The Caring Communities Program: Indigenous Issues in Palliative Care

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'If we want to provide culturally appropriate palliative care, we must ensure that the underlying assumptions of the care we are providing relate to the culture of dying of the patients to which the services are being provided' (Willis, 1999: 423)

Introduction

Indigenous people in Australia have significantly higher mortality rates than the non-Indigenous population, yet studies continue to demonstrate that Indigenous people rarely utilise palliative care services. The factors that contribute to this under-utilisation are complex, and have not been adequately described. It could be that predictable death or early detection of health problems are not so common in some Indigenous communities. For example Weeramanthri (1997) found that Indigenous people in the Northern Territory were seven times more likely to die suddenly and have an autopsy. The high incidence of sudden death does not mean however that Indigenous people do not also suffer from diseases that cause a more gradual decline. For example, mortality due to cancer among Indigenous communities is similar to that in the non-Indigenous population. In Alice Springs, Fried (2000) considered that 47% of the people requiring palliative care were Indigenous.

Indigenous people are disadvantaged in their access to palliative care. In urban settings authors such as Mobbs (1995) and Prior (1997) have described a reluctance of Indigenous people to use mainstream palliative care services. Attitudes towards mainstream care and experiences of health services are an important contributing factor. Reid and Dhamaarandiji (1978) describe a range of reasons why Aboriginal people avoid health services, including fear of being separated from their families, fear of hospital procedures and mis-communication between hospital staff, the patients and their families.

"People don't want to know about sickness inside, if they find problems, they'll go and chop you up, and then you'll have sickness. As soon as you touch hospital you get sickness. If someone told me that my brother or sister has cancer, then the whole family would be sick with worry" (Senior, 2001:27)

In rural and remote areas, there simply may not be services to deliver appropriate care for people with a terminal diagnosis (Willis, 1999). Long distances may make it impossible for doctors or specialists to visit the individual and already stretched community-based staff may not have the time or resources to provide adequate care. Under such circumstances essential aspects of palliative care, such as regular review of the pain a person is experiencing and updating of their pain control, and even the provision of aids and equipment, become extremely difficult.

The desire to die on country

Despite the difficulties of providing palliative care in rural and remote settings, a key theme in Indigenous discourses on death and dying is the desire to die in one's own country (Williamson, 1996). Willis describes how essential the relationship with country is for all stages of life and death for the Pitjantjatjara:

As in all stages of life, substance and spirit come from and return to country throughout this long process, and the well-being of the sick and dying continues to be drawn directly from the ancestral kuranitja which infuses the soil, air, food and water of home country.

Giving people the choice to die at home, with their friends and family is, of course a key component of the National Palliative Care Strategy, and home is considered to be the most appropriate place to receive palliative care for many non-Indigenous Australians.

However important, dying on country is not the reality for many Indigenous people who are evacuated from their communities as their symptoms and pain control become difficult to manage. Willis, however considers that preventing people from being evacuated from their communities may also involve reconsidering Western notions of patient comfort as the desire to be on country may take priority over all other considerations (Willis, 1999: 434).

The burden on carers

The generally low level of services in remote communities result in families having much of the responsibility for caring for sick, disabled and dying people. Although there is often a very strong rhetoric of families desiring to care for their relatives (Reid et al, 1978, Williamson, 1996:18) the reality often is that carers become exhausted. Senior (2003) found that many of the women in a community who were involved in the care of elderly or disabled relatives talked about being "worn out" by the responsibilities of caring. The need for a home within the community to provide respite for families, while not depriving the person the comfort of being on their own community, was clearly stated. Once again, this is not different to the experiences of carers in mainstream communities, but the needs are more difficult to meet because of the significant disadvantage of remoteness.

Palliative care programs need to be aware of the people in the community who are in the appropriate kin relationship to care for an individual and provide them with appropriate support, while ensuring that these people are not overwhelmed by all their caring responsibilities.

Communication about dying and death

In any culture, talking to patients about death and helping to make decisions about the type of care that they need are difficult undertakings. Doctors and other health staff discuss the need to be aware of the patients' situation and to provide them with clear information that the individual is able to cope with. Talking with people across different cultural backgrounds can be very problematic. Mobbs (1986) described the mis-communication that can occur between

medical staff and Indigenous people. Weeramanthri (1999) discussed the difficulty that medical practitioners have with communicating with Indigenous families about the cause of death, due to the conflict between Western and Indigenous theories about the causality.

Clear communication with families about the cause of death is essential. Indigenous people often complain that they do not receive the "true story" (Reid & Munanggurr, 1977) about the cause of a relatives' death, which makes them vulnerable to sorcery accusations.

The importance of the Caring Communities Indigenous projects

The Caring Communities Projects are well placed to address some of the issues raised above. They all have a focus on involving Indigenous people in discussions about what their experiences and expectations of palliative care are, and what sorts of services they consider to be the most appropriate and suitable for their particular circumstances. The Indigenous projects appear to be keen to work together, and have arranged to have regular teleconferences to discuss issues such as project methodology, most appropriate ways to involve and feedback results to the community, writing up papers, and strategies to deal with any problems that arise.

The dates of these teleconferences are organised for:

- Wednesday 27th August
- Wednesday 29th October
- Wednesday 10th December.

So far all Northern Territory Projects and the two projects from the Kimberley are involved. If you would like to be included in this link up please contact the CHSD.

References

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Bulletin Evaluation

We would appreciate it, if you could take some time to provide feedback on the bulletins that we have been producing for the Caring Communities Project. Could you please rate these bulletins from: **5: Very informative and useful to 1: Not informative or useful at all.**

Please circle your choice.

Bulletin No 1: Introduction to the caring communities project

1 2 3 4 5

Bulletin No 2: Ethics

1 2 3 4 5

Bulletin No 3: Qualitative research methods

1 2 3 4 5

Bulletin No 4: Literature Reviews

1 2 3 4 5

Bulletin No 5: Indigenous issues in palliative care

1 2 3 4 5

Please tick whether you agree or disagree with the following statements:

I always have a look at the Bulletins	Agree ☐	Disagree ☐
I pass the Bulletins on to other staff who may be interested	Agree ☐	Disagree ☐
The information in the Bulletins is useful and relevant	Agree ☐	Disagree ☐
E-mail is the best way to receive the Bulletins	Agree ☐	Disagree ☐
The Bulletins should continue throughout the project	Agree ☐	Disagree ☐

Do you have any suggestions for topics that could be covered by future Bulletins?
(please describe)

Please fax your response to the Centre for Health Service on (02) 4221 4679 – Thank you