



Culturally Responsive Palliative Care

Arabic-speaking background communities Cultural Profile

2014



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Introduction

Cultural perspectives and values from culturally and linguistically diverse communities in Victoria

Background to the Project

The Culturally Responsive Palliative Care Community Education Project formed part of Palliative Care Victoria's Cultural Responsiveness Strategy. The project was undertaken in partnership with the Ethnic Communities' Council of Victoria in 2013-2015 and with the Multicultural Centre for Women's Health (MCWH) in 2013-2014.

It involved community engagement and peer education to raise awareness of, and access to, palliative care services and focused on ten larger communities: Chinese, Maltese, Italian, Turkish and Vietnamese during 2013-15 and the Greek, Macedonian, Polish, Croatian and Arabic-speaking background communities in 2014-15.

In 2013-2015, 33 trained bilingual health educators delivered 150 community education sessions in eleven community languages to 4846 participants.

Further information about the Project, and links to the evidence base and summaries of the external evaluation of the Strategy are available [here](#).

Peer Education Resource

The bilingual peer educators delivered the information sessions using a Peer Education Resource that was tailored for each community in partnership with a Community Reference Group. In 2013-14, this process was coordinated by Maria Hatch and Dr Jasmin Chen from MCWH and in 2014-15 by Mike Kennedy from Palliative Care Victoria.

The first part of the Peer Education Resource contained background about the community and its cultural perspectives and values. These community summaries are set out below in this document and can also be accessed as individual PDF files.

A community reference group was established for each participating community and provided the project partners with invaluable advice and guidance in preparing the Peer Education Resource documents.

When referring to these documents, care needs to be taken to avoid cultural stereotyping and profiling. In undertaking this project, we learned multiple times that there is as much diversity *within* each ethnic community as there is between them, and that cultural perspectives and values are evolving and changing. However, this information may be useful in identifying some issues to be explored with clients or patients from culturally and linguistically diverse backgrounds to deliver culturally responsive person-centered care.

Discussing palliative care in the Arabic-speaking background communities

Talking about palliative care can be difficult for people from all cultures and communities. Although in Arabic-speaking background communities there is no specific taboo around talking about death, many people from Arabic-speaking background communities may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings because of its association with illness, death and dying. These negative feelings can trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

Arabic-speaking background communities in Victoria and Australia

The Arabic-speaking background population in Victoria is very diverse in terms of religion, language, age and country of origin. It is made up of over 68,000 people of both Christian and Islamic denominations coming from different countries which are members of the Arab League of Nations where the official language is Arabic. Arabic was the sixth most common language other than English spoken at home in Victoria in the 2011 census.

Countries which are members of the Arab League of Nations

Algeria (125)	Lebanon (22)	Somalia (64)
Bahrain (119)	Libya (92)	Sudan (43)
Comoros	Mauritania	Syria (72)
Djibouti	Morocco (113)	Tunisia (134)
Egypt (27)	Oman (117)	United Arab Emirates (76)
Iraq (26)	Palestine (98)	Yemen (142)

Jordan (103)	Qatar (135)	
Kuwait (89)	Saudi Arabia (67)	

Note: The numbers in brackets are the ranking order in the top 150 overseas countries of birth for Victoria in the 2011 census.

The Arabic nation is Arabic speaking. There is great diversity in the ethnicity of the nation – the Arabic race is the largest group; other ethnicities are Kurd, Chaldean, Assyrian, African, Pharo and Armenian. There is diversity in religious practice as well. Thus migration from a particular Arabic League country may not indicate the migrant’s ethnicity, religion or language spoken at home. Some individuals think of their identity in nationalistic or sectarian terms. Although they speak Arabic and share Arab culture, some individuals may refer to their identity as Lebanese (national term), Chaldean or Coptic (religious term) or Kurdish (ethnic term).¹

For the purposes of this Peer Education Resource, it is not necessary to do a detailed breakdown of the distribution of the Arabic-speaking background population of Victoria by local government areas. Based on the countries of birth for Arabic-speaking background communities in Victoria (using data from the 2011 Census and countries in the top 50 Overseas counties of birth), there are significant Arabic-speaking background communities in Hume, Moreland, Whittlesea, Brimbank, Casey, Greater Dandenong, Darebin, Wyndham, Hobsons Bay and Manningham.²

About Arabic-speaking background communities in Victoria and Australia

People from an Arabic-speaking background in Australia came from various countries in the Middle-East and North Africa, mostly over the last 40 years. They migrated due to displacement by war and political upheaval, or a desire for professional or economic advancement.

Many are Muslims, for whom the religious perspective over-rides the cultural background, especially when issues of death and dying arise. Another group is the Coptic Orthodox. Most householders are qualified doctors, engineers, lawyers and teachers who migrated originally from Egypt and surrounding countries. A significant group of people from an Arabic-speaking background in Australia is from Lebanon. These people are from four religious groups: Muslim, Maronite, Orthodox and Druze. They have similar cultures in their way of living but have different ways of burying their dead.

