceptions that is noteworthy and it demonstrates the need for information and support to all people, irrespective of our cultural or linguistic backgrounds.

Additional background information about this project is detailed in the Perceptions of Dementia in Ethnic Communities project report, which is available on the Alzheimer's Australia website: alzheimers.org.au

Introduction

The Arabic-speaking community is diverse and includes people from 22 countries. Many of the immigrants from Arabic-speaking countries have come to Australia as refugees or displaced persons. The largest communities of Arabic-speaking people are from Lebanon, Egypt, Syria, Iraq, Jordan and Palestine. The main language is Arabic, however some of these communities may speak other languages or dialects as well. For example, Assyrian and Chaldean languages are different from Arabic but all elderly can also speak Arabic.

Many people from Arabic-speaking countries are Muslims and for some this takes precedence over their cultural background. There is also diversity within Islam including: Sunni, Shi'a, Alawi, Druze and Isma'ili Muslims. There are also a significant number of Arabic-speaking communities practising different religions including Catholics, Orthodox Christians, Chaldean, Copts and Maronites.

According to the 2006 Australian Census, Arabic is the sixth largest spoken language in Victoria, with Arabic-speaking community comprising 5.6% of the older population speaking a language other than English at home.

Perceptions of dementia

Dementia is considered by many Arabic-speaking people to be a normal part of ageing but associated with mental illness. There is some reluctance in the Arabic community to admit to the illness and, because of the stigma, may stay away from friends and community and become isolated. The family is also likely to limit visits in fear of mockery or criticism.

People experiencing symptoms of dementia are most likely to be in denial and may become defensive when questioned about their memory. Family members will try to cover up for them by reminding them constantly. Some think that Alzheimer's is the beginning of the illness when it just starts, and then dementia is when the person forgets everything.

The causes of dementia are not well understood in the Arabic community and the perceived causes include family events such as loss of family member, divorce or stress. Hereditary problems, lack of activity, other illnesses, shocks, accidents, medicines, drug overdose, age and isolation may also be blamed.

There is a lot of stigma attached to dementia in Arabic-speaking communities due to the terminology that is currently used in translations. The word most commonly used in Arabic is 'kharaf'. This word has several interpretations but is most commonly interpreted to mean 'unravelling', 'lost their mind', 'when someone talks nonsense'. In most cases the term is understood in negative terms and carries negative connotations.

Diagnosis and treatment

The first point of contact for the community is the doctor. However there are some concerns from community members that some doctors lack sufficient knowledge about the illness. A combination of negative perceptions of dementia may lead to late diagnosis.

The preference as to whom the diagnosis is told varies according to which country the person comes from. In some Arabic-speaking communities the family may prefer that the diagnosis not be told to the person affected in order to prevent further deterioration. In other communities it is important to involve the person as well as the family. This is something that needs to be discussed with the family members. Often families do not seek a diagnosis until people around them realise the person has a problem and decide that medical advice is needed.

Once diagnosis is established, use of modern medicine would be accepted. There are some people who would also rely on alternative therapies such as natural herbs.

Role of the family

Generally speaking the Arabic community is family-oriented and the male is the head of the family and makes decisions. It is expected that children will care for the parents. The main carer initially is the spouse, supported by the family members. Traditionally, the son is expected to care for the parents, while the daughter is expected to care for parents if she is not married. If the daughter is married, she is responsible for both her husband and his family. Even though the attitudes and expectations are changing for more traditional Arabic communities, the expectation that children will care for their parents is deeply embedded, including in religious beliefs. For these communities it is not acceptable for children to put their parents into nursing homes and this carries a lot of stigma and shame. A common belief is that if children are good they will care for their parents as this is what Allah wants of them. If they do not take care for their parents then in turn their children may not care for them when they grow old.

Attitudes towards community care

As there is a strong preference for members of the Arabic-speaking communities to stay at home, they are likely to accept services which will help them to do so. There is however conflicting information as to how these services are provided. Some people prefer the services to be provided by someone who is not from an Arabic background due to issues of privacy and shame. For others, Arabic background is necessary. Gender matching is an important requirement.

Attitudes towards residential care

Placing family members in nursing homes is not an option for Arabic-speaking communities unless as a last resort. Most people perceive residential care negatively, and if they had to access it, would prefer an Arabic-specific facility. Some of these views may also be due to negative perception of this type of care in their home country and a combination of attitudes that it is not acceptable to place members of the family in such facilities.

Attitudes towards counselling

The main concern expressed in the community around counselling is that they feel as if they are speaking to a 'stranger'. Carers expressed a fear that they would be betraying their family members and treating them as a burden if they sought external assistance. It is therefore common that carers may resist support services and often pretend that they have more help than they actually do. Where counselling

services are used, most people prefer face to face contact with someone that speaks their language and with whom they have built a relationship over some time. Overall, counselling for dementia is not very common.

Religion and its role in dementia care

For Arabic-speaking communities who are Catholics, religion is important for comfort. It is separate from everyday life and does not have an impact on decisions relating to illness. In some cases the priest may visit the family and act as a counsellor to help ease the stress on the family.

For those who practice Islam, dementia is God's will and should be accepted. However, this does not prevent the community from seeking treatment, because they believe that God enabled us to create treatment so we should use it.

Key issues to consider

- Language
- Lack of knowledge about dementia services
- Inappropriateness of translated information
- Stigma and sense of guilt when seeking external help

Dementia-specific information available from Alzheimer's Australia Vic in Arabic

1. Our services
2. Getting help
3. Worried about your memory
4. Mind your Mind – user's guide and brochure
5. What is dementia?
6. Diagnosing dementia
7. Early planning
8. Communication
9. Taking a break
10. Changed behaviours

Key community contacts

Victorian Arabic Social Services (VASS) (Head Office)
178 Dallas Drive
Broadmeadows, VIC 3047

Tel: (03) 9309 0055
Fax: (03) 8307 6447
Email: mail@vass.org.au

Victorian Arabic Social Services (VASS) (Newport Sub-Office)
16 Oxford Street
Newport, VIC 3015

Tel: (03) 9391 0195
Fax: (03) 9391 0197
Email: mail@vass.org.au

Victorian Arabic Social Services (VASS) (Dandenong Sub-Office)
South East Region MRC,
Level 1, 314 Thomas Street
(PO Box 1139)
Dandenong, VIC 3175

Tel: (03) 9706 8933
Fax: (03) 9706 8830
Email: mail@vass.org.au

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

Croatian migration to Australia dates from the 1850s through to 1990s when a large number of Croats migrated due to the outbreak of war in former Yugoslavia. Many Croatian traditions are connected to religious festivities and family events.

The majority of Croats in Victoria are Roman Catholic. The Croatian population over 65 years constitutes approximately 12% of the total CALD population. This number is expected to grow by 127% by the year 2021.

Perceptions of dementia

Memory change or memory loss is seen as a normal part of ageing and dementia is often not distinguished from normal forgetfulness. It is generally believed that memory loss happens to everyone. Many people will not admit to an illness being present and will use other reasons to justify memory problems.

The term 'dementia' is more recognized than 'Alzheimer's disease', however there is a lack of understanding of the difference between the two or how are they related. Lack of knowledge and understanding about dementia and the nature of its symptoms can often result in people thinking that people with dementia are having mental health problems.

In the Croatian community, mental health issues carry a lot of stigma and are not openly discussed in the community. The opposite is the case with other illnesses such as heart disease, diabetes and other organic conditions. People suffering from mental illness or dementia will not discuss their problems in the community and will come up with reasons as to why they are behaving differently.

An understanding of dementia and perceptions in the Croatian community also varies according to educational levels. Most of the established Croatian migrants came from villages and have had little or no education in their own language, whereas a significant number of people who arrived in Australia since the conflict in the 1990s are well educated professionals.

Diagnosis and treatment

If a member of the community is concerned about their memory they are likely to first contact their general practitioner who in many instances is likely to be of Croatian background. Older Croats are more likely to have more respect for doctors who have been educated in their home country as they believe that system of education is better in Croatia than it is in Australia. In Croatia, doctors are generally well respected and considered as an authority. They also rely on Croatian-speaking doctors due to the lack of English language skills. Some Croats will visit non-Croatian speaking practitioners to avoid long waiting periods for an appointment. This raises an issue of communication with their doctors. Many Croatian elderly do not speak English well and, with no interpreters present, explanations are limited.

Considering that memory loss is considered normal in older people and there is a lack of knowledge about the symptoms of dementia, members of the Croatian community are usually diagnosed late. This is made worse by people trying to hide the fact that they are having trouble remembering. Diagnosis usually occurs when symptoms become pronounced and

more than just memory loss. The absence of physical symptoms may lead to a perception that everything is fine with the person and there is no need to diagnose particularly when a person feels well physically.

Most Croats use modern medicine and often do not believe in alternative therapies especially those that do not involve any medications. There is also a tendency by Croats to think that just because they are taking medications there is no need to make any lifestyle changes.

Role of the family

The Croatian community is quite family-centred. Family members are primary carers for the elderly and the carers are predominantly daughters or spouses. There is a strong sense of family expectation that the children will take care of their parents, especially as parents commonly pay for a child's education fees and children usually live with parents until they are married. In Australia, children are often unable to meet these expectations, due to longer distances between family members and greater commitments of the children. This may cause considerable stress and conflict in the family.

There is a tendency for older Croats to visit frail and elderly community members who live either at their home or in nursing homes. However this is only the case if they previously knew the person. The community will usually withdraw from contact if the person is considered to be mentally ill or has dementia as they do not see a reason to visit someone who does not recognize them.

Furthermore, due to lack of understanding of the illness and the absence of physical symptoms, some carers may think that the person with dementia is behaving strangely on purpose. It is believed that it is the person, not the illness, who is responsible.

Attitudes towards community care

Croats rely on their doctors for information, assistance and referrals. They are open to using community services to remain in their homes for as long as possible. This is especially the case as there is a growing realisation that the children are no longer able to care for their parents and this type of assistance is necessary to avoid going into a nursing home. Many Croatian clients are likely to clean the house before the service provider arrives as it is culturally unacceptable to welcome someone into your home if it is not perfectly maintained. This may in turn create a perception that help is not needed. On the other hand they have high expectations of the care workers when it comes to the type and quality of work provided. The gender of the care worker is also an issue and there is a strong preference for female workers due to the belief that cleaning, washing etc. are 'women's jobs'. There are also gender issues in relation to the provision of personal care and it is inappropriate for a male worker to assist a female client with personal care.

Attitudes towards residential care

Residential care is viewed negatively in the Croatian community. There are no Croatian-specific facilities in Victoria and there is a strong fear of isolation if the person is placed in a non-Croatian speaking facility. There are limited services

for the aged in Croatia. Residential care in their home country was rare and was seen as institutionalisation and not the right thing to do to a family member.

