



Culturally Responsive Palliative Care

Maltese Community Cultural Profile

2013



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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 Maltese community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Maltese community, there is no specific taboo around talking about death, many Maltese 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 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.'

About the Maltese Community in Australia

The Maltese community in Australia has a significantly ageing population, and is composed mainly of migrants who arrived in the mid-fifties or early sixties, their children and grandchildren. Most Maltese speakers were born in Malta (68.5%), followed by Australia (27.2%). There were two significant intakes of Maltese migrants in 1954 and again in 1963-4, however migration of Maltese speakers to Australia has dwindled significantly in the last ten years. Perhaps because of this, the largest age demographic recorded for Maltese speakers in 2011 was 60-64 years for both men and women.

The 2011 census recorded 41,274 Malta-born people in Australia with the largest population in Victoria followed by New South Wales. According to the census, the main languages spoken at home by Malta-born people in Australia were Maltese (23 559), English (16 789) and Italian (397). Of the 24 486 Malta-born who spoke a language other than English at home, 88.1 per cent spoke English very well or well, and 10.4 per cent spoke English not well or not at all.¹

Because Malta was a British colony until 1964, there is sometimes a perception that most Malta-born speakers are also fluent in English because they were raised in a bi-lingual environment. This

¹ Department of Immigration and Citizenship. (2011) *Community Information Summary: Malta-born*. Accessed on July 12 2013 from http://www.immi.gov.au/media/publications/statistics/comm-summ/_pdf/malta.pdf.

perception may be perpetuated by some older generation Maltese speakers, who may describe themselves as having English proficiency. In consultation with the community in Victoria, it seems unlikely that English proficiency is as high as reported among the older generation from Malta. It is possible that many of the first generation Maltese speakers who arrived in Australia during the mass migration period are more inclined to say they speak English because of their colonial heritage as 'British subjects'. Many Maltese speakers migrated before English proficiency was necessary to migrate to Australia and before English classes were provided or made easily accessible. It may also be that many older generation Maltese Australians had poor access to education, with 20.6% of Maltese speakers reporting that they had finished their Year 12 studies (or equivalent) in 2011.

Nationally, a significant majority of Maltese speakers identify themselves as being Western Catholic (95.4%). Religion is central to the cultural identity of many Maltese Australians, and plays a strong social and spiritual role in the community.

Maltese 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.

Maltese speakers, who migrated in the 50s and 60s, often strongly identify with the regional culture, heritage and language in which they grew up. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in their home country. In this sense, despite close ties with Malta, Maltese culture as it exists in Australia can not necessarily be generalised from contemporary Maltese culture or with Maltese communities living in other parts of the world.

The following are a number of commonly held Maltese Australian 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 Maltese speaking community. It is important not to make assumptions about people's values and beliefs.

Community & Religion

Religion is paramount in the life of many Maltese Australians, and is very much a part of daily and social life, particularly for the older generation. A large majority of Maltese speakers identify themselves as Western or Roman Catholic and even nominal or non-practicing Catholics often identify closely with Roman Catholic values and observe traditional religious celebrations and rituals which are central to Maltese cultural life. Often religion becomes increasingly important to Maltese Australians as they age and religious mass plays an important social role for Maltese communities.

Because the Maltese community is closely connected, there are occasions when individuals or families may feel protective of their privacy, particularly in situations related to health or hardship. This can even make people reluctant to engage interpreting services for fear that they know the interpreter socially. Educators may want to keep discussions away from personal experiences, and to emphasise that palliative care services are bound by similar rules of conduct and privacy to GPs and professional counsellors.

Family

Family is central to the life of Maltese-Australians and involves a closely knit extended family. Grandmothers often play an important role in caring for children and while children leave the family home when they marry, it is relatively uncommon for a child to leave the home to live alone. As well as being very close, Maltese families tend to be insular and will often try to solve problems within the family, without seeking external help from friends or outside sources. Particularly because the community itself is quite closely connected, families can be quite protective of their privacy, particularly in relation to sensitive or personal issues. Depending on their level of education and English proficiency, many older generation Maltese speakers rely completely on their family to make decisions.

