PALLIATIVE CARE AND CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES

Position Statement

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.[1]

Palliative Care Australia believes

- Quality care at the end of life is realised when it is individualised to meet the person's needs and upholds their preferences which are based on many factors, including individual cultural beliefs.

- The process of dying, perhaps more than any other moment in the course of medical care, can accentuate cultural differences between patients, families, and providers.[2]

- Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people.

- The consequences of culturally inappropriate care can include psychological distress and unnecessary suffering for the patient, family, carers and community.

- As Australia's cultural diversity increases, cultural misunderstandings resulting in the provision of inappropriate end-of-life care to people from linguistically and culturally diverse backgrounds has the potential to grow.

- There can be issues with translators and medical interpreters where they do not feel able to honestly relay information due to their own cultural beliefs.

- Respecting and being sensitive to people from diverse cultural and linguistic backgrounds and their community ties is integral to the delivery of quality care at the end of life.[3]

- Cultural practices are not the sole determinants of patient preferences and there may be significant individual differences within communities.

- The needs of older people from culturally and linguistically diverse communities and new and emerging communities raise broad equity and access issues.

- The cultural implications of patient autonomy in regard to decision making, acceptance and utilisation of advance directives, and truth telling must be understood and respected on a case-by-case basis.

- All health professionals must have a proactive engagement in culturally and linguistically diverse issues, and therefore need a level of cultural competence when caring for people from different cultural backgrounds and the knowledge of when and how to consult further cultural expertise when required.

- The experience of care and the nature of death have as significant an influence on the subsequent grieving process of people from culturally and linguistically diverse communities as they do for people in the mainstream Australian community.

Palliative Care Australia calls for

- adoption of initiatives that build the cultural awareness and cultural competence of the broad health care workforce

    - a commitment by governments to education and training that builds the cultural competence of Australia's health workforce through undergraduate, postgraduate, vocational and continuing professional education

- flexibility in models of end-of-life care to accommodate the care preferences of people from culturally and linguistically diverse backgrounds

- training, funding and resourcing of cultural liaison officers with the necessary skills, experience and knowledge

- resourcing and actively utilising community consultation mechanisms to ensure local palliative and end-of-life care services develop a clear understanding of the needs of the communities they serve and develop appropriate strategies to meet these needs

- availability of and support for qualified and trained translators and medical interpreters who can ensure effective, efficient and reliable communication between health professionals and patients, their families and carers, particularly at the end of life[4]

    - development of protocols for health professionals to guide the use of interpreting and translation services, including addressing the issue of people not feeling able to honestly relay information due to their own cultural beliefs

- commitment to community capacity building in relation to palliative and end-of-life care through

    - the provision of comprehensive health information in a range of community languages, including information that specifically addresses concerns communities have about particular health issues such as privacy and confidentiality

    - specifically targeted health promotion programs to develop community capacity to access appropriate care when required

- systematic research in the Australian context of the cultural implications for quality care at the end of life to reliably inform policy and funding decisions.

Background

Differences in beliefs, values, and traditional health care practices are of particular relevance at the end of life.[5] As noted by Krakauer et al, culture, even for people who do not usually follow traditional practices, is particularly important in shaping attitudes about dying, death, and preference for end-of-life care. Clinicians also hold strong culturally determined beliefs about dying and death and these inform their practices in caring for people who are dying.[6]

Health care providers must recognise that the basic values, principles, and assumptions of western medicine and bioethics are themselves culturally determined and may be alien to patients from different cultural backgrounds. The concept of "good", of what is beneficial and right for the patient, is influenced by the cultural framework from which the health professional comes and from their personal and professional experiences.[7] These culturally informed actions can be in conflict with the desires of the patient.

However, it is important to realise there can be tremendous diversity within specific ethnic groups manifest through wide variation of beliefs and behaviours.[8] It is important to avoid the danger of a 'cookbook' approach to diversity which could compound misunderstandings. People may uphold certain cultural practices, or they may in fact be agents for change within a certain culture, for example, within second generation immigration populations. Furthermore, cultures change and evolve over time. [9]

Increasing CALD constituency

As a result of profound worldwide demographic change, doctors and other health professionals will increasingly care for patients from cultural and faith backgrounds other than their own. Australia is one of the most culturally diverse countries in the world and will remain that way for generations to come. In Australia, over 300 languages are spoken, more than 100 religions and beliefs are practised and many of the world's ethnic groups are represented from over 230 different countries. Further, Australia's ageing culturally and linguistically diverse population is experiencing more rapid growth than the general population and by 2011 it is estimated that over 1 million Australians over 65 will be from culturally and linguistically backgrounds.[10]