Attitudes towards counselling

Counselling is often considered to be something that people accept when they are suffering from a mental illness. Most people responded that people with dementia are 'not crazy' and do not need to see a counsellor. The service is more likely to be used by subsequent generations of Croatian migrants. If it is to be utilised by the Croatian elderly, it would need to occur in their language and in a face to face meeting.

Religion and its role in dementia care

Croats are predominantly Catholics while a small minority may belong to Jehovah's Witnesses or Seventh Day Adventists. Religion is important to the Croatian community and in Victoria there are two Croatian Catholic Churches and one Adventist church. Most aspects of everyday life are kept separate from religion. However, some people may consult with the priest about the illness if they do not know where else to go.

Key issues to consider

Many older Croatian migrants have low English literacy and information needs to be in Croatian. However, it needs to be simple as many migrants are from villages with little or no formal education in their own language. In order to reach a large number of the community members, audio information on Croatian radio and TV is preferred. Word of mouth is also a good way to disseminate information.

Culturally inappropriate services are a problem, especially with services providing food, as many Croats do not eat the food provided by Government subsidised delivered meals services. Furthermore, when providing any type of service it is important for service providers to send a worker with a Croatian background where possible. It may be difficult for mainstream service providers to make a distinction between Croatian, Serbian and Bosnian language or culture and care needs to be taken to ensure that the worker is of the appropriate cultural and linguistic background. This also applies when an interpreter is required.

Dementia-specific information available from Alzheimer's Australia Vic in Croatian

1. Our services
2. Getting help
3. Mind your Mind user's guide and brochure
4. What is dementia?
5. Diagnosing dementia
6. Early planning
7. Communication
8. Taking a break
9. Changed behaviours

Key community contacts

**Australian Croatian
Community Services
(Footscray Office)**
40 Pickett St,
Footscray, VIC 3011

Tel: 03 9689 5811
Fax: (03) 9689 8419
Email: services@accs.asn.au
www.accs.asn.au

**Australian Croatian
Community Services
(Dandenong Office)**
128-130 Walker St,
Dandenong, VIC 3175

Tel: (03) 9791 6000
Fax: (03) 9791 6011
Email: services@accs.asn.au
www.accs.asn.au

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction/key characteristics:

Chinese migration to Australia began in the mid 1800s during the gold rushes in Victoria and NSW. The second notable arrival of Chinese migrants was during 1950s which saw Chinese students coming to Australia. Many also remained following the Tiananmen Square incident in 1989. Most Chinese migrants, however, arrived in Australia during 1970s and 1980s from China as well as other countries such as Malaysia, Cambodia, Hong Kong and Vietnam. Each of these waves has been followed by a significant number of family sponsorships.

The Chinese language includes over 20 different dialects with most migrants from China speaking Mandarin, while those from Southern China and Hong Kong speaking Cantonese. Migrants from Malaysia and Singapore speak Mandarin, Hokkien and Hakka, while those from Vietnam speak Vietnamese, Cantonese and Teochew. All Chinese dialects use the same written characters.

Cantonese is the fourth largest language other than English in Victoria and Mandarin is the fifth largest. Combined, there are 131,227 people in Victoria who speak Cantonese or Mandarin.

Perceptions of dementia

Understanding of dementia varies within the Chinese community. In some sections of the community, dementia is stigmatised as a form of mental illness. Sometimes even slight memory loss is considered to be dementia. In other sections, forgetfulness and memory loss may be attributed to old age and considered a normal part of ageing. Some members of the community recognise a number of symptoms of dementia apart from memory loss, such as confusion, wandering, language problems and incontinence. However, causes of dementia are not very well understood in the more traditional Chinese community.

Dementia is not openly discussed within the community and friends and family may stay away from the person with dementia. This raises some concerns around social isolation. Isolation is especially a problem if the family members are working and the person with dementia is left on their own, with limited contact with friends and family.

There are no major issues with terminology that relates to dementia. The words that are used in translations are recognised and accepted.

Diagnosis and treatment

Dementia is still not openly discussed in the Chinese community and some people may try to mask the symptoms in order to try and hide them from the family. Even for those who are comfortable to discuss their problems with their family members, this is often not discussed with non-family members or the community. This usually results in late diagnosis.

Once problems become more apparent the first point of contact for information and diagnosis is the family doctor. Elderly members of the community often attend the appointment with a family member, especially if a non-Chinese speaking doctor is involved. Diagnosis is usually

given directly to the person and the family members if present.

The Chinese community is accepting of the modern medicine for the treatment of dementia, but the medications may be combined with traditional Chinese medicine. Chinese herbs are used to treat a range of illnesses. Treating the cause of the illness is seen as equally significant as treatment of the symptoms. Acupuncture and cupping are commonly used for a range of illnesses and may result in bruising so it is important not to mistake it for signs of abuse.

A considerable emphasis is placed on dementia prevention through healthy eating and physical and mental exercise. Mahjong, for example, is a common game involving skill, memory and calculation.

Role of the family

Chinese community places high value on their elderly and filial piety. The traditional concept of filial piety (hsiao) includes obeying parents completely and caring well for them as they grow older. Old age is seen as time of great wisdom and elderly are generally well respected in the family. The traditional family structure is hierarchical and patriarchal and there is an expectation that the children will take care of the elderly. Many of the elderly members of the Chinese community have been sponsored to Australia by their children to help care for their grandchildren and there is an expectation that in turn their children will take care of them.

This expectation may cause conflict in the family for a number of reasons. Many children are working full time in order to provide for their own families and are unable to provide full care for their parents. There is also a tendency for intergenerational conflict to occur between Chinese elderly and Australian born children and grandchildren due to differences in values and expectations.

Attitudes towards community care

Senior Citizens groups, support groups and Planned Activity Groups are highly valued in the Chinese community and help reduce social isolation. Chinese place a great importance on peer support. In terms of practical care at home, most are welcoming of the services that are available, especially when they are provided in their own language. Large number of community members accesses their ethnic organization for assistance and information.

Attitudes towards residential care

Residential aged care is still perceived negatively and considered as a last resort. It is more accepted if it is in a Chinese-specific facility. Respite care is becoming more accepted either in the home service or the community.

Attitudes towards counselling

Counselling is not used widely for dementia but those who would consider counselling would prefer it in Chinese. Counselling is seen as useful for mental illness and may be sought by those who suffer from depression rather than dementia. This tendency may also be the result of preference of the Chinese community to deal with issues in private and within their own families.

Religion and its role in dementia care

Religion is important to the Chinese community and may become even more so in times of illness, however it does not play a major role in dementia care. Chinese elderly practice Buddhism while the new generations may also practice Christianity. Many Chinese elderly also place a great emphasis on ancestor worshipping. Buddhism promotes harmony and belief that positive actions bring happiness while negative actions bring negative consequences upon a person and their family.

Key issues to consider

The language barrier is the most significant issue for the Chinese elderly. Lack of English means that they rely heavily on their families and feel that they cannot fully participate as equal members of the community. Language is also a major barrier in accessing mainstream services. As there are so many spoken dialects in the Chinese language it is important that the appropriate interpreter be used.

There is also a low literacy level in written Chinese in some pockets of the community so, even though written information about dementia is valued, many prefer verbal information. Transport is also a significant issue for Chinese elderly and may prevent them in accessing the appropriate services and result in social isolation.

Dementia-specific information available from Alzheimer's Australia Vic in Chinese

1. Our services
2. Getting help
3. Worried about your memory
4. Mind your Mind user's guide and brochure
5. What is dementia?
6. Diagnosing dementia
7. Early planning
8. Communication
9. Taking a break
10. Changed behaviours
11. Wandering
12. Activities
13. Caring for someone who lives alone
14. Later stages of dementia
15. Making the most of respite care

Key community contacts

**Chinese Community
Social Services Centre**
16 Livingstone Crescent,
Burwood VIC 3125

Tel: (03) 9888 8671

Fax: (03) 9888 8673

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

The Greek community has long migration history in Australia, although the vast majority arrived between 1945 and 1982. Greek-born residents constitute the second largest non-English speaking group after Italians. The Greek community in Australia has well established organisations and institutions committed to the preservation of the Greek language, culture and identity.

Even though many Greek migrants were self-employed, literacy in English as well as their own language remains a problem for many elderly Greeks. Greek is the official language, with some spoken variations, which is understood by almost all members of the Greek community.

According to the 2006 census, there are 117,875 Greek-speakers in Victoria making Greek the second largest language spoken at home. It also has a high number of people with low English proficiency, especially in the 45-64 and 65+ age groups. The Greek elderly population is expected to increase, especially in the 65+ and 80+ age groups. By 2011 older people born in Greece will make up 2.4% of the total older population in Australia and by 2026, persons born in Greece are projected to account for 1.5% of the Australian population aged 65+, and 3.2% of those aged 80 and over.

Perceptions of dementia

Despite the Greek community being perceived as having the best access to services and information, there is still very little understanding of dementia in much of the Greek community. Most community members describe dementia in terms of its symptoms, and most can only identify memory loss as one of the symptoms. In relation to the understanding of the causes of dementia, it is generally attributed to heredity, some sort of shock or trauma or constantly worrying or thinking about the same thing. Some people attribute dementia to stress or to environmental factors such as pollution. Some also believe that dementia is associated with stroke.

Dementia is not openly discussed in the community and many people will become isolated from the community due to a breakdown in communication and visitors not knowing how to behave around the person with dementia. Many people also feel that they would not be taken seriously even if they spoke about the condition as there is a perception that it is normal to forget, particularly when there are no physical symptoms. There is a lot of stigma attached to dementia and some community members feel they would be labelled negatively if they said they have dementia. They may perceive dementia as 'losing sense of sanity'.

However, care needs to be taken when considering second and third generations as they are becoming more open to discussing these issues in the community. As there is a perception that memory loss happens to older people, there is no acknowledgement of this happening to younger people. One case was identified of person in their 50s not being diagnosed five to six years after exhibiting the initial symptoms.

The term most commonly used in Greek for 'dementia' translates as memory loss in English and may play a part in lack of understanding of the illness.

Diagnosis and treatment

Some community members are unsure when they need to seek a diagnosis. Many agree that they should go as early as possible but they do not act. Most people with memory concerns would seek the advice of their doctor. Many people would attribute the symptoms to old age. Diagnosis is usually sought when more pronounced behaviours occur such as wandering.

It is important that information about diagnosis and the process for diagnosis be explained in full to the person as well as their family. It is expected that the diagnosis would cause some emotional distress to the person and the carer and they may be in denial when first informed of the diagnosis. They may also become fearful as they do not know what will happen next and how will they cope in the future.

