



Katherine Clark
Jane Phillips

End of life care

The importance of culture and ethnicity

Background

Australia is a culturally and ethnically diverse country. Within such diversity there will be differing beliefs systems about death and dying. This may be a challenging prospect for health professionals.

Objective

This article discusses how cultural diversity may impact care and provides some strategies for the general practitioner when considering the provision of end of life care.

Discussion

This article does not attempt to provide GPs with a prescriptive approach to multicultural care, as this would run the risk of stereotyping individuals. Rather, it discusses the barriers to end of life care among different cultural and ethnic groups, and suggests ways in which to improve understanding of different cultural needs in end of life care.

Keywords: vulnerable populations (health); palliative care



Australian society is culturally diverse. The 2006 National Census revealed that only 46% of migrants since 1945 are of Anglo-Celtic origin. Currently, there are almost 400 different languages spoken in Australia, with 79% of the population speaking only English at home.¹ After English, the most commonly spoken languages include Greek, Italian, Cantonese, Arabic, Mandarin and Vietnamese (Table 1).

Despite Australia's cultural diversity, there is little doubt that ethnic minority groups continue to have less access to health care systems, let alone culturally appropriate care,²⁻⁵ including palliative and end of life care.^{4,5} Such disparity of access for all individuals requiring such care ignores a basic human right to live and die in comfort.

This article will discuss some barriers that may limit people of different cultural backgrounds receiving appropriate palliative and end of life care, and provides some generic approaches that may assist general practitioners when considering care needs of people from different cultural backgrounds. It also highlights care issues that GPs may need to consider when providing terminal care for someone from a different cultural background.

Barriers to end of life care among different cultural and ethnic groups

Providing appropriate end of life care for all population groups requires health care professionals to be culturally aware, and to develop cultural sensitivity and cultural competence.

Culture is the internal and external manifestation of a person's values, norms and beliefs that is learnt throughout life. There are numerous factors that influence this. Cultural awareness is the ability to acknowledge differences.⁶ In the health care context, cultural sensitivity refers to a health professional's understanding of how culture may shape their patients' views and the health professional's ability to acknowledge and respect differences.⁷ The health professional must be respectful of their patient's belief systems, while mature enough to reflect on their personal beliefs. Doctors, like the rest of the community, inherit belief systems from their ethnicity of origin and adapt these beliefs to their place of residence. Doctors also adopt the culture of medicine. Like any other cultural group, medicine has its own language, belief systems and values that may require translation and explanation to lay people.



Table 1. 2006 census: top 10 languages spoken at home in Australia¹

Language	Number	Proportion of population
English	15 581 300	78.5
Italian	316 900	1.6
Greek	252 200	1.3
Cantonese	244 600	1.2
Arabic	243 700	1.2
Mandarin	220 600	1.1
Vietnamese	194 900	1.0
Spanish	98 000	0.5
German	75 600	0.4
Hindi	70 000	0.4

Cultural competence is an amalgam of skills, abilities, capabilities, and competencies necessary for the establishment of respectful and culturally appropriate relationships.⁸ Rather than just appreciating different beliefs or values, cultural competency illustrates a doctor's skills when approaching a consultation with a person outside of the doctor's cultural group. This includes the special skills that are best learnt through formal communication skills teaching programs.⁷

Improving access to end of life care

Ensuring that people have equity of outcomes at the end of life requires an awareness and commitment to deliver culturally appropriate palliative care. Seeking an understanding of the

patient's beliefs about the causation of illness is imperative. Furthermore, an appreciation of whether or not there may be social, political, and historical contexts, including highly significant events such as war or famine that could impact on the patient-doctor relationship should be sought. Considering these issues may allow the doctor to identify opportunities to interrupt unequal power relations. Delivering culturally appropriate care is founded on mutual trust, respect of the patient's nationality, culture, age, gender, and political and religious beliefs.

