

REVIEW ARTICLE

Considering Aboriginal palliative care models: the challenges for mainstream services

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ABSTRACT

This review discusses palliative care and end-of-life models of care for Aboriginal people in the Australian state New South Wales, and considers Aboriginal palliative care needs by reflecting on recent literature and lessons derived from Aboriginal consultation. Aboriginal people in Australia account for a very small proportion of the population, have poorer health outcomes and their culture demonstrates a clear resistance to accessing mainstream health services which are viewed as powerful, isolating and not relevant to their culture, way of life, family and belief systems. Aboriginal people regard their land as spiritual and their culture dictates that an Aboriginal person needs to know their origins, emphasising the value placed on kin and also demonstrating a strong desire to remain within their own country. Currently Aboriginal people tend to not access palliative care services in mainstream facilities; and there is very little data on Aboriginal admissions to palliative care centres. Over the last two decades only two models of palliative care focusing on and developed in Aboriginal communities have been implemented. The seminal contribution to Aboriginal Palliative Care was in the form of a resource kit developed to support palliative care providers to examine their practice for cultural appropriateness for Aboriginal and Torres Strait Islanders. The 'living model' coming from this project is adaptive and flexible, enabling implementation in different Aboriginal country as a participative process with community input. The Australian government's National Indigenous Palliative Care Needs Study similarly indicated that Australian empirical research on Aboriginal palliative care service provision is in its infancy, and comprehensive data on the rates of Aboriginal access to palliative care services



did not exist. What literature does exist is drawn together in an argument for the development and need for culturally specific Aboriginal palliative care models, which are culturally appropriate, locally accessible and delivered in collaboration and partnership with Aboriginal controlled health services. This is essential because Aboriginal people are a minority cultural group who are disconnected from mainstream health service delivery, and have a sense of cultural isolation when accessing mainstream services. It is preferable that palliative care is delivered in a collaboration between Aboriginal Controlled Health Service and mainstream palliative care services to ensure a dignified end of life for the Aboriginal person. These collaborations and partnerships are fundamental to ensure that a critical mass of Aboriginal clinicians are trained and experienced in end of life care and palliation. Developing palliative care programs within Aboriginal communities and training Aboriginal Health Workers, promoted and developed in partnership with the Aboriginal community, are important strategies to enhance palliative care service provision. Further partnerships should be championed in this collaborative process, acknowledging a need for palliative care models that fit with Aboriginal peoples' community values, beliefs, cultural/ spiritual rituals, heritage and place.

Key words: Aborigines, Australian, culture, end-of-life care, Indigenous health services, Indigenous population, palliative care, rural palliative care, terminal care, terminally ill.

Introduction

This review discusses palliative care and end-of-life models of care for Aboriginal people in the Australian state New South Wales (NSW), in preparation for collaboration with the Aboriginal nations in the Hunter New England region NSW. As this article forms the background for a review of regional Aboriginal palliative care models in NSW, in keeping with the NSW Health Policy Document¹, the term 'Aboriginal' will be used in this article in preference to 'Aboriginal and Torres Strait Islander', in a recognition that Aboriginal people are the original inhabitants of NSW. Occasionally the words Indigenous and Aboriginal and Torres Strait Islander will be used because of the context of content used in the development of the article.

In Australia, empirical research on Aboriginal end-of-life palliative care provision remains in its infancy. The seminal contribution to this area was in the form of a resource kit developed by the Mungabareena Aboriginal Corporation, Wodonga Institute of TAFE and Mercy Health Service Albury², designed to support palliative care providers to examine their practice for cultural appropriateness to Aboriginal and Torres Strait Islanders. This material

exemplifies the challenges associated with providing culturally relevant services to Aboriginal peoples³. Preceding this work was the Australian Government's *National Indigenous Palliative Care Needs Study* conducted by Sullivan et al⁴. A key finding from their 2003 research was that comprehensive data at that time on the rates of Aboriginal access to palliative care services did not exist. Furthermore, the research indicated that Aboriginal and Torres Strait Islander clients are either not referred to palliative care at all, or are referred at a very late stage of their illness.