Most Greeks would follow their doctor's instructions and use medications. Some may use natural herbs and medicines in combination with medications.

Role of the family

The elderly are traditionally cared for at home and most rely on family for support and access to information and services. There is, however, a growing realisation that families and children have their own responsibilities and may not be able to care for the elderly, and the traditional extended family support role is declining. There is also a growing concern that the second and third generations do not speak or have only limited Greek and therefore may not be able to assist their parents or grandparents when they are having language difficulties.

One of the main concerns in the Greek community has been for carers. Most people agreed that caring for someone with dementia is difficult both physically and mentally and some carers' own health may be compromised.

Attitudes towards community care

Considering that the Greek elderly still rely heavily on the family for assistance, there is still some reluctance to use external services. This is especially the case with services provided by mainstream organisations. However, there is a growing acceptance of community services that enable the person to stay at home for as long as possible. Greek-speaking workers are preferred but non-Greek speaking workers are also accepted.

Attitudes towards residential care

Residential aged care is seen only as a last resort, reserved for people who are alone and have no family members to take care of them. There is a prevailing perception that the person deteriorates much quicker when they are placed in residential care than when they are cared for at home.

Spouses are the main carers of people with dementia. The wife or the husband usually provides the care as dependency

increases. There is a significant resistance to being placed in a nursing home and many believe that it is better to die earlier in their own home than be placed in a residential care facility. A person may only be placed in a nursing home once the carer dies or the carer becomes too ill to look after the person with dementia.

It is however important to note that once again these attitudes may vary across different generations of Greek-speakers and some community members feel comfortable in placing family members in care provided that they are satisfied with the quality of care provided.

Attitudes towards counselling

Counselling as a service for people with dementia and their carers is not familiar to the community. Most members agree that it would be utilised if there was a greater knowledge and awareness of the service but even so it would have to be offered face to face and in the Greek language. Telephone counselling is not considered as appropriate as many elderly would have a difficulty accessing the service through an interpreter. Children are not necessarily appropriate as interpreters as they do not always speak the language or understand it fully.

Religion and its role in dementia care

Most of the Greeks are members of the Greek Orthodox Church while a minority belongs to Jehovah's Witnesses and Seventh Day Adventists. The role of the church is important in the Greek community but it is mostly separate from other aspects of everyday life. The importance of religion and the priests varies from person to person. Some members of the Greek community often will not actively seek assistance through the church but may find prayer and church help them cope with caring for a person with dementia. Others will seek advice from the priest and some Greek priests will actively organise information sessions for their community.

Key issues to consider

There are some issues relating to English literacy in the Greek community. According to the 2006 Census, in Victoria Greek-speakers are the third largest group with low English proficiency. They are the second largest group in the over 65 year age bracket. Therefore language continues to be an ongoing barrier to access for many Greek elderly.

This lack of English proficiency also contributes to lack of familiarity with available services. The community relies heavily on their families for support and information and also on ethno-specific service providers. Dementia services require greater promotion and understanding.

In view of the above issues, it is important to provide information that is simple and easy to read in both English

and Greek. Many Greek elderly cannot read well even in their own language so verbal information would also be useful. Promotion of dementia information and services through Greek radio is beneficial.

There is a need for more services and support for carers. In the Greek community many carers are elderly spouses who need support themselves. They are often frail and ill themselves and have issues with language and transport. It was reported that caring for a person with dementia is physically and mentally exhausting and there is a need for more services.

Finally, language and culture is extremely important to the Greek community. They prefer to be addressed in their own language by those who understand their culture. Many rely on ethno-specific services for support and advocacy as well as access to support groups and even on information about mainstream services. Family and community support also plays an important role.

Dementia-specific information available from Alzheimer's Australia Vic in Greek

1. Our services
2. Getting help
3. Worried about your memory
4. Mind your Mind user's guide and brochure
5. What is dementia?
6. Diagnosing dementia
7. Early planning
8. Communication
9. Taking a break
10. Change behaviours
11. Memory changes

Key community contacts

Australian Greek Welfare Society
7 Union Street
Brunswick, VIC 3056

Tel: (03) 9388 9998
Fax: (03) 9388 9992
Email: agws@agws.com.au
www.agws.com.au

Froniditha Care (Northern Region)
335 Station Street
Thornbury, VIC 3071

Tel: (03) 9495 2303
Fax: (03) 9495 2319
www.froniditha.org
www.greekcare.org.au

Froniditha Care (Southern Region)
94 Springs Road
Clayton South, VIC 3169

Tel: (03) 9552 4111
Fax: (03) 9552 4194
www.froniditha.org
www.greekcare.org.au

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

Italian migration to Australia dates back to 1800s, with the majority of migrants arriving after World War II and up to the 1980s. Since then there has been a small additional influx, mostly professionals and relatives.

Standard Italian language is recognized by the majority of the Italian community but there are many dialects. In some instances, speakers of different dialects may not understand each other and older Italians may have a problem with speaking standard Italian.

According to the 2006 Australian Census, 82,851 Victorians were born in Italy, while the number of people who speak Italian at home is estimated at around 133,327. Italian-speakers are the second largest group with low English language proficiency, including the over 65 year age group. The majority of the Italian-speaking population is over the age of 60.

Perceptions of dementia

Views and opinions on dementia vary across the community and according to the level of education and knowledge of English. For some, dementia is still perceived as benign forgetfulness. Having memory problems, forgetting things and being repetitive is thought to be a normal part of ageing.

Social isolation is one of the major issues raised by the Italian community. This is mainly because friends and family may tend to reduce social interaction with the person with dementia and their family. Some community members are also not sure how to behave around someone who has dementia as they feel they have little understanding of the condition. Some carers may feel that they need to apologise or explain a person's behaviour when they are around other people. This may be seen by some carers as admitting guilt or being somehow responsible for the person's behaviour.

'Dementia' in Italian is a medical term and has mental health connotations. Some older Italians may still refer to dementia as 'sclerosis' which was the term commonly used in the past.

Diagnosis and treatment

The majority of the Italian community would see their family doctor for diagnosis, although for most people, diagnosis would only be sought once the person was experiencing more severe symptoms. This may indicate that a diagnosis may be obtained late when the options for some treatment have diminished.

Communication is another issue when it comes to diagnosis as many Italian older people do not speak English and are not aware of where to go for diagnosis or why they should seek diagnosis. It is very common that the diagnosis and the full details of the illness are presented to the family rather than to the person with dementia as it may be considered insensitive for a doctor to give grave news to the person directly.

Role of the family

The role of the family in dementia care depends on the family itself. Whilst it is preferred that the person be cared for by their family members, it is up to the individual families as to how

they approach this issue. Most of the time, the spouse takes on the caring role and many carers report that they continue to care for their spouses even when it is beyond their ability to do so. There are many instances of carer stress and burnout.

Attitudes towards community care

Views on community care also vary. The community is generally still family-centred and the family members will take on the required tasks. Carers who seek services may see it as help for themselves rather than for the person with dementia. In other words, they may see help as doing jobs they should have done. It is very common that the carer would clean the house prior to the arrival of an assessment officer or the home care worker.

Overall, in-home support services such as home help may be accepted with hesitation and only if the spouse or the carer is no longer able to undertake certain tasks. Since many Italian older people do not speak English it is important that the care worker speaks their language or dialect.

Attitudes towards residential care

Residential care is often not an acceptable option for a number of reasons. Italian-speaking people have a strong attachment to their home which is a symbol of success and a part of their identity, and the house is often re-created to resemble the dwelling they had in Italy. Placing someone in residential care is usually the last resort, and many families will undertake significant modifications to the house to keep the person at home until they present a danger to themselves or to the family if they stay at home.

There is a significant level of stigma also attached to placing someone in a nursing home, particularly if the person's spouse is still alive. There is a perception among spouses who are carers that they will be judged by the community if they place their partners in residential care.

Another issue is identifying a facility that is culturally appropriate and where the linguistic needs of clients are taken into consideration and provides Italian food. If the carer is an elderly spouse then the facility would also need to be accessible so that they can regularly visit. 'Word of mouth' is strong in the community and people talk amongst themselves about their experiences around nursing homes. So, negative perceptions when people go to a facility and visit someone are likely to be conveyed to other members of the community.

Attitudes to counselling

Trust is considered to be a key ingredient for use of counselling. For counselling to be utilised, the relationship would need to be developed over a period of time and provided in the person's primary language rather than through an interpreter. Telephone counselling is considered impersonal and is not likely to be utilised. The process of accessing this type of service though a telephone interpreting service is considered to be too complicated. There is also no specific term for counselling in the Italian language.

Religion and its role in dementia care

Majority of Italians are Roman Catholics although there are minority groups who are followers of other religions such

as Jehovah's Witnesses and Pentecostals. The importance of religion and the role it plays in dementia care varies from person to person. For some people religion is an important, but separate, aspect of everyday life which may not play a role in dementia care, while for others it provides comfort in difficult times. There is great respect for priests in the community and some families may have a close relationship with their local priest and would consult the priest for advice or guidance on a difficult family or health issue.

Key issues to consider

Literacy is a significant issue for the Italian older people. Many are illiterate in their own language as well as in English. Translated material needs to be targeted at the level of literacy of the local community. Information about dementia that is provided in written form needs to be clear, simple and concise. There also should be a greater use of ethnic media such as radio and newspapers. Where information is conveyed in a group setting such as an information session, it is preferable that it is provided by a professional who speaks Italian, and to have food available at the presentation to achieve maximum attendance.

Also, when it comes to language, the person may revert to one of the numerous dialects of the Italian language that they spoke in Italy as the dementia progresses. This will create problems with effective interpreting and even communication with family members, as children and grandchildren do not necessarily speak or understand their parents' dialect.

Service providers need to have cultural understanding and relevant personal experiences, that is, to understand what it means to be a migrant. It is also important for service providers to use appropriate language as some terminology around dementia has negative connotations which further reinforce the stigma in the community when they are translated in Italian. It is also important to emphasise how a person with dementia can participate rather than highlight their limitations.

Lack of forward planning is also a common issue. Most people tend to be interested in what they can do at the moment rather than knowing what is going to happen in the future. The information on the progress of the illness and the deterioration of a person's abilities is confronting. People do not necessarily want to know all the details but rather only what is important at that given point in time.

