Culturally Responsive Palliative Care

Chinese 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

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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 Chinese community

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

The Chinese speaking community is one of the largest and most diverse cultural groups in Australia, both culturally and linguistically, spanning many different countries of origin and regional dialects. The two most common 'Chinese' languages spoken in Australia are Cantonese and Mandarin and the experiences of these speaking groups will be focused on in this resource. Most Mandarin speakers living in Australia were born in China, Malaysia, Taiwan, Singapore, Indonesia, Vietnam or Hong Kong, with a significant number of Mandarin speakers born in Australia. Most Cantonese speakers who are living in Australia were born in China, Hong Kong, Malaysia, Vietnam, Singapore, Cambodia or Macau.[1]

Chinese immigration to Australia began as early as 1818 but was seriously curtailed by the introduction of the White Australia Policy in 1901. The policy restricting the migration of non-Europeans was lifted in the 1970s, at which time the number of Cantonese speaking immigrants increased dramatically, peaking in 1989. In contrast, Mandarin speakers began arriving in the 1980s and immigration numbers have sharply increased in the last decade, from 8,670 in 2000 to 23,259 in 2010. In 2011 there were 336,409 Mandarin speakers in Australia, representing 1.6% of the entire Australian population, and 263,673 Cantonese speakers, representing 1.2% of

[1] SBS (2012). *SBS Census Explorer*. Accessed on February 28 2013 from http://www.sbs.com.au/censusexplorer/.

the entire population. Most of the Chinese speaking population is concentrated in Sydney and Melbourne.[2]

Given their different patterns of immigration, most Cantonese speakers are Australian Citizens (79.3%) whilst around half of Mandarin speakers are not (49.8%). Although palliative care services can be relevant for any age group, both Cantonese and Mandarin communities have a significant emerging ageing population. Cantonese speaking seniors are more likely to have aged in Australia and to have citizenship than Mandarin speaking seniors who have often arrived in later life to live with their adult children.[3] A high proportion of Chinese speakers aged 65 years or over do not speak English well or not at all, with 76% of Mandarin speakers, 63% of Cantonese speakers and 62% of other Chinese language speakers experiencing a significant language barrier.[4] This is no indication of education however, given that the majority of the Chinese-speaking population has finished Year 12 or equivalent (87.1% of Mandarin speakers and 70.1% of Cantonese speakers).

There is great diversity within the Chinese speaking community, not least in relation to faith. A large number of Chinese speakers reported having no religion in the 2011 census (55.2% of Mandarin speakers and 42.5% of Cantonese speakers). However there are significant numbers of Chinese speakers who identify as Buddhists (19.6% of Mandarin speakers and 25.4% of Cantonese speakers) or who identify with some form or denomination of Christianity (approximately 14.3% of Mandarin speakers and 23.6% of Cantonese speakers).[5] Despite the wide diversity of spiritual perspectives, and depending on their individual views, some Chinese speakers may still observe particular religious traditions and attitudes as part of their cultural heritage.

Chinese 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, family background, 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 the Chinese speaking community in particular, shifting cultural values can become more apparent through the migration experience and there can be great difference between the views and values of two generations within the same family.

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 Chinese cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these

[2] SBS (2012). SBS Census Explorer.
[3] SBS (2012). SBS Census Explorer.
[4] Australian Bureau of Statistics (2011). Table generated 28 February 2013 using English proficiency by age in five year groups and language spoken at home. www.abs.gov.au.
[5] SBS (2012). SBS Census Explorer.

perspectives will not apply to everyone in the Chinese speaking community and it is important not to make assumptions about people's values and beliefs.