Improving palliative care outcomes for all people requires attention to the cultural competency dimensions, including:

- the culture of individual patients and their families, informed by the beliefs and practices about health, illness and death that they bring to the palliative care experience
- the cultural practices and values of the health professionals involved in the delivery of palliative care, and
- the health care system's capacity to foster culturally competent palliative care delivery by addressing the socioeconomic gradient, systemic and institutional discrimination and gaps in understanding between culture and health.⁹

Understanding cultural differences in end of life care

Cultural factors shape patients' preferences around decision making, receiving bad news and end of life care.¹⁰ The developed world's emphasis on patient autonomy, informed consent and truth telling is often at odds with the beliefs and values of some cultural groups, who may place greater value on family involvement in decision

Table 2. Key questions for GPs when exploring cultural beliefs of patients at their end of life

Focus	Potential questions
Communication	<ul style="list-style-type: none"> • Some people want to know everything about their medical condition and others do not. How much would you like to know?¹⁰ • Do you prefer to make medical decisions for yourself, or do you prefer your family to decide for you?¹⁰ • Would you like to be in the room when I speak with your family?¹¹
Cultural values	<ul style="list-style-type: none"> • Is there anything that would be helpful for me to know about how you and your family view serious illness?¹⁰ • Are there cultural beliefs, practices or preferences that might affect you at times of significant illness?¹¹ <p>If the patient is open to discussions about death, the following questions may be considered:</p> <ul style="list-style-type: none"> • What concerns do you have about death?¹¹ • Are there things that are important to you and your family that I should know about?¹¹
Comprehension	<ul style="list-style-type: none"> • Can you tell me, in your own words, what you have heard from me and what's most important to you about what I have said?¹⁰
Customs	<ul style="list-style-type: none"> • Are there any specific practices that you would like to have in the hospital or home?¹¹ • Are there aspects of medical care that you wish to forgo or have withheld because of your cultural beliefs? • Is there anything that is discouraged or forbidden?¹¹ • Are there any specific practices that are important to you at the time of death, or afterward, that we should know about?¹¹



making as opposed to individual autonomy.¹⁰ Discussing death is actively discouraged in some cultures as it is viewed as an indication of disrespect, likely to extinguish hope, invite death, and/or cause distress, depression and anxiety.¹⁰ Understanding each patient's, and their family's, cultural needs and preferences is essential to provide palliative care in a manner that conforms to their individual values and ideals. Asking a series of respectful open ended questions about an individual's culture provides critical insights into the person's values, beliefs and needs in the context of advanced and incurable illness (Table 2).^{10,11} An interpreter may be required (see the article, 'Using interpreters: a guide for GPs', in this issue).

Care around the time of death

Common themes have been identified as important to the dying, regardless of cultural background. Aspects of care that are deemed highly important include:

- comfort and not being in pain
- good communication between patient and doctors
- maintaining hope
- honouring spiritual beliefs
- fixing relationships
- making plans, and
- saying goodbye.¹²

While these themes are common, approaching the delivery of care that meets the needs of the individual is not.

Death is an inevitable outcome of every person's life but each individual's experience of death is unique. Providing care for a person as they enter the final stages of their life is often stressful and sad for families, a situation that may be worsened when health professionals make assumptions about a patient's beliefs. Different groups will have different attitudes to reducing or ceasing supplemental fluids and discussions around resuscitation, and approaches to providing symptom control may be dictated by an individual's belief systems. In some cultures, pain must be experienced, as this is evidence of the body fighting to overcome disease. In other cultures, pain is viewed as punishment.¹³

To add to this complexity, there are numerous differing attitudes to analgesia, some of which contribute to the ongoing problem of inadequate pain management. Negative attitudes to analgesia may be held by individuals (both professional and lay people) and different social and cultural groups.¹⁴ However, it is naïve to assume that all individuals hailing from a particular group will choose to deal with pain or other symptoms common at the end of life in an identical manner. This may be a challenging time for GPs who are professionally obliged to deliver care as medically appropriate for the dying person, while respecting the cultural needs of the person and their family.