Individualising care

Whilst there may be cultural specifics broadly applicable to people from similar cultural backgrounds, and these may guide the delivery of care, 'patients should never be approached as empty vessels, as the bearer of particular cultures'.[11] Rather, patient care should be individualised, taking into consideration a range of factors. 'Care is, in the end, given to a particular individual, here and now, in his or her time and place and particular circumstances.'[12]

Patient autonomy and other cultural considerations

The concept of patient autonomy and patient-directed care is a key principle in the Australian health context. This approach is not equally applicable across cultural groups and can thus cause ethical dilemmas for health professionals who associate autonomy with the right to know. In some cases, physician and family based decision-making may be preferred over patient autonomy: family duties and obligations take precedence.[13] Diagnosis may be first conveyed to the family and indirect nuances preferred over truth telling in relation to prognosis. The patient may exercise the right not to know.[14]

Furthermore, tools and treatments considered integral to the provision of quality care at the end of life are not universally accepted. Advance care directives may be seen as prolonging autonomy when autonomy is not sought. There are also large variations in attitudes towards pain relief.[15]

Other cultural considerations include:
- care setting – there may be strong resistance to institutionalised care
- language and communication - English language skills not universal
- role of the family in caring
- diet and food
- personal care rituals
- specific cultural beliefs and religious practices.

Building cultural competencies in health

Quality, appropriate and comprehensive care is culturally sensitive and requires health professionals to understand each patient's view of their situation and their expectations of the mode of decision making and type of care that should follow.[16]

Lickiss[17] identifies cultural competence as constituting more than an awareness of a range of customs. Cultural competence includes, but is not limited to:
- communication issues, including disclosure and consent
- modes of decision making – how or when is the patient or family involved, the role of advance care planning
- concepts of disease, the meaning of pain and other symptoms
- ways of conceptualising death and dying in relation to the rest of life
- customs surrounding death, burial or cremation, and bereavement
- attitudes to medication (especially opioid drugs and sedatives) and to nutrition
- privacy issues
- spiritual matters, as well as religious issues, including rituals.

It is not realistic for health professionals to understand the breadth of cultural beliefs in relation to illness. However, it is reasonable that they understand this in relation to populations they see often, and have the skill to identify when they need further assistance and the pathways to access this assistance.

Building community capacity

Culturally and linguistically diverse communities may not have the same approach to health issues as the western medical system. These differences include:
- individualism versus collectivism
- definition of family

- common views on gender roles and care of older adults
- communication patterns – direct versus indirect, nonverbal
- views of physicians, suffering and afterlife.

From the community perspective, the capacity of culturally and linguistically diverse communities to interact positively with the health care system can be seriously hampered by a number of factors:
- lack of knowledge about available health and social services
- fears the health care system will not understand and respect their health care needs, belief systems, and patterns of health service use
- low levels of literacy in English and first language.[18]

In partnership with efforts to improve the cultural competence and responsiveness of the health system, much can be done to improve the capacity of culturally and linguistically diverse communities to interact positively with the health system through the provision of educational materials in community languages and the empowering of communities to provide information to the health system on culturally appropriate approaches to care.

[1] The following definitions of end of life, end-of-life care and palliative care are used throughout this position paper.
End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.
End of life care: End of life care combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care.
Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goals is quality of life.
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[3] Palliative Care Australia, *Strategic Plan 2008-2011*, Palliative Care Australia, Canberra, 2008.
[4] L Crawley, P Marshall, B Lo & B Koenig, 'Strategies for culturally effective end-of-life care', *Annals of Internal Medicine*, vol. 136, no. 97, May, 2002, pp. 673-679.
[5] ibid.
[6] E Krakauer, C Crenner & K Fox, op. cit.
[7] L Crawley, P Marshall, B Lo & B Koenig, op. cit.
J Lickiss, 'Approaching death in multicultural Australia', *Medical Journal of Australia*, vol. 179, no. 6 supplement, 2003, pp. S14-S16.
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[9] Lickiss, op. cit.
[10] National Health and Medical Research Council, *Cultural competency in health: a guide for policy, partnership and participation*, 9 December, Australian Government, Canberra, 2005.
[11] BA Koenig in J Lickiss, op. cit.
[12] J Lickiss, op. cit.
[13] F Kanth, *Cultural competence in end-of-life care for Asian Indian immigrants*, 8 September, research presentation, Dalhousie University, Canada, 2006.
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K Chater & C Tsai, 'Palliative care in a multicultural society: a challenge for western ethics', *Australian Journal of Advanced Nursing*, vol. 26, no. 2, December 2008/February 2009, pp. 95-100.
[14] K Chater & C Tsai, op. cit.
[15] H Searight & J Gafford, op. cit.
[16] Lickiss, op. cit.
[17] ibid.
[18] Federation of Ethnic Communities' Councils of Australia, *Improving health and well-being outcomes for Australians from culturally and linguistically diverse backgrounds*, Health policy statement, FECCA, Canberra, 2007.