

# The Cultural Considerations Relating to Palliative Care in Australian Indigenous Communities'

[The writer briefly examines the approach to palliative care in the indigenous communities with an emphasis on the key role of cultural differences and their interaction with mainstream strategies in palliative services delivery]

The World Health Organization (WHO) describes palliative care as 'an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care.'<sup>1</sup> The following table lists the nine key elements', considered by WHO, to be the fundamental principles' underpinning appropriate palliative care.

- *Provides relief from pain and other distressing symptoms.*
- *Affirms life and regards dying as a normal process.*
- *Intends neither to hasten or postpone death.*
- *Integrates the psychological and spiritual aspects of patient care.*
- *Offers a support system to help patients live as actively as possible until death.*
- *Offers a support system to help the family cope during the patient's illness and in their own bereavement.*
- *Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.*
- *Will enhance quality of life, and may also positively influence the course of illness.*
- *Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'*



1. World Health Organization. (2013). WHO Definition of Palliative Care

# How does Australia interpret this definition provided by the WHO?

The interpretation can be found in the 'National Palliative Care Strategy' published in 2018 and is intended for use by 'all Australian governments, as well as organisations and individuals, in guiding the improvement of palliative care across Australia'<sup>1</sup> Based on the premise that Australia has been identified as a world leader in the provision of palliative care and in the quality of our palliative care research programs the definition is short but inclusive, 'Palliative care is holistic care that helps people nearing the end of their life to live as well as possible for as long as possible.'<sup>2</sup> At the same time, the paper concedes, 'that palliative care is not equally available to all people across Australia, for reasons of geography, awareness, economics, workforce, and accessibility, [and that] Aboriginal and Torres Strait Islander people,

in particular, are impacted by unique factors such as intergenerational trauma, cultural dislocation, oppression, and systemic racism that influence their decision making around end-of-life considerations.'<sup>3</sup> While conceding that these aspirational goals are indeed laudable, nevertheless, as the old adage goes, 'actions speak louder than words'. This writer feels obligated to point out that the 'Care Strategy' does contain an 'Implementation [Action] Plan' with a glaring absence of any acknowledgment of the Aboriginal and Torres Strait Islander communities. Yet, it might be conceded, that these communities are given a passing reference with the statement that the Implementation Plan that 'an indication of what the Implementation Plan might include is outlined in the table below.'<sup>4</sup>

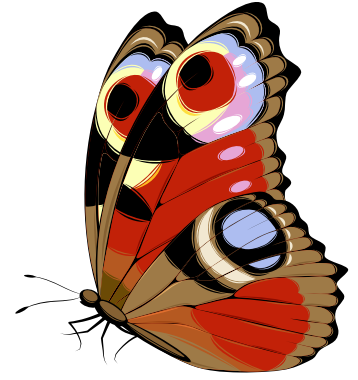
## Implementation Plan

Goals	Priorities	Activities
Goal 1: Understanding- People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care	1.1 More people are aware of the benefits and the local availability of palliative care	The specific actions at regional, state or national levels that will be undertaken to support achieving the goal
Responsibilities	Timing	Data sources
The organisation(s) accountable for implementing the activity	The expected timeframe for undertaking this activity	The evidence that will be used to report the progress made towards achieving the goal

Similarly, and unsurprisingly, the follow-up Monitoring and Evaluation Plan makes no reference to the Aboriginal and Torres Strait Islander communities.

1. National Palliative Care Strategy 2018 Australian Department of Health  
 2. Ibid  
 3. Ibid  
 4. Ibid page 26

However, the Australian Department of Health has addressed the aforementioned short-fall vis-à-vis special palliative needs of our indigenous communities. In September 2019 a paper entitled 'Exploratory Analysis of Barriers to Palliative Care Issues Report on Aboriginal and Torres Strait Islander Peoples' in which a detailed analysis of such barriers revealed a re-curing truism, [that], readers will not be surprised to learn that the key message (actually stated in the introduction to the paper) is one which is repeated in both historical and current observations concerning our indigenous communities'. The message is as follows:



**Considerable discrepancies in health and life expectancy mean that Aboriginal and Torres Strait Islander peoples experience the death of family and community members far more frequently than the non-Indigenous Australian population. ... [and the] history of dispossession, racism and systemic discrimination contributes to significant health disparities ... of particular importance in the context of palliative and end-of-life care.<sup>1</sup>**