Dementia-specific information available from Alzheimer's Australia Vic in Italian

1. Our services
2. Getting help
3. Worried about your memory
4. About dementia booklet
5. Mind your Mind user's guide and brochure
6. What is dementia?
7. Diagnosing dementia
8. Early planning
9. Communication
10. Taking a break
11. Changed behaviours
12. Memory changes
13. Alzheimer's disease
14. Vascular dementia

About you (information for people with dementia):

15. What is dementia
16. Early planning
17. Looking after yourself
18. Driving
19. Keeping involved and active
20. Talking about the diagnosis
21. Talking with your doctor

Key community contacts

CO.AS.IT
189 Faraday Street
Carlton VIC 3053

Tel: (03) 9349 9000
Fax: (03) 9349 1063
Email: coasit@coasit.com.au
www.coasit.com.au

Yanada House
– Dementia Specific Day
Centre

92 Dennis Street
Northcote, VIC 3070

Tel: (03) 9481 9570
Fax: (03) 9261 4867

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

Macedonian migration to Australia dates back to the 1890s, but the number of arrivals at the time was small and they were mainly Macedonian men working away from home due to poverty and deteriorating conditions in Macedonia. Most were from villages with very little education and they worked in the mining industry or as manual labourers. It wasn't until the 1920s and late 1940s that the numbers increased. Macedonians migrated to Australia mainly as Displaced Persons during the Greek Civil War (1944-1949).

Further migration to Australia occurred during late 1960s and early 1970s when Macedonians came either sponsored by their families or as economic migrants and were slightly better educated. Macedonians continued to migrate to Australia during the late 1980s due to the lack of political stability in former Yugoslavia. Many of these migrants were skilled professionals.

Most of the Macedonian immigrants come from the former Yugoslav Republic of Macedonia (now Republic of Macedonia) with smaller numbers coming from northern Greece (Aegean Macedonia), Bulgaria and Albania. The main language spoken by the Macedonian community in Australia is Macedonian although there are a number of specific dialects depending from which part of the country they arrived.

Macedonian language is one of the top ten languages spoken at home in Victoria and it is eighth largest in terms of people with low English proficiency. According to the Australian Institute of Health and Welfare, between 2011 and 2026, the number of Macedonian-speakers is expected to increase by 55% while the number of Macedonian-speakers who are 80 and over is expected to increase by 130%.

Perceptions of dementia

There is little understanding about dementia in the Macedonian community, however the awareness is being raised through ethnic organisations. There is a lack of knowledge of the service system and how to access services and information. Both older and younger generations of Macedonian community believe that dementia is a normal part of ageing.

There are some sections of the community who consider dementia a mental illness due to a lack of understanding of the causes and the nature of the symptoms of the illness. For more traditional members of the community, illness may be seen as punishment for mistakes of the past or even considered as a curse that has been placed upon them by someone else. In this case there may be some reliance on spiritual guidance. Stigma is still attached to the condition and families feel embarrassed to discuss it with friends and the community. Those who were previously involved in activities and social groups will stop participating if the person or their partner has been diagnosed due to stigma.

Overall, there is little knowledge about the symptoms of dementia or what causes it. Many Macedonian elderly see dementia as sclerosis. The term 'dementia' is still not heavily utilised when describing the condition. There are also some literacy issues in the community which contributes to the

lack of understanding of the illness even when information is provided in their own language.

Diagnosis and treatment

Dementia is often diagnosed late in the Macedonian community as people tend to deny the symptoms and do not actively seek information even if they have concerns. Where possible, and once the symptoms reach critical point, they will see a family doctor. There is a lack of Macedonian-speaking practitioners and some members of the community will see non-Macedonian speaking doctors even if there are no interpreters present. This raises concerns around effective communication with the patient and the level of understanding of the illness even once the person has been diagnosed.

The diagnosis is either given to the patient or to the family depending on the individual cases. Some family members may prefer to keep the details of the diagnosis away from the person with dementia in order for them not to lose their will to live and give up on any possible treatment.

The Macedonian community holds doctors and medical professionals in high regard and will use modern medicine for treatments. Some members of the community have a fatalistic view of illnesses that have no cure and this may limit possibilities of early intervention and health promotion. Some community members would discuss their concerns with their community workers also.

Role of families

There are variations in the attitudes towards elderly and roles of the family members in the Macedonian community. Elderly Macedonians who migrated to Australia still have high expectations from their children and expect children to care for them. They perceive this as their children's obligations because they came to Australia to provide a better life for them and if their sons and daughters don't take care of the parents in time of need it is viewed as betrayal. Some elderly feel a burden to their family but would still prefer to stay in their homes.

In contrast, the attitudes of second generation Macedonians whose values are mixed with Australian values may find it difficult to care for their parents due to work and their own family commitments. There is a tendency for children to feel guilt if they are unable to care for their parents and this is may be accentuated by the guilt that is placed on them by the parents.

Overwhelmingly, in cases of married couples, the main carer is the spouse. Spouses commonly care for as long as they are able. Families remain the main support networks for elderly Macedonians and there is reluctance to seek help outside the extended family.

Attitudes towards community care

As the concept of extended families dissolves, and with growing recognition that families are unable to provide adequate care for their elderly, the community is becoming more accepting of services outside the family network. The services are usually accepted once neither member of a couple can perform certain chores or if a person is living on

their own and have no family members to assist. There are still issues with access to services but home care services are more accepted, mainly because they provide the opportunity for the person to remain in their own homes. It is important to note that services such as home care, lawn mowing and transport may be accepted but there are often considerable issues with personal care because it is seen as embarrassing to have someone else help with such a personal task. In terms of the workers' backgrounds, Macedonians tend to prefer services in their own language.

Attitudes towards residential care

There is a very strong objection in the Macedonian community to being placed in residential care. Residential care is perceived extremely negatively in the community and there is a lack of acceptance of even respite care in a residential facility. There are no Macedonian-specific nursing homes in Victoria which further prevents the community to access this type of care in fear of being isolated and not being able to speak to someone in their own language.

Most carers would continue caring for their spouse with dementia for as long as they are alive. Residential care is mainly considered once one of the couple dies and the other one is unable to care for themselves. It is also still considered shameful to place your family members in a nursing home and some elderly feel that this is a way of their family getting rid of them because they are a burden.

People consider that the person has a better quality of life at home and this should be the place where they are cared for even if it is difficult to sometimes do so. There is an overwhelming perception that people who are placed in nursing homes deteriorate very quickly. "It's like you are completely paralysed".

Attitudes towards counselling

As there is a strong preference to deal with issues in private, there is some reluctance to use counselling services. Counselling as a service, or even the term itself does not tend to be recognised as most people consider psychologists and psychiatrists as specialists who provide this type of service. It may be used for depression but it is not common. If this type of service is to be used it would have to be done in a face to face contact with a person who either speaks Macedonian or with an interpreter.

Some community member would also speak to their community workers instead of professionals if they were having issues with dementia or any other problems. Most people are not aware of the telephone helpline and would not feel comfortable in using it without knowing the person on the other side of the line.

Religion and its role in dementia care

Religion still plays a significant role in the Macedonian community but it is usually kept separate for other aspects of life and therefore may not play a major role for the dementia patient. Macedonians are predominantly Orthodox with small numbers being Muslim or belong to Roman Catholic, Presbyterian and Baptist churches.

As with many other communities, importance of religion varies in Macedonian community. Some people go to Church to pray and observe customs and traditions and would not seek assistance through priests, while for others religion is an active part of many aspects of their life.

Key issues to consider

Language is a major barrier when accessing services. Due to low literacy levels in English and in Macedonian, dementia information should be simple if written. Audio visual information is useful as it is easier to understand. Promotion of dementia through Macedonian radio programs is another useful option to written information.

Face to face interaction is also preferred and information sessions are useful. The information needs to be presented in a simple manner and include audio visual materials, complemented by written materials.

Knowledge of the service system and dementia services is limited. This is mainly due to language barriers and the tendency of the Macedonian community to rely on informal support networks.

Dementia-specific information available from Alzheimer's Australia Vic in Macedonian

1. Our services
2. Getting help
3. Worried about your memory
4. Mind your Mind user's guide
5. What is dementia?
6. Diagnosing dementia
7. Early planning
8. Communication
9. Taking a break
10. Changed behaviours
11. Memory changes

Key community contacts

Macedonian Community Welfare Association
Shop 19, 1 Princess Street
St Albans VIC 3021

Tel: 9310 7566
Fax: 9310 7588
www.mcwa.org.au

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

The Polish community in Australia has come through several different waves of migration. Polish migration dates back two hundred years but the major wave of Polish migrants came under the Displaced Persons Program following the World War II, while the next wave came under the Special Humanitarian Program. Victoria has the largest Polish population in Australia and almost half aged over 65 years. Experiences of the Polish community prior to arrival in Australia such as loss of family and friends, incarceration and labour camps have significant implications for dementia care.

The main language spoken by the Polish community in Australia is Polish although there may be those who speak German, Ukrainian or Russian.

Polish community is ageing and this is mainly because the majority of Polish migrants arrived in Australia by the late 1960s. There has been a decrease in number of Polish-speakers in Victoria between 2001 and 2006 Census. There are currently 17,787 people who speak Polish at home and 18,071 Polish-born people in Victoria. While the number of Polish elderly will continue to decrease there will still be increases in the 80+ age group.

Perceptions of dementia

Dementia is either seen as a normal part of ageing, usually memory loss, while more pronounced symptoms of dementia may be attributed to mental illness. Dementia is highly stigmatised in the Polish community and denial is a common issue. This is often due to a fear of how will people around them react, and a lack of understanding from friends and family.

Social isolation is often an issue for many Polish elderly. There is a decreased participation in social activities and decreased visits by the family members. Members of the Polish community are stoic and proud, and admitting that they have a problem may be seen as loss of independence.

There also seems to be a lack of knowledge about dementia in the younger members of the Polish community. Often the grandparents will take care of their grandchildren while they are attending school and there is a prevailing belief that their grandchildren may not have sufficient information to understand the illness.

An important thing to keep in mind when it comes to dementia and the Polish community is that there is a prevalence of Post Traumatic Stress Disorder which may mask or exaggerate the symptoms. This also plays a role in later stages of dementia as many people may suffer from depression, have nightmares and flashbacks as they start to revert to their past experiences.

Some members of the community are familiar with the word 'dementia' but overall the community still tends to refer to the condition as 'sclerosis'.

Diagnosis and treatment

Diagnosis is often late in members of the Polish community due to the person denying that they have any symptoms.

There is a fear that if they admit that they are having some trouble they will lose their independence or that the family will use the diagnosis to place them in a nursing home or take control of their finances. Apart from being unfamiliar with the condition and its symptoms, the person may feel ashamed to admit to having a problem and decline to seek a diagnosis.

When they do seek assistance, the family doctor is the first point of contact for diagnosis, information and advice. The community members tend to see Polish-speaking practitioners or discuss their concerns with their community worker if they have one. Ethnic organisations and ethnic workers are also often the first point of contact for information and referral.

