

section 6.2: Aboriginal and Torres Strait Islanders

considering context and culture

Central to providing palliative care to Aboriginal and Torres Strait Islander patients is an awareness of the implications of cultural identity, the powerful role of traditional beliefs about sickness and death, the role of family, community and traditional healers and the impact of experiences with western civilisation that span generations.

Aboriginal and Torres Strait Islander people have poorer access to medical care, domiciliary nursing care, palliative care, allied health care, bereavement and home care support in comparison with their non-indigenous counterparts.¹ This is likely to be the result of a range of factors including the lack of culturally respectful care shown within health care services, geographic isolation, difficulty in accessing services or fear or lack of understanding of the role that services can play and mistrust of all government agencies due to past experiences of injustice.

A key step in providing “culturally safe”² and “competent”³ care is an acknowledgement that differences between cultures exist, that these require respect and that our usual ways of relating to people can cause them to feel uncertain, unsafe or offended.⁴

particular issues facing indigenous patients

- 1 in 4 live in remote or very remote regions of Australia; that is 100 kms or more away from a hospital or community health centre
- death rates for Indigenous Australians are amongst the highest in the world, particularly in the 25-45 years age group
- Aboriginal and Torres Strait Islander people are more likely to present with advanced illnesses and have multiple health problems, including hypertension, diabetes, respiratory and renal disease
- Aboriginal and Torres Strait Islander people may or may not speak English or it may be a second, third or fourth language
- the burden of grief is high and includes unresolved grief dating back to colonisation, recent deaths, traumatic deaths, loss and abandonment, loss of culture and identity
- poor literacy or numeracy, poor living conditions and poverty may all impact on patient management, particularly in accessing and managing medications

specific considerations

Dying as secret

- discussing death and dying is still taboo in many Aboriginal cultures – even visiting the doctor or being in a surgery or hospital can be an extremely uncomfortable experience

Relationship with family and community

- family and community are highly valued – family may be an extended one and involve complex relationships of obligation, support and avoidance
- elders in the community are the respected holders of knowledge

Relationship with home

- "country" or traditional homelands is a central theme for many people
- people will often use regional terms to describe themselves, eg Nunga or Adelaide person
- spirituality and identity are often determined by the land
- the wish of many Aboriginal people is to die on their own "country"

Communication styles

- traditional western ways of showing respect may not be appropriate
- verbal communication of needs can be a really difficult issue

Pain and symptom management

- addressing the cultural and spiritual needs of the patient may be more important than meeting the physical needs such as pain relief⁵
- patients may be reserved and unobtrusive about experiencing and reporting pain
- patients may be reluctant to accept that medications may be required to manage symptoms and that they may be necessary for the rest of their lives

Decision-making and consenting

- establish early with the patient who is the right person to make decisions
- the person nominated as the next of kin may not be the most culturally appropriate person to give consent, nor might it be the escort if the person had travelled from a distant region
- a decision may need to be made by a group of people living in the patient's home community – this may take longer than the usual consenting procedures
- arranging a family meeting may be of great benefit – this may take some time to arrange if the family is large
- choosing the right person for consent may avoid "payback" issues with people who hold traditional concepts of death and dying
- Aboriginal Health Workers can assist in the consenting procedure

Role of interpreters

- English is not the first language of many patients
- interpreters can make family members more at ease and ensure that consenting and decision making is based on adequate information
- interpreters can assist in explanations, particularly if difficult or complicated information must be conveyed

Gender and kinship based issues

- particular customs may determine rules for care provision, eg a male son may not care for his ill mother, a son-in-law is unable to be in the presence of the father-in-law – however, never make assumptions and always check

practical suggestions when caring for patients and their families

1. Providing care during hospitalisations

- offer to involve the family in providing direct care
- consider the use of a larger room if there are large numbers of the patient's community who travel long distances to visit
- provide access to open spaces