It is not an uncommon practice in specialist palliative care in Australia to offer people the opportunity to die at home. While this may be acceptable to some families and cultural groups, for others with different belief systems it is not. For some people, a death in the home may dictate the need for elaborate cleansing rituals, or may

mean the house has to be abandoned. In other cultural groups it will be important for religious or spiritual practitioners to attend the dying person.¹⁵ As there may be important rituals during the dying process, most cultures have significant rituals to be observed after death. It is important that GPs have an appreciation of what the particular needs of a family are, and how this may be best matched with the doctor's own legal responsibility to properly certify death. In some instances, this needs to happen very quickly with minimal contact between the deceased person and the doctor. In other instances, the body must not be disturbed until the family's spiritual advisor indicates that it is safe to do so (see *Case study*). In a person's own home, such restrictions are clearly more easily surmountable compared to an institution, where such requests will require negotiation and planning. When a person is dying in hospital, a degree of flexibility is required. This is best achieved by facilitated open communication between all parties. One of the most important steps in this process is identification by the health team of a spokesperson for the family.

Regardless of the cultural group, rituals around the time of death are important for the person who died, for those close to the deceased, and for their community. Such rituals allow confirmation of the death and provide a clear separation between the living and the dead. This allows those who are grieving for the dead person an opportunity to begin the task of assigning a new identity to the deceased, an important part of successful bereavement.

Case study

Mrs VH, 66 years of age, was born in Vietnam and immigrated to Australia with her son and daughter-in-law 15 years ago. She is a devout Buddhist. Mrs VH has been hepatitis B positive since birth and this is now complicated by advanced hepatocellular cancer. Over the past week, she has become increasingly unwell. Her family are concerned and bring her to the hospital for admission. During hospital admission, her liver function rapidly deteriorates and she develops hepatorenal syndrome. Her son is most concerned as he wishes the correct preparations to be made for her death.

In discussion with Buddhist monks, the inpatient unit agreed that she would be nursed through the final hours of her life with minimal noise and activity in her room to ensure that her soul was as untroubled as possible. It was agreed that immediately after her death the family would advise staff, but that she would not be touched, allowing her consciousness to depart and embark successfully on the way to her next life.

On the day of her death, close friends and spiritual advisors were present to oversee the process, and when it was deemed, 8 hours later, that her consciousness had departed, she was examined and the death certificate issued.

Conclusion

In the Australian palliative care context, being culturally appropriate requires an understanding of:



- the disclosure and consent preferences of the patient
- the degree to which individual versus family decision making is preferred
- specific privacy issues
- the meaning assigned to the disease and its symptoms
- the patient and their family's attitudes toward medications and nutrition, preferred end of life rituals, and customs and spiritual and/or religious preferences.¹⁶

Taking the time to understand each patient's unique cultural needs, values and beliefs is the most respectful way of delivering palliative care and facilitating a dignified death.

Summary of important points

- An individual's culture is influenced not only by their ethnicity but other learned beliefs and values that evolve over a person's life.
- Cultural diversity is associated with differing belief systems regarding death and dying.
- General practitioners are challenged to provide medical care within the context of an individual's biopsychosocial needs.
- Open communication aimed at understanding how each person's belief system shapes their palliative care and terminal care needs forms the basis of optimal care.
- Despite disparate beliefs, universal care needs valued at the end of life include the provision of comfort, appropriate communication between the patient and doctor, respect for spiritual beliefs, and the opportunity for the dying person to say goodbye.

Resources

- CareSearch multicultural resources: www.caresearch.com.au/caresearch/ForPatientsandFamilies/SpecificGroups/Multicultural/tabid/229/Default.aspx
- CareSearch indigenous resources: www.caresearch.com.au/caresearch/ForPatientsandFamilies/SpecificGroups/Indigenous/tabid/522/Default.aspx
- Palliative Care Australia. Multicultural palliative care guidelines: www.palliativecare.org.au/Portals/46/Multicultural%20palliative%20care%20guidelines.pdf
- The RACGP. Clinical resources for cultural and linguistic diversity: www.racgp.org.au/cald.

Authors

Katherine Clark MBMS, MMed(pain), FRACP, FACHPM, FACP, is Associate Professor, The Cunningham Centre for Palliative Care, The University of Notre Dame Australia, Sacred Heart Centre, Sydney, New South Wales. kclark3@nd.edu.au

Jane Phillips RN, PhD, is Professor Palliative Nursing, Cunningham Centre for Palliative Care and School of Nursing, The University of Notre Dame Australia, Sydney, New South Wales.

Conflict of interest: none declared.

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correspondence afp@racgp.org.au