Most members are not familiar with the process for diagnosis. Families are often involved in seeking information and support and would accompany the person for diagnosis. In terms of treatment, modern medical practices are accepted, with some people using herbs and natural medicines or home remedies in conjunction with doctor prescribed treatment.

Role of the family

Because dementia is highly stigmatised in the Polish community there is a reluctance to seek support and assistance outside of the family network. Family still remains the strongest and most important source of support. There is an expectation that the family will care for the person with dementia and that the person will stay at home, often regardless of their health status. There is a strong attachment to the home and a reluctance to go into a nursing home.

The main carers are usually females and most often spouses. Culturally it is the duty of the spouse to care for the husband or wife and they often feel shame to accept services. This often results in increased stress and ill health in carers. As there is a tendency for families to be isolated from the community, carers themselves have little social interaction with other members of the community. It is important to extend dementia services to support the person with dementia and their carers at home.

Attitudes towards community care

Family still remains the main support network for the elderly members of the community but this is increasingly supplemented by external services. Polish elderly are still reluctant to use mainstream services due to lack of knowledge of the service system and unfamiliarity with service providers. Many access services through ethno-specific organizations and then may be referred on with the involvement of the ethno-specific workers.

Once services are introduced they are generally well accepted but they need to be provided by bilingual workers. The gender of care workers may be an issue on occasions, with female workers sometimes considered inappropriate for a male client. Careful selection and matching of carers and workers is essential.

Attitudes towards residential care

The expectation that the family will care for person with dementia still prevails in the Polish community, and it is seen

as shameful to place your parents or family members into residential care. There is a perception that decline is very rapid once the person is placed in residential care facility. Some members of the community feel quite adamant about staying in their own homes. The overall perception is that people will die quickly in residential care due to loneliness, depression, isolation and lack of communication.

Attitudes towards counseling

For those who use or would use counselling, it is mostly for issues around depression and Post Traumatic Stress Disorder. Most people feel more comfortable talking to family members or ethnic community workers than to professional counsellors. If counselling is used, it would need to be face to face with a Polish-speaker. Telephone counselling services are difficult to access due to complicated process of accessing interpreters in order to access the service. This type of service is also seen as too impersonal.

Religion and its role in dementia care

Approximately 68% of Polish community in Australia are Roman Catholics and 15% practice Judaism. There are also some minorities such as Jehovah's Witnesses, Seventh Day Adventists and some who are Orthodox. Religion plays an important role in the community but it does not play a major role in dementia care.

Key issues to consider

The Polish community is reluctant to seek assistance outside family for reasons ranging from language barriers to lack of knowledge or familiarity with existing services. There is also a lot of stigma related to dementia, and especially to mental illness. Due to past experiences, Polish elderly have a strong fear of authority and also fear of invasion of privacy which may prevent them from accepting services. It is therefore important to know understand each person's past experiences and try to maintain their independence as far as possible.

It is important to use workers who speak Polish and develop close working relationships with ethno-specific organisations. Information about dementia can be provided in a variety of ways including use of the Polish SBS radio program, written and audio visual information and information sessions.

Another important issue to keep in mind relates to potential problems with the Power of Attorney. There may be limited forward planning for some people in the community, and attempting to get a person to sign a document may be seen as invasion of privacy or as an imposition on their independence. This is also an issue that extends across many people irrespective of the cultural or linguistic background. More education needs to be provided around Powers of Attorney and the implication for people with dementia.

Dementia-specific information available from Alzheimer's Australia Vic in Polish

1. Our services
2. Getting help
3. Worried about your memory
4. Mind your Mind user's guide
5. What is dementia?
6. Diagnosing dementia
7. Early planning
8. Communication
9. Taking a break
10. Changed behaviours
11. Memory changes

Key community contacts

**Australian Polish
Community Services**
77 Droop Street,
Footscray VIC 3011

Tel: 8371 2312,
Fax: 9687 7446,
www.apcs.org.au

**Polish Community
Council of Victoria**
Level 2, 43-51 Queen St,
Melbourne VIC 3000

Tel: (03) 9629 8277
Fax: (03) 9629 8377
www.pccv.org.au

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

Russian migration to Australia extends from the early 1900s through to today and the type of migration depends on the time of arrival. The majority of Russian migrants arrived in Australia between 1940s and 1980s and included displaced persons after World War II, Russian immigrants from China and immigration of Russian Jews from the Soviet Union. Most recent arrivals followed the collapse of the USSR. The majority of Russian migrants have come from the USSR Union followed by arrivals from China and former Yugoslavia, with smaller numbers from central and Eastern Europe.

The main language is Russian although, depending on the country of origin, Russians may speak Ukrainian, Belarusian, Yiddish, Hebrew, German and other languages.

Perception of dementia

The perception and understanding of dementia in the Russian community depends on where the community came from and when they arrived to Australia. Most immigrants who arrived in Australia in the early 1940s and 1950s tend to have mastered English. For those who arrived post 1980s, however, English still presents a major barrier, particularly for the elderly. The established migrants are familiar with dementia and its symptoms and, because they are now ageing, many have friends and family members with dementia. There is, however, still some confusion about what causes dementia and some still attribute it to stress and other health conditions such as high blood pressure.

There is a lack of understanding of the illness in the newly arrived sections of the Russian community and dementia may be understood as a form of mental illness. There is also a perception that it is caused by stress, trauma and lifestyle choices. The elderly members perceive dementia as senility and only recognise it in terms of memory loss. There are also some remnants of a term that was used in the past that describes the illness as an 'elderly imbecility' but it is used less often these days.

When considering dementia perceptions in the Russian community, there is a need to see it context with the experiences prior to arrival in Australia. Many migrants suffered torture and trauma during Second World War, while others have lived most of their life under an oppressive communist regime developing a strong distrust of institutions and authority. This is likely to have a major impact on the type of care that is likely to be utilised for a person with dementia.

Diagnosis and treatment

For most members of the Russian community the family doctor is the first person they would speak to if they had concerns regarding their memory. Most people would discuss their concerns with close friends and members of the family. There is some indication from the community that family members may regard it as a normal part of ageing and would not take the issue seriously. The community members overall are unaware of the benefits of early diagnosis and would tend to delay seeking diagnosis. The early symptoms are also not seen as serious enough to warrant diagnosis.

In instances where dementia is diagnosed it is generally expected to be told to the patient and their family. Russian community mostly adheres to modern medicine for treatment of dementia. There is also a strong interest in preventative measures.

Role of the family

The elderly are respected in the Russian community and the family tends to play a central role in the care for the elderly. The primary carer is usually the spouse. There is a strong expectation that the family will care for the elderly, but this seems to be declining. Even though family members still play a major role in supporting the elderly person, many members of the Russian community are becoming isolated and reliant on help from external service providers. Family care and being cared for at home is still preferred by many Russian elderly.

Attitudes to community care

Acceptance of the services depends on where the person comes from and their command of the English language. Migrants from larger cities who have higher education and sound English are generally accepting of mainstream services. On the other hand, the elderly Russians who came from small villages or have been sponsored recently by their families and have little English remain resistant to external help, tending to family care at home. Major reasons for a lack of acceptance of services include an incomplete understanding of the service systems and strong fear and distrust due to experiences in their country of origin, as well as lack of English language. Community care services may be accepted as the last resort and may require detailed explanation and convincing. But overall, independence is highly valued and services are sought fairly late.

Attitudes to residential care

There is a strong preference to stay at home for as long as possible. Residential care is viewed negatively and there is a dominant opinion that the person will deteriorate quicker once they move into residential care and that they will lose their independence and become isolated from their communities. Many Russian elderly are fearful of being placed in residential care even if among other Russian-speaking residents. There is a strong fear of the loss of independence and freedom and having nothing to do if they are placed in a nursing home.

There are perceptions that these attitudes are changing the longer the community is in Australia and that it would be acceptable to place someone in a nursing home if they have progressed to the final stages of the illness. However, most people agree they would try and avoid residential care for as long as possible.

Attitudes to counselling

Most of the community are unaware of counselling as a service for dementia and have reservations about using it. It is seen as interference in one's private life and a form of inquisition. Due to past experiences there is a strong fear of providing personal information. If counselling is offered, there needs to be a familiarity with the service providers and trust needs to be developed. It would need to be face to face and in the person's preferred language. Telephone helpline is also not a familiar service and there are some reservations about

using the service, mainly for those who do not speak English.

Religion and its role in dementia care

Religion is a personal choice for most people. Some consider it more of a tradition than an actual belief. Others have retained a deep connection with their faith. Religion has an important role for the Russian elderly and is respected by all members of the community. There is no specific role, except pastoral care, that religion plays in dementia care for the Russian community.

Key issues to consider

Language still remains a major barrier to access for many Russian migrants. There is a strong emphasis on providing information about dementia in a language that is easily understood and also in verbal form on television and radio. Written information needs to be clear and simple.

Past experiences play an important role in how dementia is perceived as well as the services are utilised. Culture and tradition needs to be taken into consideration when working with Russian migrants.

Some issues were raised regarding more emphasis to be placed on carers and importance of having a break or respite and also on more information about the Powers of Attorney and Guardianship as there is a lack of knowledge on these issues.

Dementia-specific information available from Alzheimer's Australia Vic in Russian

1. Our services
2. Getting help
3. Mind your Mind user's guide
4. What is dementia?
5. Diagnosing dementia
6. Early planning
7. Communication
8. Taking a break
9. Changed behaviours

Key community contacts

Russian Ethnic Representative Council of Victoria

118 Greeves Street
(PO Box 2811)
Fitzroy, VIC 3065

Tel: (03)9415 7955
Fax: (03) 9415 9866
www.nerc.org.au

St John of Kronstadt Russian Welfare Society

13 Conway Street
Dandenong VIC 3175

Tel: (03) 9793 5955
Fax: (03) 9791 3933,
Email: kronstadtgardens@russianwelfare.org.au
<http://russianwelfare.org.au>

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

The Serbian community migrated to Australia from a number of countries of the former Yugoslavia but predominantly Serbia, Bosnia and Croatia. The first Serbian migration occurred post World War II when a number of migrants came under the Displaced Persons Scheme. The second wave occurred during the 1960s and 1970s and predominantly included economic migrants. The final wave of migration occurred in the 1990s following the conflict in the Former Yugoslavia. An important issue to note with Serbian migration, particularly the recent arrivals, relates to issues of torture and trauma especially for those arriving from Bosnia and Herzegovina.

The main language spoken by Serbian migrants is Serbian although this varies according to the country from which they migrated, and some may speak Bosnian, Croatian or a combination of Serbo-Croatian. In view of the recent conflict between the countries of the former Yugoslavia, particular care needs to be taken when working with interpreters to ensure that the interpreter not only speaks the relevant language but is also of Serbian background.