Family and filial piety

Traditionally, family is highly valued in Chinese speaking cultures and care and respect for one's family is seen as a great and fundamental virtue. "Three (or sometimes five) generations under one roof" (sān dài tóng táng)[6] is a complimentary mainland Chinese saying used to describe a happy family and grandparents often play a key role in caring for their grandchildren (This can even be a reason for some older generation Chinese speakers to migrate to Australia).[7]

In this sense, there is a strong expectation in traditional Chinese speaking communities that sons and daughters will respect and care for their elderly relatives. Filial piety is a highly valued and deeply ingrained cultural value that recently there have been attempts in China to legally enforce children's responsibility to care for their parents. [8]

Traditionally the responsibility of a parent's welfare falls primarily to the eldest son or daughter, who occupies a privileged position in the family. The role of the eldest son, in particular, is often valued as the head of the family and the one who will continue the family line, however day to day care, and domestic duties are still seen as the role of women in the family and are more likely to fall to the daughter(s), or daughter(s)-in-law. This can lead to tensions when, for example, parents are brought under the care of their son, but the responsibilities of daily care fall on the daughter-in-law.

While this is the traditional view, the responsibility of care depends greatly on individual circumstances. The expectations of older generation Chinese speakers in relation to family responsibility can conflict with the socio-economic pressures of younger generations, and vice versa. Nevertheless, most Chinese speaking families want to be highly involved in care and it may be important for educators to emphasise that palliative care services do not diminish family involvement in decision making or interfere with established caring roles. Because of the importance of family, many Chinese speakers will care for their loved ones at any cost, financial or personal, and it may be important for educators to make participants aware of the support that palliative care services provide to help carers in their role. Family members may feel guilt and shame that accepting palliative care is avoiding their filial responsibility and may even fear being stigmatised by the community if they access palliative care services for their loved one. If this is the case, it is important that educators emphasise that palliative care supports families to provide the best care with dignity and respect for their loved one.

Keeping face in the community

The importance of 'keeping' or 'saving face (mian/lian)' is acknowledged to a greater or lesser extent in some Chinese speaking communities. Saving face often relates to maintaining personal integrity, dignity and not bringing shame to one's family and, depending on the extent of their

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[6] Chyi, Hau, and Shangyi Mao. "The Determinants of Happiness of China's Elderly Population." *Journal of Happiness Studies* 13.1 (2012), p. 167.
[7] Wong M. Bbkayi (Baby Plus 2). MCWH: Melbourne (2012), pp. 35-36.
[8] Feng, V. "New filial piety law takes effect to much criticism in China" South China Morning post, Monday 3 July 2013, Accessed: 20 October 2013: http://www.scmp.com/news/china/article/1273003/new-filial-piety-law-takes-effect-much-criticism-china.

social networks in Australia or elsewhere, some Chinese speakers may feel pressure to meet social expectations that they perceive to exist in the wider Chinese speaking community. In relation to palliative care, social pressure to be dutiful to one's parents may create anxiety about accepting outside help. Carers may experience feelings of guilt or shame in relation to this issue and it may be important for educators to address these concerns and reassure participant's that seeking support is not an admission of weakness or irresponsible behaviour.

Attitudes to illness and pain management

The Chinese community have high regard for the medical professions and will often place great value on the opinion of their doctor and doctors more generally. Particularly among the older generation, it would not be uncommon for Chinese speakers to have consulted Eastern medicine practitioners as well and to place great importance on the types of food they eat or drink, according to traditional Eastern philosophies of health. For some Chinese speakers, ways of describing health and illness can be quite specific to the concepts and philosophy of Eastern medicine. Some Buddhists, and some older generation Chinese speakers, may associate illness with karma and see enduring suffering as part of their spiritual journey. 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. Some Chinese speakers may even feel that enduring suffering contributes to the future karma of their family.

While Chinese speakers often strongly value the opinions of their doctor, some Chinese speakers may be likely to take less than the recommended doses of prescribed medicines or to self-medicate. Educators may choose to raise this issue for discussion, if appropriate, and to emphasise to participants the importance of disclosing the use of other medicines to their doctor. It may be helpful to reassure participants that doctors will not stop them from using other herbs and medicines if they do not conflict with their prescribed medicines, but without this knowledge, other remedies can be harmful and damage their health.

It is not uncommon for families to try and keep the seriousness of an illness from their parent. This is not particular to the Chinese community, but can be motivated by the desire to keep their loved one free from worries and to ensure that they enjoy the time they have to the fullest.