- traditionally women's business and men's business are kept separate – this may have implications for the gender of health care staff and staffing allocation
- “bush doctors” or Ngangkari are traditional healers who use parts of plants and animals to make traditional medicines – these healers can play an important role for patients and may be requested by families
- consider making special arrangements to accommodate specific ceremonies eg cleansing a room with a “smoking” ceremony
- accommodation for the visiting family may be the most urgent need – consider requesting early assistance from the Aboriginal Hospital Liaison Worker and social worker

2. Financial considerations

- medications can be a costly and difficult to access, particularly in remote areas – is the medication in question PBS listed?
- funerals and transportation of the body may pose a huge financial burden to family, given the remoteness of some communities and lack of access to transport – limited specific funding for funerals is available through Centrelink, talk with the Social Worker
- the “Funeral Assistance Program” provides help for adult relatives who are genuinely unable to pay for the funeral – contact Families SA, phone 1300 762 577

3. Communication suggestions

- invest time in establishing a rapport with the patient
- tell the person about yourself, your family and children (if appropriate) and describe your work
- ask the person where they are from
- mention any ties that you may have with the ATSI community
- adjust your communication style in order to accommodate individual differences and preferences
- ensure you are talking with the right person about health care decisions – this may not be the patient
- when asked a number of questions, which is the normal mode of medical examination, the indigenous person may not feel under any obligation to reply, this makes establishing rapport even more important
- a softly spoken and informal style may be more appropriate
- speak in an easily understood manner, avoiding technical terms
- use indirect questions and silence, eg ‘You’re not feeling well today, Mrs Jones?’ ‘I can see that you are in pain – does it keep you awake at night?’
- eye contact may be perceived as showing disrespect for the person's identity and knowledge
- touch may not be considered appropriate or respectful
- understand the role of silence – care providers may mistake the person's silence for rudeness, vagueness or deliberately avoiding the question, arrogance, inattention or non-compliance, when this may be time for thinking things through
- break bad news gently, allow “circling around the topic” to give the patient time to prepare
- use the words “not going to get better” and having a “serious illness” or “about to go” or “finishing up” to indicate imminent death – these terms may be more acceptable than the word “dying”

4. Care planning

- a care plan is best developed with the input of the Aboriginal Health Worker and in partnership with the patient's local community health services and GP

- be prepared to let the patient's community explain what is needed
- returning home to spend time with kin and in the patient's own country may be more important than receiving treatment, eg radiotherapy
- facilitating a rapid return to the community may take greatest priority
- cultural norms within Indigenous communities can vary enormously – if you are concerned about offending the patient or family, always ask what is the appropriate way to approach a particular person.

related resources and information

The Companion Guide: Providing culturally respectful palliative care to Aboriginal people in South Australia (2006)

This publication provides an extensive listing of South Australian resources (both metropolitan and country) for Aboriginal people including:

- health services
- translating services
- travel and accommodation and financial supports

A Resource Kit: Providing culturally respectful palliative care to Aboriginal people in South Australia (2006)

Both resources can be accessed on line at www.pallcare.asn.au and from the Department of Health, South Australia

Providing culturally appropriate palliative care to Indigenous Australians: Resource Kit (2004), Australian Government Department of Health and Ageing

Can be accessed at www.caresearch.com.au along with links to related websites and references to relevant journal articles.

references

-
- ¹ Sullivan, K & associates for the Department of Health and Ageing. National Indigenous Palliative Care Needs Study. (2003)
 - ² Prior, D (Winter 2001) Cultural safety in Palliative Care issues for Research and Practice. Palliative care news (Winter 2001)
 - ³ Health and Social Policy – An introduction to Cultural competency. Royal Australian College of Physicians. November 2004.
 - ⁴ Providing Culturally appropriate care to Aboriginal people in South Australia. Resource kit (2005) South Australian Department of Health.
 - ⁵ Providing culturally appropriate palliative care to Indigenous Australians (2004) Department of Health and Ageing, ACT.