Access to and use of palliative care services in Australia is an important issue, because for Aboriginal Australians cultural, language and geographic differences are key examples of the challenges and barriers needing to be overcome in accessing and utilising palliative care services. Working to ensure that all people in Australia have access to high quality palliative care is a key objective in Palliative Care Australia's (PCA) standards⁵. Aboriginal people's palliative care needs have received palliative care attention⁶, but this has been limited. In the 4th edition of the PCA's standards⁵, for example, Aboriginal peoples' needs are represented by only a few paragraphs and the detail subsumed into care approaches for the needs of the Australian mainstream population. Mainstream palliative care services are largely disconnected



culturally and often geographically from Aboriginal communities which further adds to the sense of isolation in Aboriginal peoples participation in health service provision⁷. Aboriginal people see the mainstream medical system as all-powerful and isolating. They fear their personal stories will be lost, and negative experiences in accessing mainstream healthcare are shared by many Aboriginal people⁸. Their spiritual needs are often not met and their spirituality is expressed through rituals, which remain an important part of healing for Aboriginal people. For this and other historical reasons Aboriginal people have been reluctant to access mainstream assistance, with Aboriginal Community Controlled Health services increasingly becoming the first choice healthcare access point instead of mainstream health services⁹.

In terms of a health score card, Australia's Aboriginal and Torres Strait Islander people account for 2.5% of the total Australian population¹⁰ but have significantly poorer health outcomes when compared with the Australian population¹¹. Their culture demonstrates a clear resistance to the idea of inpatient care in mainstream services, which removes them from their homeland and 'country'¹²⁻¹⁵. Care of family members who are ill is an important family responsibility in Aboriginal culture, and caring for family is preferred to take place in Aboriginal country than in a mainstream hospital^{12,14}. In comparison, the Maoris from New Zealand (NZ) comprise a larger proportion of the total NZ population at 15%¹⁶ but also have poorer health status as a group than the non-Maori population. Poor health status coupled with an acknowledgement that Maoris have different beliefs and practices related to death and dying has led to the development of Maori-specific policies and practices in relation to palliative care¹⁷. Similarly, issues of culture and health in relation to Canada's Indigenous population are also highlighted in the literature, with calls for culturally sensitive programs to continue¹⁸. Even in Ireland, the 'travelling community' (an Indigenous cultural group who represent approximately 1% of Ireland's population), have poorer health and social conditions than the rest of the Irish population as a result of cultural differences and their nomadic lifestyle¹⁹, and have been identified as having

different palliative care needs. The principle of adapting existing services and developing new services according to different cultural needs should be extended to Australia's first people.

Australia's Aboriginal people

Traditionally, Aboriginal identity is nurtured in the kinship structure via supportive mechanisms built into ways of knowing which are intrinsic in Aboriginal family structure. The family, extending to the community, is the most significant factor in the identity development of most Aboriginal people, and the family is deeply concerned to see its young people grow up with a strong sense of Aboriginality¹⁴. Aboriginal people traditionally regarded the land as spiritual, staying within their own country, identified by a group or tribal name²⁰. Despite many Aboriginal people living in cities and regional areas and not remote and isolated areas, these beliefs and values have prevailed over many thousands of years²¹.

Traditional Aboriginal culture was a combination of material things and spiritual, with ritual present in all aspects of life. In the face of mainstream influences from the non-Aboriginal population and culture, Australia's Aboriginal people have generally held firm to their origins, beliefs and cultural traditions, all of which are integral to their cultural identity²¹. Spirituality is important for Aboriginal culture and it could be described as 'transcendence' in that it relates to being beyond the physical world and a preparation for the afterlife. Aboriginal culture is not singular, but rather consists of a number of diverse cultural groups who share some common values and beliefs². Aboriginal cultures are ancient, with many dialects and customs differing from one 'country' (home territory) to another, based on established beliefs and values that have been handed down over many thousands of years²². Aboriginal people share a collective sense of spirituality and a belief in the Dreamtime¹⁸. They believe that an Aboriginal person needs to know their origins, emphasising the value placed on kin and attachment to a distinctive 'country'²³.



In terms of health and illness, spiritual beliefs in something other than that which is tangible appears to affect behaviour toward others and their belief/understanding of the causes of situational events such as health, illness and the loss of a family member²¹. These traditional belief systems have been disrupted as a result of the different contact experiences between Europeans and Aboriginal peoples over the last three centuries²⁴.

