



THEME

Palliative care



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Palliative care for specific populations

BACKGROUND

Ensuring access for all Australians to high quality palliative care requires an understanding of special considerations for specific populations, including children, older persons, and Indigenous Australians.

OBJECTIVE

This article reviews some specific considerations for selected populations requiring palliative care.

DISCUSSION

The complex clinical and support needs of children needing palliative care requires a well coordinated multidisciplinary team, inclusion of parents and siblings as part of the unit of care, and the use of developmentally appropriate communication strategies. Older people too may have different palliative needs. These include the need for careful assessment to ensure that reversible conditions, and emotional and existential concerns are not overlooked. Where the preferences and wishes of the person cannot be obtained, various clinical, ethical and legal principles will guide decisions. To ensure culturally appropriate care is provided to Indigenous Australians requiring palliative care, both Indigenous organisations and people should be included in the planning and provision of care.

Ensuring access for all Australians to high quality palliative care is a key objective of Australia's National Palliative Care Strategy. Contemporary standards for palliative care provision emphasise that quality palliative care for specific populations (such as children, older people, and Indigenous Australians) is based on respect for the uniqueness of the patient, their caregivers and their family. This requires that the needs of the patient, their caregivers and their family are acknowledged and guide decision making and care planning.¹ This article reviews some specific considerations for selected special populations requiring palliative care.

Palliative care for children

More than half of children referred for palliative care have a diagnosis other than cancer.² Four main categories of childhood diseases have been defined for which palliative care may be required. These include:

- conditions for which curative treatments have failed (eg. cancers)

- conditions for which intensive treatment may prolong and enhance life, but because of which premature death still occurs (eg. cystic fibrosis)
- progressive diseases for which treatment is exclusively palliative, but which may extend over many years (eg. lipofuscinoses)
- conditions such as severe cerebral palsy in which neurological problems, although not progressive, lead to vulnerability and increased susceptibility to complications and premature death.³

The clinical context associated with caring for children with such life limiting conditions presents many challenges for general practitioners. Many families prefer their child to die at home, with the involvement of their GP in the child's care often increasing as curative options are exhausted. At the same time, the specialised clinical needs of this group often mean that much of the medical care is provided by specialists in the acute care sector.² The transition between curative and palliative care is not straightforward, and the range and type of services required for the child and their family varies considerably.⁴

The diagnosis of a life limiting condition in a child also presents profound social and emotional challenges for all involved in the child's care. For example, the developmental stage of the child can influence the way they understand illness, treatment and death; the way they communicate and respond to symptoms; and their degree of dependence on others for their physical, emotional and social wellbeing. The unique place of children in society means that parents are usually very actively involved in their end of life care.^{2,5} Studies suggest that the grief process for parents facing death of a child is often more prolonged and intense, with a higher risk of complicated grief.⁶

The complex clinical and support needs of children requiring palliative care requires a well coordinated multidisciplinary team, including paediatricians, GPs, nurses and social workers. The team may also include services from the education and disability sectors.² Close collaboration between hospital and community based primary palliative care teams and primary care providers is necessary to enable families to continue to care for their children in the home environment.²

It is recommended that a developmentally appropriate explanation of the condition and the potential benefits of treatment options be given to children, and guidance be given to parents about how to communicate with children about difficult issues.⁷ For example, pre-school children typically have a beginning level of understanding about illness. It may be helpful to talk about the illness with pictures or dolls, or to read a picture book about the illness.⁸ School aged children may be able to understand more complex explanations of their diagnosis. Explanations should be simple and brief, and repeated when necessary.⁸ Teenagers are usually capable of abstract thinking and can think about things they have not experienced themselves. For this group, it is often helpful to encourage talking about feelings, although some teenagers may confide more in friends or other trusted people.⁸ Importantly, when communicating with children in any age group, it is important take cues from the child and respond accordingly.

Parents of children who are dying need to be actively involved in the child's care. Several studies report that parents generally have a high need for information about their child's illness or condition, as well as practical issues concerning the implications of the illness.² Parents often need responses to questions about what the illness may mean for the child and family and their every day lives, what they will be able to do or unable to do, what effect the disease will have on the child's schooling and social life, and what types of activities

the child will be able to participate in.² Parents will also often have questions about the last stages of life and what they should do at that time. Ensuring consistent messages are provided to parents – in a manner that is sensitive to the parent's readiness for such information – is critical.

Siblings of children requiring palliative care can also experience significant distress. How a child dies can influence their sibling's ability to make and maintain friendships.⁹ Including siblings in the unit of care to ensure their needs are identified and addressed is important.

