Culturally Responsive
Palliative Care

Vietnamese 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 Vietnamese communities

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

The Vietnamese were the first large group of Asian migrants to settle in Australia after the end of the White Australia policy and are the fourth largest overseas-born population from a non-English speaking background.[1] In 2011, there were 233,390 Vietnamese speakers recorded in Australia, making up 1.1% of the entire population.[2] Most Vietnamese speakers in Australia were born in Vietnam (63.6%), followed by Australia (31.1%). The community is also distinctive as Australia's largest refugee community, although this identity is changing with a new wave of international student migration and many second generation Vietnamese speakers.

In the immediate post-Vietnam war period, Vietnamese refugees arrived in three broad waves. The first group was made up of mostly young, well-educated and wealthy Catholics who faced severe reprisals from the new government in Vietnam and fled in 1975. The second wave of refugees, beginning in 1976, was a much more diverse group and included those who had escaped to refugee camps outside Vietnam. This group included people with different ethnicities, nationalities, religions and languages. Collectively, refugees in this wave were less educated, less literate and

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[1] ABS. (2013) Cultural Diversity in Australia: Reflecting a Nation: Stories from the 2011 Census, 2012-2013. Accessed 12 June 2013: http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features902012-2013.

[2] SBS Census Explorer. (2013) *Vietnamese*. Accessed 2 August 2013 from http://www.sbs.com.au/yourlanguage/vietnamese/censusexplorer/page/in/english.

came from more rural settings. This group also included the arrival of 'boat people', travelling to Australia directly. The third group, arriving in 1978, were mostly owners of private businesses expelled by the new Vietnamese Government or small traders described as 'economic refugees'.[3] From 1982 onwards many more refugees arrived under the Family Reunion Program. Many Vietnamese refugees experienced trauma and torture before and during their escape. For that reason, many first generation Vietnamese Australians are still traumatised and have strong feelings of antagonism towards the Vietnamese government. This attitude is changing with successive generations, but is still the case for many older generation Vietnamese speakers.[4]

According to the 2011 Census, 5.3% of the Vietnamese population living in Australia are 65 years or older. 93.8% of Vietnamese speakers who completed the census recorded that both parents were born overseas. 85.2% were Australian citizens and 61.7% of Vietnamese speakers recorded that they have finished their Year 12 studies (or equivalent).

In 2011, most Vietnamese speakers identified as either Buddhist (52.6%) or Western Catholic (27.4%) with 12.8% identifying as having no religion. Because religion in Vietnam is closely bound up with Vietnamese history and culture, some Vietnamese speakers may observe religious traditions and rituals despite classifying themselves as non-religious.

Vietnamese 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.

The following are a number of commonly held Vietnamese 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 Vietnamese speaking community and it is important not to make assumptions about people's values and beliefs. There are many nuances within these categories and they can never replace engaging with the individual views of participants.

There is no history of formal palliative care in Vietnam and although the Vietnamese government began a palliative care initiative in Vietnam in 2005, few older generation Vietnamese migrants are connected to their home country.

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[3] Ben-Moshe D & Pyke J. (2012). The Vietnamese Diaspora in Australia: Current and Potential Links with the Homeland. Report of an Australian Research Council Linkage Project, p. 18; Racism No Way! (2013). *Australian Communities: Vietnamese Australians*. Teaching Resources Fact Sheet. NSW Government, Education and Communities. Accessed on 4 September 2013: http://www.racismnoway.com.au/teaching-resources/factsheets/76.html.

[4] Ben-Moshe D & Pyke J. (2012). p. 10, 21.

Family

A strong and closely connected family life is highly valued in Vietnamese communities and traditionally, the good of the family is thought to outweigh the needs of the individual, although this may be better understood as a tendency for Vietnamese people to prioritise their family's feelings over their own. Particularly among the older generation, there is an expectation that children will care for their elders and households are commonly made up of extended family. Day to day primary care and domestic duties are more likely to fall to the women in the family: wives, daughter(s) or daughter(s)-in-law. When talking about palliative care, educators may choose to emphasise the important ways that palliative care services can support families to provide the best possible care for their loved one at home.