Demography and health of Aboriginal people

Utilizing the Australian Standard Geographical Classification of the Australian Bureau of Statistics, the majority of Aboriginal people in Australia live in the Major Cities (31%) with the remaining Aboriginal population being evenly distributed across Inner Regional (22%), Outer Regional (23%) and Remote/Very Remote Australia combined (24%); however, in the Northern Territory and Western Australia, the situation is reversed with 81% and 41% of Aboriginal people living in remote or very remote areas, respectively²⁵. An increased incidence of disease in rural and remote areas is thought to be related to decreased access to primary healthcare services and GPs; limited access to specialist diagnostic equipment, and the large distances people living in remote areas have to travel for health care, compared with those living in cities²⁶. For example, in Queensland, while the incidence of cancer (all cancers combined) is 21% lower for Indigenous people compared with non-Indigenous people, the mortality rate is 36% higher²⁷. Some of the reasons for an increase in cancer-related Aboriginal deaths compared with those in non-indigenous people are due to lack of access to care, lack of support, living remotely, or living in regional areas²⁷.

Australia's Aboriginal people are similarly disadvantaged when compared with other Australians across a huge range of health related and socioeconomic indicators²⁸. The levels of education and qualifications among the Aboriginal population have improved over the last two decades, and while this is associated with better health outcomes, the life expectancy of Aboriginal Australians is still significantly lower than for others in the Australian population. Life expectancy is

11 years less than the Australian average, with higher rates of child mortality, lower levels of education (reading, writing, numeracy, and completion), lower levels of employment and household income, and higher levels of family and community violence²⁹. Combined with higher rates of negative health behaviours such as smoking and excess alcohol consumption¹¹, Aboriginal people's disadvantage is a compounded, complex and multifactorial issue, which is difficult to disentangle and cannot be attributed to any single cause¹¹.

Aboriginal Australians and end of life

In Australia, empirical research on Aboriginal end-of-life service provision remains in its infancy, and comprehensive data on the rates of Aboriginal access to palliative care services does not currently exist. What is known is that Aboriginal and Torres Strait Islander clients are either not referred to palliative care at all, or are referred at a very late stage in their illness⁴. As a result, Sullivan et al argue that Aboriginal people, who are likely to have complex symptoms, may not be receiving adequate care from generalist healthcare providers⁴, and this is despite the evidence that supports the delivery of specialist palliative care. Importantly, in terms of the present discussion, it is acknowledged that referrals to palliative care services will not be taken up unless supported by cultural advocacy and/or participation by Aboriginal staff. The strong recommendation from the study is the need for Aboriginal and Torres Strait Islander people to be able to access culturally appropriate health services⁴.

One response to the need for a culturally appropriate model for end of life (EOL) care is the development of *The Living Model: a Resource Manual for Indigenous Palliative Care Service Delivery* based on NHMRC-funded research with Aboriginal peoples and service providers in the Northern Territory^{4,30}. The model is one of advocacy to be used by those 'at the coalface' of Aboriginal care to ensure there are appropriate resources to carry out the work of end-of-life care. The intent is not one of a static model to be imposed on services or communities, but rather a living and flexible



model to assist with service development, delivery and health policy implementation. The model acknowledges that every Aboriginal health and palliative care service will be different and there will be great diversity in regard to needs, obstacles, resources, geography, populations and service aims. Thus, the 'Living Model' is only the first step in the process of providing palliative care which has cultural relevance to diverse Aboriginal communities. More recently, a resource aimed at clinicians wishing to support family carers of Aboriginal Australians has also been released³¹, and while this is definitely a positive step, more needs to be done to build on these initial studies to ensure that the call for culturally appropriate end-of-life care for Aboriginal people is translated into clinical practice.

A start, however, has been made and a number of baseline concepts are documented to inform further development in this area. For instance, the distinct differences exist in the way Aboriginal Australians view life and death, in comparison to non-Aboriginal Australians. The Aboriginal perspective incorporates a whole-of-life outlook which not only focuses on the social, emotional, spiritual and cultural wellbeing of the individual, but also of the entire community^{12,32-34}, and includes a cyclical life-death-life concept³⁵ so death is not feared but seen as the time when a person's spirit leaves their body and returns to the Dreaming and the eternal life stream, to await reincarnation³⁶. Mourning and grieving customs, and ceremonies that assist the spirit to leave the physical body and return to its sacred place are common among Aboriginal people, but they also vary widely among Aboriginal groups and communities³⁷.

Australian studies have also found that there is a lack of understanding about palliative care among both Aboriginal Australians and Aboriginal healthcare professionals such as Aboriginal health workers (AHWs)¹³. Given that Aboriginal people consider the care of family members who are ill as an important family responsibility in their culture, there is a clear resistance to the idea of inpatient care which removes the Aboriginal Australian from their homeland and community, and relocates them to a metropolitan area^{13,38}.

