



Culturally Responsive Palliative Care

Italian 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 Italian community

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

The Italian speaking community is one of the most established cultural groups in Australia. In 2011 there were 299,833 Italian speakers in Australia, representing 1.4% of the entire population.¹ Of that number, around 41% (124,858) Italian speakers live in Victoria.² 49.9% of Italian speakers were born in Italy, with the majority of Italian migrants coming from Sicily, Calabria, Veneto and Campania.

There is a long history of Italian migration to Australia, beginning in the late nineteenth century. However, the largest wave of migration from Italy occurred post World War II and in the following decades, with the number of Italian migrants rising from 33,632 in 1947 to 289,476 in 1971.³ The majority of Italian migrants in this period came from rural and farming areas in Sicily, Calabria, Veneto and Campania. These areas were often economically poor and provided limited access to education.

¹ SBS. (2012). *SBS Census Explorer: Italiano*. Accessed on July 12 2013 from <http://www.sbs.com.au/yourlanguage/italian/censusexplorer>.

² ABS. (2011) *2011 Census of Population and Housing Expanded Community Profile based on place of usual residence: Victoria*, Cat. No. 2005.0.

³ Parts of this section are taken directly from Co.As.It (2008). *A Profile of Italian Australian Culture for Aged Care Service Providers*, p.6.

The Italian-speaking community has a significant ageing demographic with 111,361 Italian speakers reported being 65 years or older in 2011.⁴ In Victoria, 45,399 Italian speakers were over 65. For a variety of reasons, older Italians may not speak English well or at all, and may also speak standard Italian as their second language, preferring a regional or local dialect as their first language. Many Italians migrated before English proficiency was necessary to migrate to Australia and before English classes were provided or made easily accessible. In 2011, 19,466 Italian speakers in Victoria reported not speaking English well or at all.

Many Italian speakers living in Victoria, and older migrants in particular, have maintained strong links with their culture, language, heritage and community as an essential part of their sense of identity and wellbeing. Nationally, a large majority of Italian speakers identify themselves as being Roman Catholic (89.0%).⁵

Italian 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.

Particularly for those older generation Italians who migrated in the 50s and 60s, Italian Australians often strongly identify with the regional culture, heritage and language in which they grew up. Significant differences in cultural attitudes can exist between these regions, and can vary depending on levels of education and urban and rural settings. 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 Italy, Italian culture as it exists in Australia can not necessarily be generalised from contemporary Italian culture or with Italian communities living in other parts of the world.

The following are a number of commonly held Italian Australian cultural perspectives and values that may have bearing on responses to a discussion about palliative care in this community. Please keep in mind that these perspectives will not apply to everyone in the Italian speaking community and it is important not to make assumptions about people's values and beliefs.

Community & Religion

Italians tend to be highly social and there is a strong sense of community amongst Italian speakers in Australia, with many well established community organisations that keep the Italian community connected. Religion, in particular, plays a strong social as well as spiritual role in the lives of many Italian Australians with a large majority of Italian speakers identifying themselves as Western or Roman Catholic. Even for nominal or non-practicing Catholics, traditional religious celebrations

⁴ SBS. (2012). *SBS Census Explorer*.

⁵ This category is usually referred to as Western Catholic in the 2011 Census.

and rituals are central to Italian cultural life and there is an expectation that these would be observed (eg. weddings, funerals, christenings). Often religion becomes increasingly important to Italian Australians as they age and religious mass plays an important social role for Italian communities.

Family⁶

Family plays a central role for Italian-Australians and tends to be involved at all stages of decision making and social life. Because of the value Italian communities place on family, it is often assumed that caring roles should be taken on by family members and there is an expectation among many older family members that the family will deal with most issues and that they do not need outside assistance or services.

Women in the family are traditionally expected to be the primary care givers, whether they be the wife, mother, daughter or daughter in-law. However, family involvement in daily life is often a constant and responsibility in caring for loved ones is shared to a greater or lesser extent. This can include extended family and uncles, aunts, cousins and family friends are often regular visitors. 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 Italian community, and their opinion carries great authority. It is not uncommon for Italian speakers to have long established and trusted relationships with their GP and to share trusted GPs with family and friends.

While it is common for people in the Italian community to discuss their general health, serious illness is rarely discussed openly, and is often referred to in general terms (for example, as 'una brutta malattia' or "un brutto male").

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 Italian 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

There is a strong stigma around mental health issues in the Italian community in Australia and among many older generation Italians, counselling is a completely foreign concept. Because of their unfamiliarity with ideas about mental health, older generation Italians 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 strong support networks amongst their female friends, there is a strong culture amongst men of not

⁶ Parts of this section are taken from Co.As.It. (2008) *Profile of Italian Australian Culture for Aged Care Service Providers*, Co.As.It. Sydney, It.So.Wel. Wollongong, St. Carthages Lismore.

speaking about their personal feelings and a tendency to avoid admitting weakness or vulnerability. Although attitudes are changing, many Italian speakers would be reluctant to consider counselling, and may be more likely to describe their emotional or mental state in terms of physical symptoms, such as nerves (*nerve*). In this regard, Italian Australians may be more likely to seek medication from a doctor to treat mental health issues. 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 ones effectively.

Attitudes to Death and Dying

Being a predominantly Roman Catholic culture, Italians in Australia do not have specific taboos around discussing death and dying in abstract terms, and it is common for many older Italians to have made some arrangements for their final resting place such as investing in burial plots. Religion often plays an increasingly important role for many Italians as they age and observing traditional Catholic practices and rites is usually an important consideration for someone who is nearing the end of life.

The notion that the death of a loved one can leave an *impressione* where they died can sometimes lead to reluctance or anxiety about whether or not it is good for a loved one to die at home. While this attitude depends on the individual, it may be worth raising this issue with participants and the fact that dying at home was a very common traditional practice in Italy.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.⁷ 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.

For many first generation Italians 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. Many older generation Italian Australians express great nostalgia for their past, and idealise the lifestyle and traditional values of their home country and regional community.

Particularly for older members of the Italian community, 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.⁸ Fears around being mistreated, confined or the cost of services can all act as deterrents to accepting external support.

In turn, the second generation Italians 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

⁷ 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 Chinese community education resource kit around elder abuse prevention, p. 2.

⁸ Co.As.It (2008). *A Profile of Italian Australian Culture for Aged Care Service Providers*, p.3.

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 Italian, depend greatly on family to access information and services, and families can feel enormous duty to their loved ones and guilt if they feel they are not meeting their responsibility.

The generation of Italian migrants who arrived in the 50s and 60s are the first large population of Italian Australians to have reached older age, and are for that reason probably less familiar with services and processes related to ageing and end-of-life care.

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 Italian will involve a different set of meanings and cultural associations.