Attitudes to Death and Dying

Broadly speaking, Chinese speaking cultures often have a history of taboos and superstitions around the discussion of death and dying, although this depends greatly on the individual, levels of education and whether people were raised in urban or rural environments. A lingering example is the traditional avoidance of the number four, which in both Cantonese and Mandarin, sounds similar for the word for death and is considered 'unlucky'. While superstitions such as these can be quite superficial, they indicate a strong cultural sensitivity around the issue and Chinese speakers may be reluctant or unwilling to discuss their experiences or views. Depending on their audience, educators may consider employing humour as a way of approaching the issue.

Chinese speakers confronting the death of a loved one are commonly unwilling to accept or acknowledge this possibility and will typically do anything possible to delay death. The importance of maintaining strong hope in the face of death often means that Chinese speakers will expect active or curative care to continue until the last possible minute. Although this attitude is not

particular to the Chinese speaking community alone, educators may wish to address it in relation to palliative care, which Chinese speakers may wrongly associate with giving up hope or inviting death. At the same time, it is important not to create unrealistic expectations about the role of palliative care, which does not seek to prolong life at any cost. In this regard, it may be worth emphasising the important role of palliative care services in relieving pain, without ruling out the possibility of recovery.

Despite any cultural reluctance to discuss death and dying, it is not uncommon for older Chinese speakers to have made plans for their final resting place and have clear ideas about the way they would like their affairs to be managed after their death. Particularly for those from a traditional Buddhist background, where and how one is buried can have great importance and older generation Chinese speakers may have made advanced preparations for this, with or without discussion with the family, to ensure that they will be taken care of after death.

In relation to death itself, it is difficult to generalise about whether or not Chinese speakers would prefer to die at home or not and depends greatly on the individual, the specific cultural or regional traditions of their home country and religious beliefs. Educators should be aware of the differences across Chinese speaking cultures, and may wish to raise this for discussion. Many Chinese speakers living in Australia will prioritise the level of care they or their loved one can receive during their illness and may prefer hospital or a hospice (particularly if it is ethno-specific) for that reason. Educators may want to reassure participants that some specialist palliative care nurses are available 24 hours a day if they choose to care for their loved one at home.

Attitudes towards Mental Health

Depending on their level of education and experience, there is strong stigma around mental illness amongst many Chinese speakers. This stigma may be more prevalent among older generation Chinese speakers, who are more likely to describe their mental health in terms of physical symptoms (eg. lethargy, tiredness). Some Buddhists, and some older generation Chinese speakers, may also connect mental illness with karma and see mental suffering as a test or consequence of actions in their life or past life. In general and as is the case in many cultures, Chinese speakers may feel reluctant to discuss personal issues relating to mental health outside their family circle, depending on the level of trust established with others and may be reluctant to consider counselling or other forms of support.

Many Chinese speakers living in Australia, particularly in the older generation, may lack social networks and support during the grieving process and can experience isolation and depression. Depending on their audience, educators may wish to emphasise that palliative care provides ongoing support for 12 months after someone has experienced the loss of a loved one.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.[9] 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 Chinese speaking migrants, the settlement process and lack of cultural continuity can be 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. In addition to this, many older generation Chinese speakers who migrate to Australia later in life may find themselves socially and financially dependent on their children, which can create additional pressures within families. A combination of these factors can erode communication and confidence levels and affect general health and mental well-being. Lack of language and limited literacy levels also contributes 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.

In turn, the second generation growing up in Australia can feel conflicting cultural pressures and 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. This can create conflict and intergenerational divisions which can play out in relation to issues and expectations about care. Family dynamics are rapidly changing for many Chinese speakers, not only for those who have migrated to Australia, but in many countries of origin as well. Grandchildren increasing adopt more Western attitudes and the divide between the traditional views and the Western views can sometimes be irreconcilable.

It is important for educators to be aware of intergenerational tensions and where appropriate, to encourage thoughtful and reflective discussion around these issues if they arise during a 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 Buddhists than to atheists. In both cases, it is important to recognise that your audience may respond differently to the words you use.

[9] 10 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.