Culturally Responsive Palliative Care

Turkish Community

Cultural Profile

2013

PalliativeCare VICTORIA
Living, dying & grieving well

eccv
The Voice of Multicultural Victoria

Multicultural Centre for Women's Health
Putting Immigrant & Refugee Women's Health First

State Government Victoria

LORD MAYOR'S CHARITABLE FOUNDATION

Contents

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 Turkish community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Turkish community, there is no specific taboo around talking about death, many Turkish people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings and 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 also 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 will not be 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.'

About the Turkish Community in Australia

The Turkish speaking community in Australia is well established, being largely made up of families who have been living in Australia for longer than a decade.[1] According to the 2011 Census there are approximately 59,623 Turkish speakers in Australia, representing 0.3% of the entire population.[2] Most Turkish speakers are Australian citizens (90.5%) and the majority of the population is concentrated in Sydney and Melbourne.

The Turkish community was the first large Muslim population to settle in Australia. In 2011, 87.6% of Turkish speakers still identified as Muslim, with 6.8% identifying as having no religion.

The Turkish speaking population is an increasingly ageing demographic. 86.7% of all Turkish speakers living in Australia recorded that both parents were born overseas and 66.5% of Turkish speakers reported that they did not speak English well or not at all. The ageing population of Turkish speakers who arrived in the 1960s are particularly likely to not speak English well or at all, and to have low literacy and education levels. This is even more likely to be the case for older

[1] Australian Turkish Association Inc. (2009) *Turkey community profile and its implication for service delivery*. Accessed on 1 September 2013 from http://www.austurkish.org.au/history.html.
[2] SBS Census Explorer (2013) *Turkish*. Accessed on 1 September 2013 from http://www.sbs.com.au/yourlanguage/turkish/censusexplorer/page/in/english.

women, who may traditionally have been discouraged from pursuing their education, although attitudes to women and education have changed decisively for most Turkish speaking migrant families today.[3]

Turkish 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.

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.

Studies looking at the Turkish Community in Australia have found that place of birth, 'mother-tongue', and religion are often symbolic markers of Turkish ethnicity.[4] More generally, notions of family loyalty, the social organisation of marriage and traditional segregation of gender roles have shaped Turkish youth identities in Australia.[5] The following are a number of commonly held Turkish cultural perspectives and values that may have bearing on responses to a discussion about palliative care in that community. Please keep in mind that these perspectives will not apply to everyone in the Turkish speaking community and it is important not to make assumptions about people's values and beliefs.[6]

Community & Religion

There is a strong sense of community amongst Turkish speakers in Australia. Geographical concentration in particular cities and areas has kept the Turkish language and other cultural traditions alive and well across generations living in Australia.[7] Because of these strong networks, Turkish speakers may be reluctant to seek services or support outside their community, without having established relationships of trust (for example, with their General Practitioner).

This reluctance may be more profound for the majority of Turkish speakers who practice Islam. Many Turkish speakers in Australia strongly identify being Muslim with their Turkish identity[8] and may not feel that service providers are aware or respectful of customary Muslim codes of conduct and ethics, particularly concerning gender roles and accepted rules of association. The importance of faith for both practicing and nominal Muslims in matters concerning their health can be heard in the Turkish expression, "God first and then the doctor." Turkish speakers of

---

[3] Australian Turkish Association Inc. (2009).
[4] Elley J & Inglis C. (1995) Ethnicity and gender: The two worlds of Australian Turkish youth. *Ethnic minority youth in Australia*, 193-202.
[5] Zevallos, Zuleyka. (2008) 'You Have to be Anglo and Not Look Like Me': identity and belonging among young women of Turkish and Latin American backgrounds in Melbourne, Australia. *Australian Geographer*: 39(1), p. 24.
[6] Parts of the following section are taken or closely adapted from Australian Turkish Association Inc. (2009). *Turkey community profile and its implication for service delivery*.
[7] Windle J. (2009) 'Soft' and 'Hard' Landings: the Experience of School under Contrasting Institutional Arrangements in Australia and France. *Turks Abroad: Settlers, Citizens, Transnationals*: *11*(2), 174-194.
[8] Zevallos. (2008) p. 27.