Arabic-speaking background communities’ Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors, including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

For Arabic-speaking background communities, shifting cultural values can become more apparent through the migration experience and there can be great differences between the views and values

¹ South Eastern Region Migrant Resource Centre, “Arabic Cultural Profile – Older People”, 2010.

² Victorian Multicultural Commission, Community profiles 2011 Census, <http://www.multicultural.vic.gov.au/population-and-migration/victorias-diversity/community-profiles-2006-census>, accessed 27 August 2014.

of two generations within the same family. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in their country of origin. In this sense, culture as it exists for Arabic-speaking background communities in Australia cannot necessarily be generalised from contemporary Arabic-speaking background culture or with Arabic-speaking background communities living in other parts of the world.

Nevertheless, certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Here are a number of commonly held Arabic-speaking background cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these perspectives will not apply to everyone in the Arabic-speaking background communities and it is important not to make assumptions about people's values and beliefs.

Community and Religion

The main religion in most Arabic-speaking countries is Islam, the second being Christianity in various forms. Sunni and Shia are the two main streams of Islam. Another religion, the Druze, practiced mainly in Lebanon and Syria, originated from Islam.

The majority of Christian groups reside in the following Arabic-speaking countries: Lebanon, Jordan, Syria, Egypt, Palestine and Iraq. Christian Maronites (Catholic) and Christian Orthodox form 30 percent of the population in Lebanon. Coptic Orthodox is a minority group in Egypt and Chaldeans/Assyrians and Christian Orthodox are minority groups in Iraq. There was a small Jewish population in Egypt, Lebanon, Iraq and Morocco before the creation of Israel and the current conflict between Arabs and Israelis.³

Muslim patients and families

Though Islam is a single religion, it is important to recognise that Muslim people are not a single homogenous group. The cultural diversity of the Muslim community in Victoria makes it difficult for anyone to prejudge the expectations or needs of individual patients, for example, with regard to religious observance. When in doubt, it is always best to ask.⁴

Catholic patients and families

For Arabic-speaking background 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.⁵

Family

Generally speaking, the Arabic-speaking background communities are family-oriented and the male is the head of the family and makes decisions. It is expected that the 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

³ South Eastern Region Migrant Resource Centre, "Arabic Cultural Profile – Older People", 2010..

⁴ Islamic Council of Victoria, Muslims Australia, "Caring for Muslim Patients", 2010.

⁵ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

the 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-speaking background 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 of their parents then, in turn, their children may not care for them when they grow old.⁶ Family honour is an important cultural value, and extremely important for people who migrated from a rural background.⁷

Attitudes to illness and pain management

People from Arabic-speaking backgrounds may use western medicine concurrently with herbal remedies or traditional healing practices. Doctors and qualified medical people are well accepted and respected by Arabic-speaking background community members. A medical diagnosis should be given to the closest family member, preferably the oldest son or daughter.

Gender issues can affect relationships with the wider community and should be considered when offering a service, matching where possible a client with a worker or interpreter of the same gender.

Elderly people may face difficulty reading health information and promotional materials in Arabic as many of them may not be literate in their first language. People may prefer to communicate through a personal contact who can speak the same dialect.⁸

Islamic teachings give mentally competent adult patients the full right to refuse current or future treatment. Many medical ethicists and Muslim scholars consider it equally appropriate to withhold or withdraw futile medical treatment. However, other Muslim scholars tend to be stricter about withdrawing rather than withholding treatment, even when both are considered medically futile.⁹

There are no taboos with regard to pain relief in Arabic-speaking background communities. For practicing Muslims, clinicians should check whether medications contain alcohol or ingredients made from pigs.¹⁰

The illicit use of opioids and other drugs that affect intellectual and cognitive functions is strictly prohibited in Islam. However, medically prescribed opioids are generally considered permissible because of necessity. Usually, patients and families accept the use of opioids for symptom control if the rationale is clearly explained to them. It is important to explain to the patient and family the possible side effects, as there may be significant concerns regarding drowsiness.

In terminally ill patients, it may be difficult to maintain a state of equilibrium allowing for optimal symptom control and a normal level of consciousness. In these situations, the pros and cons

⁶ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

⁷ South Eastern Region Migrant Resource Centre, "Arabic Cultural Profile – Older People", 2010..

⁸ South Eastern Region Migrant Resource Centre, "Arabic Cultural Profile – Older People", 2010.

⁹ Mohammad Zafir al-Shahri and Abdullah al-Khenaizan, "Palliative care for Muslim patients", *The Journal of Supportive Oncology*, Vol. 3, No. 6, Nov./Dec. 2005, pp.432-436.