Respect for one's elders and decision making

Traditionally, Vietnamese culture is quite strictly hierarchical, and one's parents remain decision makers for their children throughout their lives and regardless of their age. Given this, many older generation Vietnamese speakers may either exercise their authority in relation to their family or, if they are unwell, defer decision making to the eldest son (or eldest daughter). The eldest son, in particular, is traditionally seen as the head of the family and the one who will continue the family line. However all families are different and depending on the individual situation, whoever is providing direct care to the person who is unwell may play an important role in decision making. Even if one family member has the final word, they will consider the views of other members of the family in the process.

All children want the best for their parents and sometimes conflict can arise about the best way to care for loved ones and fulfil their final wishes. Educators may want to emphasise the important role palliative care can play in providing health information so that families can make informed decisions about their loved one.

Attitudes to illness

Vietnamese speakers who practice Buddhism may, on some level, connect illness with karma. In some cases, and particularly amongst the older generation, this belief may affect some people's willingness to accept the idea of pain management if they feel that their suffering in some way atones for, or is a consequence of, actions in a past life. Likewise, some Vietnamese speakers who are devoutly Catholic may feel that suffering is connected to atonement for sins. Depending on participants' views, any discussion around pain management or intervention may need to take this into account in order for the conversation to be meaningful, while reassuring participants that the palliative care team is sensitive to cultural and religious beliefs. It may also be worth discussing the role of morphine as a carefully monitored form of pain management, and not as a signal that the person who is ill is close to death.

In some instances, belief in karma can create a perceived stigma around a person's illness, because of its possible connection to actions in a past life, this life, or in relation to the discontent of ancestors. It is important to recognise that these attitudes are not the same for all Vietnamese Buddhists, and that older generations tend to be more religious than younger generations.

It is not uncommon for families to try and keep the seriousness of an illness from their parent. This is not particular to the Vietnamese community, but can be motivated by the desire to keep their

loved free from worries (particularly worries that would make them feel that the family could not cope without them), and to ensure that they enjoy the time they have to the fullest.

Attitudes to Death and Dying

Vietnamese people traditionally prefer to die at home, if possible. The thought that accepting palliative care might remove them from the home could be distressing so it is important to make the community aware that often services can be provided to allow loved ones who are unwell to remain at home. It is also important to explain that families do not lose control of the decision making process, or involvement in the day to day care of their loved one, even if they cannot remain at home. Palliative care services can help families to understand their rights and can provide accurate information to help people to make informed decisions about their or their loved one's health.

Vietnamese Buddhists believe that a body should not be moved for 8 hours after death. This may potentially influence their decision to use palliative care services, particularly inpatient services. Depending on the audience, educators may want to raise this issue or explain that palliative care services are very experienced in providing person-centred care. They respect people's individual beliefs and will observe family's wishes.

Privacy Issues

Vietnamese people prefer same sex carers if possible. Privacy and dignity are important cultural values and it should be emphasised that, if possible, personal preferences will be respected.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.[5] 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 migrants, the lack of cultural continuity can be 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, and often financially and socially dependent on their children.[6] In turn, the second 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.

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.

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[5] Parts of this section were developed from Ethnic Communities' Council of Victoria. (2013). *Respect and Dignity: Seniors, family relationships and what can go wrong. A Chinese community education resource kit around elder abuse prevention*, p. 2.
[6] Ben-Moshe D & Pyke J. (2012). p. 10.

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 Buddhists than it does to Catholics. 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 Vietnamese 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 Vietnamese, as there is no simple equivalent. *For example, cuối đời* is a good term to gently convey the end of life, but it may not capture the idea that palliative care can be accessed at any age. Other suggestions include:

1. Dịch Vụ Chăm Sóc Đặc Biệt cho người bệnh ở giai đoạn cuối / bệnh hiểm nghèo và thân nhân của họ (*A special service for people on terminally illness/with life threatening illness and their family members*)

2. Dịch Vụ Chăm Sóc cho người bệnh ở giai đoạn cuối (*Service for people who are on terminal illness*)

3. Dịch vụ săn sóc đặc biệt cho người mắc bệnh nan y và gia đình (*Palliative care is a special care for people with terminal illness and family*)

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.