Perceptions of dementia

There is very little understanding of dementia in the Serbian community. Although some members of the community are familiar with the terminology, most members of the community have little or no understanding of the symptoms or the causes of dementia. In the Serbian community, dementia is seen as a form of mental illness and mental illness is something that carries a lot of stigma. Those people who are aware of dementia are those who have a family member who has been formally diagnosed.

An important issue to consider in regards to the Serbian community and dementia is the high prevalence of Post Traumatic Stress Disorder, depression and schizophrenia which makes it difficult for many members of the community to differentiate between different symptoms. Most people who exhibit these types of symptoms would be labelled as 'crazy'. Many community members commented that even if someone tries to explain that dementia is a medical condition, the community would say that that is just an excuse and that the person is crazy.

For older members of the community with low levels of education, dementia may even be attributed to past mistakes of the family. Dementia is not openly discussed in the community and is often limited only to closest family members. For those people who are diagnosed, community contact is minimised resulting in increased social isolation.

There are some issues with the words associated with dementia in Serbian language. The term 'dementia' exists in Serbian but it is most commonly used as medical terminology. Dementia is often seen as 'senility' or 'sclerosis' but quite often a word 'izhlapeo' is used, which in literal sense means that someone's mind has evaporated. This word is sometimes given as the medical translation for the English word 'dementia', despite the fact that it is misleading and may be offensive.

Diagnosis and treatment

Because dementia is stigmatised as mental illness, members of the Serbian community are diagnosed late and usually at a crisis point. Even once a diagnosis is established, it is not likely to be accepted or understood. Diagnosis is also likely to be hidden from the community and family members.

Most members of the Serbian community would follow the advice of doctors in cases where dementia is diagnosed and would use the prescribed medications. Many members of the Serbian community have suffered torture and trauma and this significantly complicates the process for diagnosis.

Role of the family

The primary carer of an elderly person is usually the spouse. The wife is usually the main carer and tends to provide care for the duration of partner's illness. Traditionally Serbian elderly have been supported by their children and family, however this seems to be declining in Australia. There is still an expectation that the children will care for their parents and many people would be insulted at the idea of a family member being placed in a residential care facility.

However, many Serbian elderly do care for themselves or they are reliant on external services to stay at home. This factor, coupled with poor English and lack of knowledge of services, means that they may be seriously disadvantaged.

Attitudes towards community care

Due to language barriers, social isolation and lack of information, Serbian elderly may not be aware of the available services. When the community members are aware of this type of assistance, and especially when it allows them to stay at home for longer, home care services are generally well received. However, community care is often only offered through mainstream service providers and may not be culturally and linguistically appropriate.

Attitudes towards residential care

Residential care is not seen as an acceptable care option for the Serbian community. There is a prevailing belief that people who are placed in nursing homes will not live long and most agree that caring for person with dementia at home will provide a better quality of life. The main reason people negatively perceive nursing homes is because of the belief that they are usually lonely and isolated and have no one to speak to in their own language. Some people may be more accepting of the idea of being placed in a Serbian-specific residential care facility, but only if the person has no one else to care for them.

Attitudes towards counselling

The most acceptable form of therapy or care is medication. Utilising any other form of therapy still has stigma attached to it. Counselling is considered something that is a domain of psychologists and psychiatrists and therefore has a strong association with mental health issues. Where counselling is used it generally applies to depression and trauma rather than dementia. The most effective method would be in a face to face session with a Serbian-speaking specialist. Most people would not consider telephone counselling. Being resistant to any form of counselling is even more evident in older generations of Serbian migrants.

Religion and its role in dementia care

Most of the Serbian community is Orthodox and many aspects of their life are closely tied to their religion. Religion does not play a role in treatment of the person with dementia but plays a central role in all aspects of life. The involvement from the Serbian Orthodox Church in the provision of support or information to the person with dementia or their family varies from person to person.

Key issues to consider

Most of the Serbian elderly have very low literacy levels in English which prevents them from seeking information and accessing services. Many are also illiterate in their own language, so information in their own language in writing may also be ineffective. Modern translations may also differ from the older types of language spoken by migrants. It is therefore important to have information in a simple format and translated in a language relevant to the community in Australia. The best way of disseminating information is often through radio, information sessions and ethnic organisations.

As there are no similar services in countries from which Serbian Australians originate, the knowledge of services in Australia is also very limited.

Dementia-specific information available from Alzheimer's Australia Vic in Serbian

1. Our services
2. Getting help
3. Mind your Mind user's guide
4. What is dementia?
5. Diagnosing dementia
6. Early planning
7. Communication
8. Taking a break
9. Changed behaviours

Key community contacts

Serbian Social Services and Support

Shop 5, 346 Main Rd West
St Albans VIC 3021

Tel: 9356 4555

Fax: 9356 4500

Email:

serbian_sss@iprimus.com.au

www.serbianssss.com.au

Serbian Welfare Association of Victoria

186 Foster St East
Dandenong VIC 3175

Tel: 9701 7308

Fax: 9706 9912

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimer.org.au

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Introduction

Spanish-speaking community in Australia come from 21 different countries and their customs/culture and traditions vary accordingly. The countries of origin include: Argentina, Bolivia, Chile, Colombia, Costa Rica, Cuba, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, Spain, Uruguay, Venezuela, Dominican Republic, Equatorial Guinea and Puerto Rico.

Spanish immigration to Australia was most significant during the 1960s and most immigrants who arrived from Spain were economic migrants, compared to those who arrived during the 1970s who came mainly from South American countries such as Chile, Argentina and Uruguay. These migrants arrived as political refugees fleeing from brutal military regimes. Since the 1980s, Spanish-speaking migrants have been coming to Australia in smaller numbers from Central America, mainly El Salvador, as refugees and humanitarian entrants.

The main language is Castilian or Castellano, which is the standard form of Spanish as it is spoken in Spain and Latin America but there are a number of dialects. Also, depending on where the person comes from they may speak other languages. For example, in Paraguay people also commonly speak Guarani while in Peru and Bolivia they also speak Quechua and Mapuche in southern Chile and south-western Argentina.

Perceptions of dementia

Dementia is not understood well in the Spanish-speaking community and perceptions of dementia vary. There is a lot of misunderstanding about the conditions. Across the community, dementia is either not recognised as a cognitive condition or considered as a normal part of ageing. In general, people usually identify the condition in terms of memory loss and forgetfulness and most are unaware of other symptoms. Many do not understand the long term effects of dementia on the person with the condition, effects on the family, and how the family or carer can respond to these changes and access support. Knowledge and understanding of the dementia depends on the educational levels of community members and whether they have been in contact with someone who has been diagnosed with it.

For people who are well-connected with the community and participate in social groups such as Planned Activity Groups, the knowledge about dementia is higher and acceptance of people with dementia is common. On the other hand, there are some members of the community who will try to mask the symptoms and deny they have an illness because they believe that dementia is a mental illness and there is an associated stigma. Many people also do not know how to react to people with dementia or how to deal with their behaviour. This in turn results in social isolation for the person with dementia and their family.

Knowledge of the causes of dementia is poor. Most people either do not know why dementia happens or they believe that it is caused by factors such as stress, depression or excessive thinking and worrying. It is felt by some that stress may cause forgetfulness, and that severe forgetfulness is 'dementia'.

The most commonly used translation is 'dementia' but other terminology refers to forgetfulness and memory loss. In everyday conversations people may refer to people with dementia as being 'loco' or crazy. There is also confusion around the connection between dementia and Alzheimer's disease.

Diagnosis and treatment

As there is little understanding of dementia, there is also some confusion about the need for and timing of diagnosis. Some people will not seek a diagnosis. They may see dementia simply as memory loss and think that they just need to try harder to remember things. Others will only seek diagnosis when symptoms are severe, such as with serious memory loss.

If they were to seek a diagnosis, the first point of contact would be their general practitioner and they would then follow the doctor's instruction. Most community members prefer to see Spanish-speaking practitioners as English proficiency is an issue for a many Spanish-speaking elderly. Many members also depend on family for information and support as well as on their ethno-specific organisation.

There are mixed responses about how diagnosis is accepted but the majority would accept the diagnosis. However, it is difficult to determine how well the diagnosis is understood because of the lack of knowledge about dementia. A minority of people would not accept a dementia diagnosis because they believe people will perceive them as being crazy, which further illustrates the lack of understanding in the community.

Most of the community abides by the instructions given by the doctor and would use the medication that was prescribed to them. There is a tendency in the community to try natural herbs at first or in combination with traditional forms of therapy.

It is important to note that there are members of the community who are aware of the illness and understand the need for diagnosis. This indicates that knowledge about the condition is slowly increasing, and there is a growing acceptance of people with dementia.

Role of the Family

The Spanish-speaking community is family-centred and there is generally a strong involvement in the care of person with dementia. But as with other communities there is a growing awareness of the changes in family structures in Australia compared to their country of origin. There is still a strong expectation that the family will care for the person but there is a growing recognition that families have increasing obligations and may not be in a position to care for their family members.

Partners or spouses are primary carers and they are commonly females. One lady commented that family care is important and it is not acceptable to relinquish the care and stated that "we do everything until we can't do it anymore" regardless on the impacts on the carer. It is difficult for the Spanish-speaking elderly to accept any alternative to family care as this is the arrangement that they experienced in their home country.

Attitudes to community care

Community care is generally well accepted, especially if workers are from a Spanish-speaking background but Spanish-speaking elderly are usually not aware of such services. Limited English also prevents them from accessing services and limits their ability to navigate the service system. The elderly also lack confidence in dealing with professional service providers and are disadvantaged if they are unable to communicate with the service provider. There are a small number of bilingual workers in many services. Community care may be accepted as a last resort, but only if a spouse is no longer able to perform the required tasks or both a husband and wife are ill.

Some Spanish-speaking elderly rely heavily on their families, requiring the family to take care of them and not accepting any other types of assistance. On the other hand, family members may also consider that taking care of their family is their duty and may not wish to consider other services such as Community Aged Care Packages.

Attitudes towards residential care

Individuals from the Spanish-speaking communities are reluctant to be placed in residential care and would strongly object to being placed in a nursing home. There is still an expectation that the family will care for the person with dementia and if someone places their family member into residential care they are not fulfilling their role. For example, in the case of adult children, they may be perceived by the community as 'ungrateful' for not caring for their parents until the end. For spouses, they may feel that they have 'failed' to care for their loved one. Community views may be stronger when an adult child places their family member in residential care than when an elderly spouse is unable to continue caring and therefore, have to place their partner in care. These views may be particularly negative towards daughters as they are the nurturers.