¹⁰ Andrew Taylor and Margaret Box, *Multicultural Palliative Care Guidelines*, 1999.

should be clarified to the patient and family, who may prefer to endure a slightly higher degree of symptoms in order to maintain a higher level of consciousness.¹¹

Attitudes towards mental health

In Arabic-speaking background communities, mental illness is viewed in negative terms, with the resultant stigma impacting on the whole family. The communities are also characterised by their reluctance to seek professional assistance which can be attributed to a number of reasons including: stigma surrounding the person with the mental illness and their family members,; shame that the individual or family will experience; lack of awareness of mental health illnesses and mental health service providers; and traditional and cultural dependency on other sources of help such as family, religious leaders, traditional healers and Arabic-speaking doctors.¹²

Dementia is considered by many people from an Arabic-speaking background to be a normal part of ageing but is associated with mental illness. There is some reluctance in the Arabic-speaking background communities to admit to the illness and, because of the stigma, people with dementia may stay away from friends and community and become isolated. Some of the stigma is related to the word that is most commonly used in translations – “kharaf” – and in most cases the term is understood in negative terms and carries negative connotations.¹³

The main concern expressed in Arabic-speaking background communities around counselling is that they feel as if they are speaking to a ‘stranger’. Carers sometimes express 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 who speaks their language and with whom they have built a relationship over some time.¹⁴

Attitudes towards care

Community care

As there is a strong preference for members of Arabic-speaking background communities to stay at home, they are likely to accept services that will help them to do so. There is, however, conflicting information as to how these services are best provided. Some people prefer the services to be provided by someone who is not from an Arabic-speaking background due to issues of privacy and shame. For others, Arabic-speaking background is necessary. Gender matching is an important requirement.¹⁵

¹¹ Mohammad Zafir al-Shahri and Abdullah al-Khenaizan, *ibid*.

¹² Patrycja Toczek, *Demystifying Mental Health in Ethnic Communities: Multicultural Mental Health Project Evaluation*, 2009, p.14.

¹³ Alzheimer’s Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

¹⁴ Alzheimer’s Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

¹⁵ Alzheimer’s Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

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-speaking – specific facility. Some of these views may also be due to negative perceptions of this type of care in their country of origin and a combination of attitudes that it is not acceptable to place members of the family in such facilities.¹⁶

Attitudes towards death and dying

The news about a life-threatening illness or disease is usually first given to the family, to the closest family member to the patient. The next of kin will advise the immediate family, but perhaps advice will not be given to friends. Patients are often not told about a life-threatening illness or disease, as it is felt that to do so may exacerbate their condition. However, every family is different; if the patient wishes to know, the patient's wishes are paramount.

Family and friends are very important and are a great source of support for the patient, providing constant help and attendance. Allowance needs to be made for this in hospitals and hospices.¹⁷

Death is seen as something predestined by God and families may thus appear inappropriately calm and accepting by Western standards.

Preservation of life overrides all other matters. Islamic law permits withdrawal of futile and disproportionate treatment on the basis of consent from immediate family members who act on the professional advice of the physician in charge of the case. Once treatment has been intensified to save a patient's life, life-saving equipment cannot be turned off unless the physicians are certain about the inevitability of death.¹⁸

It is important for Muslims to recite the Qu'ran or prayers in front of the dying patient or in a room close by. For a patient who has just died, the face of the deceased person should be turned in the direction of Mecca. The whole body of the deceased person must be covered by a sheet and should be handled as little as possible. The body should be handled with the utmost respect by a person of the same sex. The body should not be washed as this will be done as part of a special religious ritual before burial. Muslim burials are performed as soon as possible after death, sometimes on the same day. Cremation is not permitted.¹⁹

Intergenerational Perspectives and the Migration Experience

The migration and settlement experience of Arabic-speaking background migrants varies greatly according to the social circumstances and the country from which they have come. In terms of total population numbers, Lebanon and Egypt continue to be the largest source countries of overseas born people from an Arabic-speaking background in Australia. Wars and other civil strife in the Middle East and North Africa affect the flow of migration to Australia and since 2006 there has been a flow of refugees coming to Australia from Iraq and Sudan.

¹⁶ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

¹⁷ Andrew Taylor and Margaret Box, *Multicultural Palliative Care Guidelines*, 1999.

¹⁸ Islamic Council of Victoria, Muslims Australia, "Caring for Muslim Patients", 2010.

¹⁹ Islamic Council of Victoria, Muslims Australia, "Caring for Muslim Patients", 2010.