The diversity of languages, beliefs and cultural nuances among Aboriginal people is also a significant issue impeding ideal care. Language differences are especially prominent due to the diversity of Aboriginal languages, and in some Australian (remote) locations, English may not be spoken as a second language. The native language has strong emotional and spiritual connections for Aboriginal people, especially those living in the Northern Territory where approximately 90% of inhabitants speak an Aboriginal language and many others have limited English speaking skills¹³. The inability of clinicians and patients to be able to speak the same language, particularly at the EOL is another limitation to providing appropriate, culturally competent and person-centred care¹³.

A lack of understanding of Aboriginal belief systems, Dreamtime and spirituality, and our first peoples' links to the land leads to a 'disconnect' for clinicians³⁹. More specifically, beliefs about death and dying need to be appreciated and understood from the Aboriginal perspective³⁹.

Palliative care provision

Palliative Care Australia released a position statement on access to quality care for Aboriginal Australians⁶; and while it acknowledges Aboriginal Australians as the traditional custodians of the land and addresses many of the issues that non-Aboriginal carers should be aware of when providing end-of-life care to Aboriginal people, it does not specifically address any particular mode of care except to say it must be culturally competent and meaningful to Aboriginal views of health⁵. While there is no doubt that Aboriginal people will have taken on aspects of the non-Aboriginal culture⁴⁰, their expectations and rituals around EOL and the EOL episode, are still largely from their connection to culture, family, community and tradition. Accounting for cultural factors in service delivery is addressed in the NSW Chronic Care for Aboriginal People Program, which provides a specific model of care for Aboriginal people with chronic disease⁴¹.

Despite the fact that palliative care treatment and services are available to those who are dying from chronic illnesses, which comprise Australia's leading cause of death, patients suffering



from cancer are much more likely to be admitted to a palliative care unit⁴². Statistics from 2008-2009 indicate that just over 60% of patients who received palliative care treatment had a principal diagnosis of cancer²⁸; and while cancer accounted for 28% of deaths in the Australian population, for the Aboriginal Australian population it was just 17%⁴³. Even though the incidence of cancer may be lower in the Aboriginal Australian population, they are more likely to have a poorer prognosis and twice as likely to die from cancer as non-Aboriginal Australians⁴⁴. This is thought to be related to later presentation, and differences in treatment regimens offered and treatment accepted and completed⁴⁵. Compounding this situation is the fact that there is no Aboriginal word for 'cancer' so a diagnosis of cancer is not likely to be well understood. This is at least the case in isolated regions where English is a problem and education levels variable⁴⁶. Additionally, for some Aboriginal people living remotely, a diagnosis and its aetiology is strongly associated with beliefs about misdeeds and 'payback', making an understanding of a cancer diagnosis even more problematic⁴⁶.

Though Aboriginal Australians account for 1.5% of palliative care separations, when differences in age and population are taken into account, the rate of palliative care separations for Aboriginal Australians is higher than the corresponding rate for non-Aboriginal Australians, and the length of stay for Aboriginal Australians is lower than for non-Aboriginal Australians²⁸. Furthermore, when palliative care 'hospital in the home' care is analysed, it accounts for just 0.3% of total palliative care separations, so almost all care was delivered in an inpatient setting²⁸. These figures demonstrate that while Aboriginal Australians are accessing palliative care services, they are not remaining in inpatient settings for their care.

Clearly more research should address this issue as well as clarifying the role of social, emotional, spiritual and cultural factors in decision-making about accessing palliative care services. For example, in some hospitals no more than two or three people are permitted to be with the dying patient and for Aboriginal people this can be an impediment to their grieving and healing process⁴⁷. Space, time and respect are

important in the healing process and these elements of the illness experience are equally important to the Aboriginal person⁶. Design features of the palliative care ward may limit or inhibit access to outside areas and provide no view of the outside landscape, and the small size of rooms that inhibit large numbers of family members, all of which are thought to be contributing factors to the reduced length of stay of Aboriginal in palliative care environments¹³. Access to outside areas and seating, artwork, better explanations about care and family friendly facilities, which include access to an AHW in the delivery of care, are other critical issues for mainstream palliative care to consider in their care of the Aboriginal person.