Being placed in a nursing home is considered to be the 'end of the line' for the elderly person. Nursing homes are seen as institutions where people are isolated and have no one to communicate with in their own language. Overall, views about residential care facilities are very negative. They may be perceived as the place where people go to wait to die, as they are no longer wanted. They are not perceived as a place where more appropriate care is provided. People feel that even if the person is not that ill they will become worse when they are placed there and that nursing homes are 'not nice places to be in'. The community is also resistant to residential care as a form of respite. These attitudes may also be due to the lack of knowledge about residential care. Community members may find it difficult to differentiate between different levels of care. Hostels, low-care and high-care facilities may be classified as the same and perceived as mental institutions.

At the same time, there is also an understanding that being placed in a nursing home may become an option as a last resort when the person has no one to care for them. It is also understood that this depends on individual circumstances.

Attitudes to counselling

The community is not well aware of counselling as a service to support families living with dementia and would use it only in a face to face interaction. There is a preference for Spanish-speaking counsellors as most members agree that it is hard disclosing personal information to a stranger, let alone having to do it via an interpreter. They believe that counselling in this manner would not be effective. However, some community members may be willing to use interpreters if no other alternative is offered. Counselling may only be acceptable if the interaction is over a long period of time that allows time for trust and respect to be built between the service provider and the client. Older members of the community may not see counselling as a formal service but rather as a form of social support and information provision.

Most of the community members are not aware of the telephone counselling services and are not likely to use them. They feel that this type of service is too difficult and too impersonal. Multilingual lines may be utilised where the client has direct access to a Spanish-speaking worker rather than trying to access interpreting service first.

Religion and its role in dementia care

The majority of Spanish-speaking communities in Australia are Roman Catholic. Most members follow traditions and religious celebrations. Religion is important but plays no direct role in dementia care. However, even though it is a separate aspect of everyday life, faith through prayer helps people get through the difficulties of their situation. Prayer is used to ease the suffering of the person and to help carers deal with stress and gain strength to persevere.

Key issues to consider

Language is a major barrier to access for Spanish-speaking elderly. Many appear to have low literacy levels in English and Spanish. It is important to know the country that the person comes from and the dialect they speak. It is also crucial to provide information about dementia in a simple format if it is written, with key messages and perhaps pictures and illustrations. Verbal information provided through information sessions and ethnic radio programs is of great assistance. On the other hand, younger carers of people with dementia will most likely be better educated and be more open to access support, even from mainstream services.

Spanish-speaking community is generally family-centred and, in their country of origin, the family usually cares for the person with dementia. This makes it difficult for Spanish-speaking elderly to adjust to arrangements in Australia. Most of the community does not do well with forward planning and may not be aware of the need for Powers of Attorney to be arranged. In fact, there is a lack of knowledge that this exists and its purpose.

Spanish-speaking communities prefer a friendly and warm approach and may be reluctant to use services if the person providing the service appears cold or unapproachable. Social interaction and support is important to the Spanish elderly and most express a need to have people with dementia included in social groups or to have access to people educated about dementia so that they do not become socially isolated.

Dementia-specific information available from Alzheimer's Australia Vic in Spanish

1. Our services
 2. Getting help
 3. Worried about your memory
 4. Mind your Mind user's guide and brochure
 5. What is dementia?
 6. Diagnosing dementia
 7. Early planning
 8. Communication
 9. Taking a break
 10. Changed behaviours
 11. Memory changes
 12. Working with doctors
 13. Problem solving
- About You
(for people with dementia):
14. Looking after yourself

Key community contacts

C.E.L.A.S (Spanish Latin American Welfare Centre)
209 Nicholson Street,
Footscray 3011

Tel: 9687 0181
Fax: 9687 3613
www.celas.org.au

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

www.alzheimers.org.au

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Introduction

There were relatively small numbers of Turkish arrivals in Australia prior to the 1960s, with large-scale migration occurring around 1960 under the Assisted Migration Scheme. Until 1967, the majority of migrants living in Australia were Turkish Cypriots. The number of Turkish arrivals reduced during the 1970s and 1980s and currently there are few new Turkish arrivals.

Early migrants were generally unskilled and worked as labourers and process workers, whereas more recent arrivals are educated and skilled professionals plus and sponsored migrants. The majority of the Turkish migrants in Australia live in Victoria and New South Wales. The Turkish community is still fairly young but the earlier arrivals are now ageing. The Turkish-speaking community has a significant number of people who have low English language proficiency.

The main language spoken by Turkish elderly is Turkish, while Cypriot-born Turkish-speakers use a different sentence structure and an older version of the language.

Perceptions of dementia

Members of the Turkish community are aware of the term 'dementia' through friends who have been diagnosed and community organisations but have little understanding of the condition itself. They are mostly familiar with memory loss as a symptom of dementia but many do not understand the difference between normal memory loss and dementia. There is also further confusion about the link between dementia and Alzheimer's disease, and some members of the community believe that dementia is the term used for early stages of the illness and Alzheimer's disease is the term used for later, more advanced stage. There is also little understanding of the causes of dementia, although some people are aware that it is somehow connected to the brain.

The perception of dementia varies within the community. Some parts of the community see dementia as a normal part of ageing while others recognise that it is an illness and that it does not happen to all old people. There are also various cultural attitudes towards dementia. Most people would prefer to keep their concerns and ailments to themselves as they feel embarrassed.

The most commonly used word for dementia in Turkish language is 'bunama' but there are some disagreements around its use. It literally means dotage or second childhood, but for most people it describes something associated with old age or forgetfulness. Dementia may also be understood as senility.

Diagnosis and treatment

Most members of the Turkish community do not appear to see the need for an early diagnosis of dementia and only go to the doctor once the symptoms became more severe. Many are diagnosed while in hospital for some other problem. Diagnosis is usually given to the person directly, although because it tends to be diagnosed late the person may not be able to understand, so the family needs to be told as well. When attending non-English speaking doctors or specialists, most people would take family members with them. A suggestion

by a family member or a friend that a person has dementia will not be accepted and it is preferred that diagnosis is conveyed by a professional.

In terms of treatment of dementia, most would follow their doctor's advice and would have no problem in taking the necessary medication.

Role of the family

The Turkish community emphasises the role of the family and there is a strong expectation that children will care for the parents. Traditionally in Turkish culture the parents help their children until they are married and this includes, but is not limited to paying for university, engagement, wedding and helping with the house purchase. Hence there is a strong expectation that in return, the children will care for their parents in the time of need. Traditionally, placing one's parents in a nursing home may be perceived as a disgrace to the family.

In older more traditional Turkish households, the daughter takes on the caring role if she is not married. Otherwise it is the son. With the younger generation there is no clear preference in terms of care, however it is expected that when it comes to personal care and issues such as incontinence that the female child is preferred to provide care, especially if it is the mother who has dementia. This also applies to external services. Personal care needs to be provided by a person of the same gender.

Attitudes towards community care

Although family-centred and resistant to external assistance, the Turkish community is becoming more open to home care services. There is a preference for the workers to speak Turkish but this is not a prerequisite. People are likely to accept help when they need it even if it is provided by a non-Turkish speaking person. There may be some gender issues relating to care workers for more conservative members of the Turkish community as it may be seen as inappropriate for a female worker to care for a male patient or vice versa.

Attitudes towards residential care

Only a small proportion of the Turkish community sees residential care as an acceptable option, and only when the person is in the final stages of the illness. It is still very much preferred that the person is cared for by the family members. Placing family members in nursing homes is still considered taboo and may be perceived as a disgrace to the family. These attitudes prevail for both the elderly and the younger generation.

Attitudes towards counselling

Counselling is still considered as inappropriate and there are fears around privacy when talking to someone about intimate issues. Most people if they are to use counselling prefer face to face contact with a Turkish-speaking worker and would not feel comfortable using an interpreter. Some people are concerned with privacy issues when they are required to speak to someone they do not know and also through an interpreter. Telephone services would not be utilised as it is too difficult to get access to an interpreter and many people do not feel comfortable speaking over the phone.

The Turkish community recognises counselling as a service most commonly provided by psychologists and psychiatrists.

Religion and its role in dementia care

Most of the Turkish migrants are Muslim—mainly Sunni and Alevi. Strictness of adherence to Islam and its teachings varies in the Turkish community. Turkish Cypriots tend to be less conservative than those from Turkey. For some traditional elderly members of the community, dementia may be seen as something sent from God and they may believe that praying will bring remedy for them. Most members of the Turkish community observe religious celebrations of Ramadan and Kurban Bayram.

Key issues to consider

English literacy is low in the Turkish community, particularly with the older members. This is a major barrier to accessing mainstream services. The elderly also have low literacy in their own language and do not tend to read written material given to them by mainstream organisations. Information in an audio format is useful. Promotion through ethnic media and brochures in Turkish at medical centres is also suggested as useful way of promoting information about dementia and related services.

There is a heavy reliance on families for support and information and it is important to consult with the family around different care options and services available. Many members will also access information through their social or seniors clubs as well as through their community workers.

Dementia-specific information available from Alzheimer's Australia Vic in Turkish

1. Our services
2. Getting help
3. Mind your Mind user's guide

Key community contacts

Migrant Resource Centre (MRC) North West (Turkish Social Support Program and Community Partners Program)

45 Main Road West
St Albans, VIC 3021

Tel: (03) 9367 6044

Fax: (03) 9367 4344

Email:

mrcnw@mrcnorthwest.org.au

www.mrcnorthwest.org.au

Australian Turkish Association

33 Balcombe Road
Mentone VIC 3194

Tel: (03) 9583 4744

Fax: (03) 9583 7133

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

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Introduction

Most Vietnamese people arrived in Australia between 1975 and 1985 after the end of Vietnam War. Many arrived as refugees and commonly in fishing boats. Since 1982, a majority of arrivals have been sponsored by family members. Today, the Vietnamese community is one of the largest CALD communities in Australia.

For Vietnamese elderly, English literacy is very low and prevents them from accessing relevant aged care and social support services. According to the 2006 Australian Census, the Vietnamese community is the third largest group who speak a language other than English at home. At the same time they are the largest group with low English language proficiency. The majority of Vietnamese elderly speak Vietnamese although there are some who also speak Cantonese and Mandarin.

The older Vietnamese population is expected to increase rapidly between 2011 and 2026.

Perceptions of dementia

Younger members of the Vietnamese community are familiar with the terms 'dementia' and Alzheimer's disease but do not know a lot about the illness. Most commonly mentioned dementia symptoms are memory loss and not recognising one's children. There is an understanding that not everyone will have dementia, but most understand that the majority of people over the age of 80 years will have dementia.