Because of the value Maltese communities place on family, it is often assumed that caring roles will be taken on by family members and in particular women in the family, who are traditionally expected to be the primary care givers, and responsible for domestic matters. It may be important for educators to emphasise that palliative care services work with families to enable people with terminal illness to continue to enjoy their lives with as little interruption as possible. Family involvement is not diminished by the use of palliative care and there is no obligation involved in using services.

Attitudes to illness and pain management

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

There is some stigma around serious illness for some Maltese speakers, and a common Maltese reaction is to reflect on their spiritual life and even wonder why it should be God's will and if they are being punished or tested. In these situations, faith will play an undiminished and deeply important role but families may choose not to share news of serious illness with friends in the wider community. Cancer and mental illness are both particularly taboo for the Maltese community and often carry strongly negative associations.

It is not uncommon for families to downplay the seriousness of an illness with their parent or loved one, and to avoid discussing the nature of the illness directly with them. This is not particular to the Maltese community, and can be motivated by the desire not to 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. 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.

Attitudes towards mental health

As in many cultures, there is a strong stigma around mental health issues in the Maltese community in Australia and many older generation Maltese speakers will be unfamiliar with the concept of counselling. Because of their unfamiliarity with ideas about mental health, older generation Maltese speakers experiencing depression or other personal issues associated with grief, loss or the demands of caring may be unable to identify or express their need for support. While women in the community tend to have close support networks amongst their female friends, there is a strong culture amongst men of not speaking about their personal feelings and a tendency to avoid admitting weakness or vulnerability.

Although attitudes are changing, many Maltese speakers would be reluctant to consider counselling, and may even be concerned about community perceptions if they attended an information session which suggested they were interested in mental health. If appropriate, it may be worth discussing the stigma around mental illness and explaining the importance of mental health and wellbeing for carers and families in supporting their loved one effectively. It may also be worth discussing palliative care's commitment to respecting the wishes of the person who is ill and their families, including issues relating to privacy.

Attitudes to Death and Dying

Being a predominantly Roman Catholic culture, Maltese people in Australia do not have specific taboos around discussing death and dying; however as in most cultures, it is not often a common or comfortable topic of conversation. Although attitudes to death tend to depend on the individual, the idea of making arrangements or pre-paying for your own funeral is unpopular among many Maltese people who do not wish to tempt fate. Religion often plays an increasingly important role for many Maltese people as they age and observing traditional Catholic practices and rites is usually an important consideration for someone who is nearing the end of life.

There is a tendency among some Maltese women to remove themselves entirely from social life for a prolonged period after the death of their husband. This behaviour is more common among older generation women and women from a more traditional or rural background, however it can be a deeply isolating experience. In addition to this, couples that have maintained traditional gender roles in their relationship may struggle with independence. Widows in particular, may have very little experience of managing household finances while widowers may be overwhelmed by domestic duties. It may be beneficial to let participants know, if appropriate, that palliative care services can provide continuing counselling and spiritual support to people who have lost a loved one for a year or more.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.² 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 further possibilities for conflict or misunderstanding.

² 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.

3 Parts of this section 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.

For many first generation Maltese migrants, the lack of cultural continuity may have been a bewildering 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. Some Maltese speakers are also known to 'mix languages,' and speak a hybrid of English and Maltese which can be difficult to understand for both speaker and listener. Many older generation Maltese Australians express great nostalgia for their past, and idealise the lifestyle and traditional values of their home country and rural lifestyle, regardless of changes that may have occurred in contemporary Malta.

In turn, the second and third generation 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. Many older generation migrants who may not speak English well or at all, and who may have poor literacy in Maltese, depend greatly on family to access information and services. As a result, families can feel enormous duty to their loved ones and feel guilt if they think they are not meeting their responsibility.

In many ways, the experience of caring for older family members is new to Maltese Australians, which may make it even less likely that the community is aware of palliative care services. The generation of Maltese migrants who arrived in the 50s and 60s are the first large population of Maltese Australians to have reached older age, and they may not have experiences of supporting their parents or grandparents and perhaps less familiar with services and processes related to ageing and end-of-life care.

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 in the course of your session.

A note about terminology

In all cultures, the words you use 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 Catholics 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 Maltese 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 explaining the term Palliative Care to participants who are not

familiar with the service. '*Kura Palljativa*' is an increasingly understood idea in Malta, which has excellent palliative care services, pioneered by the Malta Hospice Movement in 1989. However the term '*kura palljativa*' is still not necessarily an informative term 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.