McGrath and Phillips argue from the remote community perspective that palliative care services should be mobile so the aboriginal person can die at home, in their community and 'country'⁴⁸. Cox et al point out that the preferred place of death contributes to the concept of a good death⁴⁹. It is important that health professionals provide the best conditions possible for people who are dying. Issues such as the availability of equipment and aides, at minimal cost⁴⁸ to people and services in remote areas, and ongoing education and support are essential in supporting the person who wishes to remain at home to die⁴⁵.

Alternatives to mainstream palliative care provision

The use of AHWs for home visits and support is vital to bridging the cultural divide between mainstream palliative care and Aboriginal culture⁴⁵. In other areas of health care and health promotion AHWs have played an integral role, linking mainstream healthcare services with Aboriginal communities in a culturally sensitive way. Healthcare systems that give the control to the Aboriginal community have also been shown to be very successful in improving access to, and in the context of acceptance of care^{8,27,50}. As mentioned, Aboriginal Australians report a fear of western medicine, and a concern that it lacks respect for the Aboriginal culture. But when AHWs are involved, these concerns are minimised because the AHWs understand their own people, and provide



a sense of cultural empowerment to Aboriginal people who need to access non-Aboriginal healthcare services⁵¹.

In a cardiac rehabilitation setting, for example, the presence of an AHW has been found to have a settling/calming influence on Aboriginal patients, making them more likely to engage with other staff and helping to prevent patients from discharging themselves prematurely from hospital care⁵². Similarly, another Australian study found that ideal care was possible when the AHW worked in unison with non-Aboriginal health professionals, facilitating communication and education in a culturally appropriate and sensitive way⁵³. Aboriginal people would prefer to be cared for by members of their own community, by someone with whom they can communicate using spoken and unspoken language⁴⁶, who know their cultural practices and who will be able to meet their individual needs and negotiate culturally respectful care delivery. Unfortunately, in the palliative care setting, there is a lack of AHWs⁵¹ for reasons that include staff turnover, training, recruitment and retention and sustainability issues. A lack of individuals to employ from local remote communities and a similar lack of culturally appropriate support for AHWs in all areas makes appointing and retaining them in these vital roles a significant challenge⁵⁴.

Family/community based palliative care: A standard principle of Aboriginal health policy is that there should never be a one-size-fits-all model for any health program, and end-of-life care is no exception. However, as the foregoing discussion has demonstrated, there are significant issues of cultural commonality that can be used to inform the development of culturally appropriate models, but this needs to be contextualised to reflect the diversity of local needs and conditions. The challenge to future development of this area is to continue to build on the baseline palliative care work already completed to develop a range of models respectful of differences in clients' geography, population and diagnostic groups.

Care delivery can follow a model that works with the Aboriginal population, by respecting the Aboriginal person's

link with the land and sense of community and family, and acknowledging cultural and spiritual beliefs about illness, dying and death. These factors are paramount to viability, and increasing usage by Aboriginal patients at EOL. Where westernised palliative-care service delivery focuses on inpatient care for the individual, palliative care for the Aboriginal person must focus on the individual as part of a larger family/community and kinship network, providing dignified care, support and education that extends beyond the individual. Further research is required to understand how the issues raised here translate to the quite specific but highly variable needs of the wide range of Aboriginal populations and services, especially in the context of 'Sorry Business' at EOL¹².

Conclusion

Aboriginal people must have culturally appropriate and locally accessible palliative care services, especially because, as a minority cultural group, they have a sense of isolation and are disconnected culturally from accessing mainstream services. It is preferable that palliative care is delivered under the auspices of an Aboriginal Controlled Health Service in collaboration and partnership with mainstream palliative care services. Mainstream health services have the resources to ensure a dignified EOL for the person and can guide and support AHWs delivering palliative care in their own country. Partnerships are fundamental to ensure that a critical mass of Aboriginal clinicians are trained and experienced in EOL care and palliation. Developing palliative care programs within Aboriginal communities, at EOL, and training AHW, promoted and developed in partnership with the Aboriginal community, are important strategies to enhance palliative care service provision. Currently Aboriginal people tend to not access palliative care services in mainstream facilities; and there is very little data on admissions to palliative care centres. Only two models of palliative care focusing on and developed in Aboriginal communities have been implemented in the last two decades. It is time for further partnerships to be championed. In such a collaborative process there is a need for palliative care models that fit with Aboriginal peoples' community values, beliefs, cultural/spiritual rituals, heritage and place.



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