Muslim faith strongly believe that their life is in God's hands, and many will turn to their faith in times of trial as a source of ongoing hope. Whilst being mindful that not all Turkish speakers are Muslims, it is important to emphasise that the Palliative Care team is respectful of individuals' personal beliefs and will be happy to work with a family's religious leader or spiritual counsellor, and their wider religious community, as well as with their trusted GP and other treating medical professionals. Religious leaders often play a supportive role for the family even after their loved one has died, as do some Palliative Care services, which can continue to offer some support to carers and family for 12 months after bereavement.

Family

Family is a central source of support for individuals in the Turkish speaking community. Traditionally, great value is placed on family loyalty and it is expected that the family would undertake primary responsibility in caring for their loved ones. The dynamics of Turkish speaking families varies greatly depending on many factors including religion, education, and family background in rural or urban settings. In traditional families, the eldest son is often the decision maker, while the day to day duties of care traditionally fall to female family members.

Families often feel a strong moral obligation to care for their loved ones at home and would be reluctant to place them in a hospice, palliative care or aged care facility. Families may feel significant social pressure from the wider Turkish community, which may perceive sending their loved ones away as abandonment of their responsibilities. Equally, amongst more conservative members of the community, inviting a stranger into the home to manage care may also be negatively perceived. Because of these community perceptions, Turkish speakers may feel reluctant to seek help from sources outside their immediate circles of family and friends and may cause feelings of anxiety or shame. It is important for educators to acknowledge the stigma around this issue and, where possible, to discuss the importance of changing community perceptions about the use palliative care, which enhances, rather than replaces the quality of care provided by the family.

Gender segregation

Traditional segregation of genders, relating to rules of association between men and women, is practiced to a greater or lesser extent within the entire Turkish community in Australia. While gender segregation is based in religious observance for those of traditional Muslim faith, it is a cultural expectation which extends to the Turkish community in general, and unmonitored interaction between men and women is discouraged. For this reason, there is a strong cultural preference that personal care should be provided by someone of the same sex, with the exception of husbands and wives. Particularly for practicing Muslims, this may bear on an individual's willingness to consider using palliative care services if there is uncertainty about whether care provided by professionals would be gender specific.

There are many implications of gender segregation and gender roles which have relevance to the discussion of palliative care, and depending on the audience, educators may want to consider conducting gender specific education sessions in order to address the particular needs and quite separate roles of men and women in the Turkish community.

Gender roles and decision making

Traditionally, gender roles are quite strictly defined for both men and women in the Turkish community, although they apply more to the older generation and may not apply to everyone. Beyond the rules of association between men and women, there is a strong division of labour in traditional Turkish families, in which men are responsible for financial and family decision making and women are responsible for the organisation and upkeep of the household, and would be assumed to be the main – and sometimes the sole – care provider in their families. Because of this, in a situation where a man became seriously ill, his wife would see caring as a natural extension of her duties and may not see the situation as one which requires additional support. In a situation where a woman was seriously ill, her husband would commonly require far more additional support in his role as carer. Educators should consider these different perspectives when discussing palliative care, depending on their audience.

As in many cultures and parts of the world, traditional gender expectations may disadvantage women from a Turkish speaking background who are, particularly in the older generation, less likely to have received education than their male peers.[9] Although Turkish-speaking families raising their children in Australia place great value on girls' education, this may be an important consideration when presenting information and resources to older generation women in particular, depending on their background.[10] More generally, the focus for most women who learn about palliative care will be on the practical aspects of caring itself.