Palliative care for older persons

Older persons with chronic and complex illnesses are considered to have different palliative needs to those people diagnosed with cancer.¹⁰ These differences may include that:

- they have multiple clinical diagnoses that require a range of treatments
- they require end of life (terminal) care for a shorter length of time (an average time of 2 days of intense care before death)
- confusion, dementia, and/or communication difficulties may be present
- they require a palliative approach for long periods to promote quality of life and reduce suffering through adequate assessment and management of symptoms.¹⁰

More specifically, older people commonly have chronic degenerative diseases which have a less predictable course than diseases such as cancer. Noncancer life shortening conditions are sometimes not considered for palliation. Careful assessment of the older person to ensure that reversible conditions are not overlooked is therefore essential.¹¹ In older people, best practice guidelines suggest that in situations such as infection and eating difficulties, active treatment to manage difficult symptoms should be combined with the palliative approach.¹¹

There is some evidence that symptoms such as pain are undertreated in older persons.¹² Moreover, the intensity of the physical care required for older persons can sometimes overwhelm the extent to which emotional, existential and social support is offered.¹³ Being attuned to these needs is essential for provision of quality palliative care.

Communication difficulties or diminished mental capacity of the older person are a further issue. Importantly, many older persons can still answer questions regarding their quality of life even when

significant symptoms of dementia are present.¹¹ An older person's preferences for quality of life concerns should still be sought and incorporated into decision making.¹¹ In cases where the preferences and wishes of the older person cannot be obtained, various clinical, ethical and legal principles will guide decisions. These include:

- capacity of the person to cooperate with the treatment
- prognosis for survival with and without treatment
- positive and negative effects of treatment options
- level of functioning before and after proposed treatment, and
- alternatives to a curative treatment strategy.¹⁴

These considerations are undertaken in the context of the broader ethical principles of doing good, doing no harm, and treating all persons fairly, regardless of issues such as age.¹⁵ Health care professionals also need to understand the relevant statutory framework in their state, and seek advice through relevant organisations or through the guardianship authority in their state or territory where required.

Each jurisdiction has established mechanisms for enabling legally binding advanced health directives or enduring powers of attorney. Such documents may give directions about future health care, and allow the person to appoint a decision maker should he or she lose the capacity to make decisions. However, unless the person with dementia has an advanced directive or medical power of attorney in place, the treating clinician in consultation with the family and any legally appointed guardian, must make decisions about treatment for an acute event.¹⁵ The seriousness of implications associated with decisions regarding withholding or withdrawing life sustaining treatments makes this area of practice one of the most difficult for health care professionals.

Palliative care for Indigenous Australians

There is no unitary Indigenous Australian experience, and care needs to be taken with generalising across Indigenous Australian communities concerning culturally based responses.¹⁶ Notwithstanding this diversity, profound cultural differences exist between Indigenous Australian and nonindigenous beliefs concerning health, especially in the context of death and dying.¹⁶ For example, traditional beliefs surrounding the sacredness of the land and the indigenous person's relationship to it through the Dreamtime are central to end of life needs and practices for many indigenous people.¹⁶ The importance of being near to one's home country at the time of death is therefore a common theme in

care for this population.¹⁷ Recent national reviews of the needs of indigenous persons who are dying have also concluded that the concept of palliation is not well known in indigenous communities. Moreover, for some indigenous persons, family may extend to distant relations and those related through traditional kinship or cultural grouping.^{16,17} These family members may experience considerable stress, and social and financial hardship. Providing culturally appropriate responses to meet the needs of indigenous people is, therefore, extremely complex.

Evidence from recent reviews commissioned by the Department of Health and Ageing suggests there is a need for culturally appropriate information for patients and families, and the need for strategies to assist Indigenous Australian health care professionals and services to understand the place of palliative care.^{16,17} Recently, a series of practice principles have been produced by the Commonwealth Department of Health and Ageing to assist health care professionals to meet the cultural needs of Indigenous Australians, their families and their communities.¹⁸

Specifically, the principles suggest that Indigenous Australian organisations and/or personnel should be included in the planning, provision and monitoring of palliative care to ensure culturally relevant requirements are addressed and preferences of the patient and/or their family are considered.¹⁸ For the GP, this may include developing policies that support cultural safety including obtaining cultural advice and accessing support from local indigenous services.¹⁹ For many Indigenous Australians, efforts to decentralise care away from hospitals is also likely to demonstrate respect for cultural needs.¹⁹

Communication with the Indigenous patient, their family, and their community must be undertaken in a sensitive way that values cultural difference. For example, techniques such as persistent or direct questioning, reflection, sharing perceptions, eye contact and touch, and use of the terms death and dying may not be appropriate for all Indigenous Australians.¹⁹ Taking time to build a relationship with the patient, and involving and checking with Indigenous Australian support personnel is important. Speaking softly, and including questions about cultural need may be helpful.¹⁹ Identifying family and kin who may need to be involved in such communication is also required.¹⁹

Conclusion

Although there are some specific issues that relate to palliative care for children, older people, and Indigenous Australians, the basic principles of respect for autonomy,

understanding diversity, and always acting in the best interests of the individual remain as cornerstones to good palliative care.

Conflict of interest: none declared.

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