Dementia is not recognised by the Vietnamese elderly as an illness and it is most commonly considered a normal part of ageing. Most Vietnamese elderly believe that this is something that happens to all old people and it is an unavoidable part of growing old.

There is very little understanding of the causes of dementia and people believe that the risk of getting dementia depends on their lifestyle and that people who are more active they will not get dementia. While it is considered that dementia is caused by old age, some people also believe that it may be brought on by excessive thinking and worrying.

Another common concern is that dementia is perceived negatively and there may be a strong reaction if a person is told they have dementia. Person may become angry or defensive. Person with dementia may be described as someone who is 'lost in their mind'. Dementia perceptions are also linked closely with religion and spirituality.

Diagnosis and treatment

Members of the Vietnamese community are likely to be diagnosed late due to dementia not being recognised as an illness but a normal part of ageing. Because there is great respect for the elderly, telling them they have dementia may be seen as disrespectful. The elderly person is likely to deny it especially because there are no obvious physical symptoms. It may then be more difficult to convince them to seek a diagnosis. Even though Vietnamese elderly do visit their family doctors regularly they would not necessarily see the doctor to seek a dementia diagnosis.

In cases where diagnosis is sought, the family is consulted first and then they speak to the family doctor. In Australia, the diagnosis may be told to both the patient and the family, but families may prefer to keep the diagnosis from the person in order for them not to lose hope and further aggravate the condition.

Vietnamese community would generally rely on modern medicine for treatment of dementia but this may be accompanied by prayer and some may use Chinese medicine such as herbs and acupuncture.

Role of the family

The Vietnamese community is family-oriented and there is a strong expectation that children will take care of their parents. The elderly are highly respected and it is part of the children's duty to look after their parents. Hence sending parents to a nursing home is seen as last resort and may be seen as bringing shame to family. Traditionally the caring role falls onto the son, as Vietnamese family structures are paternal. However in Australia, as customs and traditions are diluted, the caring role is often undertaken by daughters as well as sons. Most commonly the role of the carer is taken on by the spouse of the person with dementia.

Attitudes towards community care

Most community care services are accepted if provided by Vietnamese-speaking workers. Community care is usually supplemented by family support. The main source of support and assistance remains within the family but because the family cannot often provide the necessary support it is acceptable to have some external help. There is also a lack of familiarity with the service system as similar services do not exist in Vietnam. Lack of understanding about their rights and the social system also contributes to their hesitation to get help. However, language remains the biggest barrier in access to services.

Attitudes towards residential care

While assistance from professionals and carers is welcomed if provided in a culturally and linguistically appropriate manner, residential care is still viewed negatively and only considered as a last resort. This is particularly true for the elderly, as traditionally the family is expected to care for the elderly and the person would be quite resistant to nursing home placement. Some have noted that since arriving in Australia this expectation is changing because there are problems associated with three generations living under one roof, and the burden of children caring for their families as well as for their parents can often become too overwhelming. In this case, the children would explore assistance options through community and residential care. This type of arrangement would also be more acceptable in the later stages of dementia.

Attitudes towards counseling

Vietnamese elderly are not familiar with the term "counselling" or the service. When they have difficulties, they tend to talk to close friends or relatives, religious leader and ask for their advice. Otherwise they cope by themselves. The younger generation, with more education and information, may be less reluctant to seek counselling and open to this type of

support. However, a major concern for a number of members of the Vietnamese community is that they are worried that their stories will not be protected. That is, they may not have a good understanding about confidentiality and privacy laws and therefore tend to believe that the person may share this information with someone else.

Religion and its role in dementia care

The most common religion in Australia for Vietnamese community is Buddhism, which includes the concepts of karma and reincarnation. Buddhism and the concept of karma are based on kindness to others and belief that good deeds bring positive rewards and bad deeds bring negative consequences. Therefore for some Vietnamese elderly, illness may be seen as a consequence of some negative actions done by the person or a member of family.

Key issues to consider

Limited English proficiency is a major barrier to service access for Vietnamese elderly. Education and lack of knowledge of the service systems is also another limitation.

Dementia-specific information available from Alzheimer's Australia Vic in Vietnamese

1. Our services
2. Getting help
3. Worried about your memory
4. Mind your Mind user's guide
5. What is dementia?
6. Diagnosing dementia
7. Early planning
8. Communication
9. Taking a break
10. Changed behaviours
11. Alzheimer's disease
12. Vascular dementia
13. Safety issues
14. Activities
15. Driving
16. Working with doctors
17. Feelings
18. Problem solving

About You (for people with dementia):

19. What is dementia
20. Early planning
21. Looking after yourself
22. Driving
23. Keeping involved and active
24. Feelings and adjusting to change
25. Talking with your doctor
26. Talking about the diagnosis

Key community contacts

Australian Vietnamese Women's Association
30 - 32 Lennox Street
(PO Box 1301)
Richmond, VIC 3121

Tel: (03) 9428 9078
Fax: (03) 9428 9079
www.avwa.org.au

Springvale Indochinese Mutual Assistance Association
9 Hillcrest Grove,
Springvale, VIC 3171

Tel: 9547 7939
Fax: (03) 9558 5742,
Email:
sicmaa@satlink.com.au

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory

National Dementia Helpline

1800 100 500

alzheimers.org.au

Disclaimer

This document was produced by Alzheimer's Australia Vic. The information contained in this document is for general guidance only. It is a compilation of views that do not encompass all views of the various language, cultural and religious groups mentioned. Neither the authors, contributors, Alzheimer's Australia Vic nor Allens Arthur Robinson accept liability for cultural interpretations, errors or omissions in this document.

The following information is available by contacting the National Dementia Helpline on **1800 100 500** or visiting **www.alzheimers.org.au**

ARMENIAN

1. What is dementia?
2. Diagnosing dementia
3. Early planning
4. Communication
5. Taking a break
6. Changed behaviours

DUTCH

1. Our services
 2. Getting help
 3. What is dementia?
 4. Diagnosing dementia
 5. Early planning
 6. Communication
 7. Taking a break
 8. Changed behaviours
 9. Alzheimer's disease
 10. Vascular dementia
 11. Safety issues
 12. Activities
 13. Driving
 14. Working with doctors
 15. Feelings
 16. Problem solving
- About you:*
17. What is dementia
 18. Early planning
 19. Looking after yourself
 20. Driving
 21. Keeping involved and active
 22. Feelings and adjusting to change
 23. Talking with your doctor
 24. Talking about the diagnosis

GERMAN

1. Our services
2. Getting help
3. What is dementia?
4. Diagnosing dementia
5. Early planning
6. Communication
7. Taking a break
8. Changed behaviours

HUNGARIAN

1. Our services
2. Getting help
3. What is dementia?
4. Diagnosing dementia
5. Early planning
6. Communication
7. Taking a break
8. Changed behaviours

KHMER

1. Worried about your memory

KOREAN

1. What is dementia?
2. Diagnosing dementia
3. Early planning
4. Communication
5. Taking a break
6. Changed behaviours

LAO

1. Worried about your memory

MALTESE

1. Our services
2. Getting help
3. What is dementia?
4. Diagnosing dementia
5. Early planning
6. Communication
7. Taking a break
8. Changed behaviours

PORTUGUESE

1. Worried about your memory
2. Memory changes
3. Diagnosing dementia
4. Early planning
5. Taking a break

TAGALOG

1. What is dementia?
2. Diagnosing dementia
3. Early planning
4. Communication
5. Taking a break
6. Changed behaviours

UKRANIAN

1. Our services
2. Getting help
3. What is dementia?
4. Diagnosing dementia
5. Early planning
6. Communication
7. Taking a break
8. Changed behaviours

UNDERSTANDING DEMENTIA DVD/video

This DVD/video is available from Alzheimer's Australia Vic Bookshop and Library in the following languages:
Arabic, Cantonese, Croatian, Greek, Italian, Khmer Macedonian, Mandarin, Polish, Serbian and Vietnamese.

To learn more about specific CALD communities

There are a number of publications and resources currently available with information on different CALD communities. This is a list of resources and links that have some general information or contain listings of such resources.

SOURCE

Alzheimer's Australia Vic,
Multicultural Library Resources reading list

Alzheimer's Australia, *Dementia prevalence and incidence among Australians who do not speak English at home.* Access Economics, November 2006

Prioletti Consultants, *Cultural Diversity Resource Kit for Disability Support Providers working with People with a Disability from Culturally and Linguistically Diverse Backgrounds.* August 2005

Howe, A., *Cultural Diversity, Ageing and HACC: trends in Victoria in the next 15 years* Department of Human Services Victoria, 2006

Reichstein Foundation, *People from Ethnic Backgrounds in Commonwealth Funded Residential care – Victoria.* Australian Polish Community Services

SUMMARY

A document listing available various resources on CALD communities. List includes publications, books, articles and other materials. Available from Alzheimer's Australia website at www.alzheimers.org.au

Report on the prevalence and incidence of dementia in CALD communities. Available from Alzheimer's Australia website at www.alzheimers.org.au

Provides a listing of information resources and the corresponding links or contact details under seven categories.

This report provides population projections for the 20 largest culturally and linguistically diverse (CALD) communities in Victoria over the next 15 years and outlines the trends that can be expected into the future.

This report documents experiences of elderly CALD residents in Commonwealth Funded residential care where language and cultural support has not been provided. It provides recommendations for improving responsiveness of residential facilities to the needs of CALD residents.

USEFUL WEBSITES

- Alzheimer's Australia
- Action on Disability within Ethnic Communities
- Centre for Cultural Diversity in Ageing
- Centre for Culture, Ethnicity and Health
- Department of Immigration and Multicultural Affairs
- Ethnic Communities Council of Victoria
- Health Translations website
- Victorian Multicultural Commission

www.alzheimers.org.au
www.adec.org.au
www.culturaldiversity.com.au
www.ceh.org.au
www.immi.gov.au
www.eccv.org.au
www.healthtranslations.vic.gov.au
www.multicultural.vic.gov.au



Alzheimer's
Australia Vic
Living with dementia

You can learn more about dementia
and ways to help by contacting
Alzheimer's Australia in your State
or Territory

National Dementia Helpline
1800 100 500

www.alzheimers.org.au

1. Has this resource kit been useful to you in some way?

Yes No

2. How has this resource kit been useful to you?

3. How do you think future work could be improved if we had a chance to produce similar resources?

4. Do you have any comments regarding the length, content and presentation of this resource kit?

5. Overall, how satisfied are you with the resource kit

Satisfied Somewhat satisfied Dissatisfied

6. Other comments.

Thank you for your feedback. Please return this evaluation form to:

Multicultural Officer
Alzheimer's Australia Vic
Locked Bag 3001
Hawthorn VIC 3122

National Dementia Helpline
1800 100 500
www.alzheimers.org.au