For men in the Turkish community, their role is traditionally more powerful than that of women, but in this sense carries heavy responsibility. While the role of the mother is revered in traditional Turkish culture, men have the last word and husbands are traditionally understood to be the leaders of the family. For this reason, when addressing Turkish speaking men, it may be worth emphasising the important role palliative care can play in providing health information so that families can make informed decisions about their loved one. The palliative care team is expert in all aspects of care relating to terminal illness, including avenues of financial assistance and advice on advanced care planning, including referral to expert legal advice in matters which arise in bereavement.

Please keep in mind that expectations of gender and gendered perspectives will not apply to everyone in the Turkish speaking community and will apply differently for older and younger generations. It is important not to make assumptions about people's roles and attitudes.

Attitudes to illness and Pain Management

The medical profession is highly regarded in the Turkish community, and their opinion often carries great authority. It is not uncommon for Turkish speakers to have long established and trusted relationships with their GP.

Whether or not someone from the Turkish speaking community is comfortable talking about health and illness depends on the individual and circumstances. Men are traditionally less likely to discuss

[9] For example, in 2008 in Turkey 84% of all illiterate people were women. See Istanbul BIA News Centre. (25 August 2010). *4.7 million illiterate women in Turkey*. Bianet. Accessed on 20 September 2013 from http://bianet.org/english/gender/124367-4-7-million-illiterate-women-in-turkey.

[10] This should also be a consideration for many older generation men, again depending on their background.

their personal health issues with others (except very close friends), and may be reluctant to draw attention to anything that they may perceive to indicate personal weakness. In general, women tend to have stronger support networks, and are more able to discuss their health together, however sensitive issues, gender-specific health issues and sexual and reproductive issues are usually inappropriate to discuss in mixed company. Educators should be sensitive to these differences and may try to make the discussion general rather than personal.

It is not uncommon for families to downplay the seriousness of an illness with their parent or loved one, avoid discussing the nature of the illness or to question the definitive nature of a prognosis.[11] This is not particular to the Turkish community, and can be motivated by the desire to not upset their loved one, to hope for their recovery, to avoid emotionally painful situations and to ensure that their loved one enjoys the time they have to the fullest and in comfort. Individuals may feel like they are enacting a necessary tragicomedy, in which both parties are aware but unwilling to fully acknowledge the situation to one another. Participants should be assured that the palliative care team have a lot of experience in negotiating similar situations with care and sensitivity, and will respect the wishes of the family and their loved one.

According to Islamic belief, the relief of suffering is highly virtuous, and many Turkish speakers are very comfortable with the prescription of pain relief medications. Some practicing Muslims may have concerns about the content or use of opioids and other drugs for pain relief. For some Muslims it is important to maintain a level of consciousness as close to normal as possible towards the very end of life, however this view depends on the individual.[12] Equally, for some Muslims the use of gelatine or alcohol in certain drugs may be of concern. If it becomes relevant to the discussion, educators may want to assure participant's that the palliative care team is sensitive to cultural and religious beliefs around this issue and will discuss pain medications and medication levels closely with family if requested. Family and individuals maintain control of decision making about what pain medications are appropriate.

Attitudes towards Mental Health

There is a strong stigma around mental health issues in the Turkish community in Australia, to the extent that people who are diagnosed with a mental illness may not disclose it to their immediate family. This stigma extends to depression and may impact negatively on carers who experience stress, who are most often women, and who may not be able to identify or express their need for support. Equally, men in the Turkish community are looked to as the 'rock' of the family and may feel unable to acknowledge stress, depression or emotional vulnerability because of this expectation. While women in the community tend to have stronger support networks amongst their female friends, there is a strong culture amongst men of not speaking about their personal feelings. Although attitudes are changing, many Turkish speakers would be reluctant to consider counselling beyond seeking spiritual guidance from their religious leader, unless their trusted GP made a referral. It may be worth discussing these issues in detail if the opportunity arises, and explaining the importance of mental health and wellbeing for carers and families in supporting their loved one effectively. Educators may want to discuss the connections between mental health

[11] Zafir al-Shahri M & al-Khenaizan A. (2005). *Palliative Care for Islamic Patients*. Journal of Supportive Oncology: 3(6), 432-6.
[12] Zafir al-Shahri M & al-Khenaizan A. (2005).

and physical health and the importance of seeing mental health as part of the health of the whole person.