Migration from Lebanon:

- Lebanese migrants came in three waves: the first was before and after World War I due to economic factors, the second wave was the effect of World War II and the third wave was the immediate effect of the civil war in Lebanon in 1975.
- The majority of the two first waves were from Christian backgrounds with some from a Muslim background and some number from Druze (a sect that originated from Islamic religion one thousand years ago), while the majority of the third wave were from a Muslim background.
- Lebanese born and Lebanese descendants in Australia from all backgrounds now exceed 200,000. Early migrants worked in factories, as shopkeepers and in some professional positions, while a large number of recent migrants who came under the Family Reunion Program face unemployment problems. Skilled Lebanese migrants integrated well into the community and into professional work. Depending on their socio-economic background, some of the second generation young people from an Arabic-speaking background face issues that are common to Australian youth in addition to issues related to being part of a disadvantaged community.
- Arabic-speaking background migrants of the two first waves are reaching the retirement age now.

Migration from Egypt:

- Egyptian born migrants who settled here after the World War II between 1947 and 1971 were Coptic Christians with some Egyptians from European backgrounds (eg. Greeks).
- In a smaller numbers, Muslim Egyptians arrived in the 1970s and 1980s.
- Despite the fact that 90% of Egypt's population is Muslim, the majority of those who migrated here before 1976, and the more recent arrivals, are from Christian Coptic backgrounds and generally are well-educated.

Migration from Iraq:

- In recent times, Iraq has become the largest source of Arabic-speaking background migrants to Australia due to Iraq's involvement in the two Gulf wars and the recent "War on Terror".
- The majority of Iraqi migrants came under Humanitarian or Refugee Programs.
- The majority of the Iraqi population is from a Muslim background (Shia or Sunni), with smaller numbers being Kurds (Muslim Sunni), Chaldeans and Assyrians (Christian groups). However the majority of Iraqi migrants are Shia.
- The Iraqi people in Australia congregate along ethnic and religious lines rather than national lines.

Migration from Sudan:

- Over the last ten years Sudan has emerged as second to Iraq as a source of Arabic-speaking background arrivals.
- Victoria receives a disproportionate number of South Sudanese arrivals into Australia under the Refugee and Humanitarian Program.
- The percentage of Sudanese arriving under the Humanitarian Scheme is approximately 95%; the largest identified group amongst them is the Dinka.
- Other communities are the Nuer, Chollo, and sub-communities such as Equatorian and Nasir communities. Most Sudanese read and speak Arabic (Egyptian dialect), the official language of Sudan, in addition to their own tribal languages and dialects.

- The level of English proficiency is very low in general.²⁰

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.²¹ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the differences in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict and misunderstanding.

For many first generation people from an Arabic-speaking background who have migrated to Australia, the experience of migration has given them a strong sense of independence and self-reliance in which they take great pride. It may also have been a source of stress, homesickness and isolation.

Particularly for many older members of the Arabic-speaking background communities, accepting help from external services could be felt as an admission of weakness or giving up personal independence. Service providers have also reported that there can be fears about accepting services, particularly if service providers are entering the home. Fears around being mistreated, confined, moved out of home and the cost of services can all be deterrents to accepting external support.

In turn, the second and subsequent generations growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically, while the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs.

Of the total Victorian population, 86.3 percent are Australian citizens. The relevant percentages of people born in Arab League of Nations countries vary by country: 87.8 percent for Lebanon-born, 86.5 percent for Egypt-born, 72 percent for Sudan-born and 67.4 percent for Iraq born.²²

There are also variable levels of English proficiency:²³

Country of birth	Lebanon	Egypt	Sudan	Iraq
	%	%	%	%
Speaks English only	7.2	18.9	5	2.6
Speaks English very well or well	78.9	91.3	79.9	67.7

²⁰ South Eastern Region Migrant Resource Centre, “Arabic Cultural Profile – Older People”, 2010.

²¹ Parts of this section were developed from Ethnic Communities’ Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

²² Victorian Multicultural Commission, Community profiles 2011 Census, <http://www.multicultural.vic.gov.au/population-and-migration/victorias-diversity/community-profiles-2006-census>, accessed 27 August 2014.

²³ Victorian Multicultural Commission, Community profiles 2011 Census, <http://www.multicultural.vic.gov.au/population-and-migration/victorias-diversity/community-profiles-2006-census>, accessed 27 August 2014.

It is difficult from the available data sources to discern whether the ability to speak Arabic as a “second language” has declined in the second and subsequent generations. It is likely that the rates for fluency in Arabic vary across the Arabic-speaking background communities

A note about terminology

In the English language, words such as *grief*, *bereavement* and *illness* can have different meanings and connotations for different people. Similarly, people from ethnic backgrounds may have specific cultural values that they associate with these words. For example, some people might associate *illness* with karma or the supernatural, and discussions around possible treatment or intervention need to take this into account in order for them to be meaningful.

Words such as *grief*, *bereavement* and *illness* are used in this resource with the understanding that there will be different cultural meanings associated with them. Education sessions are intended to be delivered in participants’ first language, and therefore terms should be appropriately translated if applicable.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition
- Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.