Attitudes to Death and Dying

Philosophically and religiously, there is acceptance within Turkish culture of the reality and necessity of death and dying. The Turkish community do not have specific traditions and rituals around dying, but consider the end of life to be a time of making peace with others and one's self. (There are considerations around burial after death which the palliative care team is very likely to be aware of, or can be explained to them.) Nevertheless, the focus of conversation around palliative care should be around comfort and quality of life, treating symptoms including the management of pain and support for carers. Particularly for Muslims, some Turkish speakers may have concerns around the chemical affects or ingredients of certain drugs used in pain management. If educators feel this is the case, it may be worth discussing these concerns with participants. Again, it is important for Turkish speakers who are practicing Muslims to be reassured that the palliative care team will respect and support any spiritual beliefs or religious practices of the family.

Intergenerational Relationships and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.[13] 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 difference in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict or misunderstanding.

Generally speaking, for first generation Turkish speaking migrants, the settlement process and lack of cultural continuity has been a difficult and isolating experience. This may be even more pronounced for older members of the community, or members of the community who do not speak English well or at all and who may be more socially and culturally isolated. For many older generation Turkish speakers in the Turkish community, their cultural and linguistic isolation from wider Australian culture has seriously impaired their communication and confidence levels, leading to increased isolation, depression, anxiety and the deterioration of their general health and mental well-being. Lack of language and limited literacy levels also contribute to lack of awareness and knowledge of available services, including where to go for help and how to get there while having to navigate through a complex and rigid system. Older people with low literacy levels may also find it difficult to relate to written information even in their own community language.

In turn, younger Turkish speakers, second and third 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 where the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs.

---

[13] Parts of this section were adapted from Ethnic Communities Council of Victoria. (2013). *Dignity and respect in ageing, the role of the family and what can go wrong. A Greek community education resource kit around elder abuse prevention*, p. 2.

Depending on your audience it is worthwhile being aware of intergenerational tensions and where appropriate, encouraging thoughtful and reflective discussion around these issues if they arise during your session.

A note about terminology

In all cultures, the words used to describe or explain something can have different meanings to different people. In the English language, for example, each person will bring different experiences and associations to their understanding of words such as *grief*, *death* and *illness*. Grief will mean something different to someone who has experienced it, just as death will mean something different to Muslims than to atheists. In both cases, it is important to recognise that your audience may respond differently to the words you use, depending on their personal associations and experiences.

Many of the words and explanations in this resource are written with the understanding that translating them into Turkish will involve a different set of meanings and cultural associations. Education sessions are intended to be delivered in participants' first language, and therefore the way in which you translate material should be considered carefully.

Educators may struggle when translating the term 'palliative care' into Turkish, as it is a relatively recent concept in Turkey and other home countries for Turkish speakers. Although palliative care concepts are gaining momentum in Turkish speaking countries, they have been slow to disseminate more widely, and often focus on pain management (algology) or fall under the broader term "supportive care".[14] Nevertheless, 'Palyatif bakım' is being increasingly discussed in Turkish speaking countries, at least within the medical profession, and educators may prefer this term, despite the fact that it is not necessarily informative for individuals who have not encountered it before. Sessions should explain palliative care in a way that makes participants comfortable with the term and confident of how to access palliative care if necessary. In the end it will be up to the educator to choose what terminology feels best for them or their group, but they may find it helpful to read through and follow the suggested terminology used on the handouts translated in the back of this guide.

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.

[14] See International Observatory on End of Life Care. (2005). *Country Report: Turkey*. Accessed on 20 September 2013 from http://eolc-observatory.net/global_analysis/pdf/turkey_country_report.pdf.