Returning to the topic of 'barriers to palliative care' the Australian Government Department of Health undertook an exploratory analysis of barriers to palliative Care on Aboriginal and

Torres Strait Islander Peoples and issued their report in September 2019. At the risk of repeating what has been and still is an absolute 'that Aboriginal and Torres Strait Islander peoples experience the death of family and community members far more frequently than the non-Indigenous Australian population' <sup>2</sup> Furthermore the report reminds us all that Aboriginal and Torres Strait Islander communities' [ have a] history of dispossession, racism and systemic discrimination. This 'contributes to significant health disparities as well as barriers to healthcare access, and these factors may be of particular importance in the context of palliative and end-of-life care' <sup>3</sup> At this point, given that the Australian government commissioned this report, it is worthwhile to firstly peruse the report's starting point where they identify the barriers and then suggest what they call 'promising approaches. The report lists the following barriers:

- Lack of awareness/understanding of palliative care
- Language and communication issues
- Reluctance to talk about death and dying –
- Poor literacy/health literacy
- Lack of translated, culturally appropriate resources
- Poor access to professional interpretation services
- Mismatching cultural, religious and/or health beliefs and preferences between individuals and service providers
- Fear or mistrust of 'Western' medicine and/or healthcare providers and services
- A preference for family-based or kinship determined decision-making
- Difficulty accommodating cultural practices in palliative care settings
- Lack of/late referral to, or initiation of, palliative care
- Racism, discrimination (historical and current) and cultural stereotyping
- Financial disadvantage

1. Australian Government Department of Health Exploratory Analysis of Barriers to Palliative Care Issues Report on Aboriginal and Torres Strait Islander Peoples September 2019

2. Australian Government Department of Health Exploratory Analysis of Barriers to Palliative Care Issues Report on Aboriginal and Torres Strait Islander Peoples September 2019

3. Ibid page 5

Conversely the 'promising approaches' are submitted as per the following table:

- Community awareness-raising
- Engagement between services and communities
- Recruitment of Aboriginal and Torres Strait Islander staff
- Culturally-appropriate and translated resources
- Culturally-appropriate engagement with individuals and families
- Access to appropriate professional interpreting services
- Training for professional interpreters (in palliative care concepts and terminology)
- Community capacity-building (for palliative care provision and support)
- Cultural competence within services
  - Education and training
  - Culturally-appropriate communication
  - Facilitating cultural elements and practices in service provision
  - Identification and inclusion of appropriate decision-makers
- Trauma-informed approaches to care
- Patient navigator initiatives



## But how do such 'promising approaches' translate into action?

Well, this writer proposes that we should first of all identify so-called 'enablers' which, theoretically, should stimulate (enable) the aforementioned 'promising approaches. The first of these enablers is 'networks', partnerships', and collaborations.' The report recommends that the capacity of support organisations should be developed in order to undertake a linking role with palliative care services, and also serve as a resource for palliative care services in order to understand the needs of Aboriginal and Torres Strait Islander peoples. This recommendation sounds all too familiar to those of us working in the socio-economic context of Australian indigenous service providers. It is also emphasized that 'planning' is a fundamental requirement underpinning any awareness-raising in relation to palliative care and advance care planning within the indigenous communities. Linkages are encouraged and reciprocal collaborations between all relevant sectors as well as support organisations and other services providers as appropriate. We are also reminded that it is crucial to adhere to what has become recognised as 'best practice' thereby developing concurrent best-practice approaches to palliative care service delivery for Aboriginal and Torres Strait Islander peoples. The second recommended 'enabler' is that of workforce development.



The report's opening statement is clearly a reiteration of countless other reports concerning indigenous health matters in the Australian context, 'It would be nice to have more Indigenous Health Workers trained up to bridge the gap between mainstream services and Aboriginal and Torres Strait Islander service users'.<sup>1</sup> Furthermore, it is pointed out (again, a very familiar refrain) that, in many instances, 'Aboriginal and Torres Strait Islander peoples may also have significant fear or mistrust of 'Western' medicine and/or healthcare providers and services'.<sup>2</sup>

The second enabler (and this is a crucial area of concern) relates to workforce development. Once again, it should come as no surprise that palliative care providers should give priority to 'training and ongoing professional development initiatives that increase or improve health and social care providers':<sup>3</sup> An understanding of Aboriginal and Torres Strait Islander peoples (cultural competence) is also emphasised. A person-centred palliative care approach combined with both knowledge of and skills applying to trauma informed approaches is considered a fundamental requirement. Lastly, once again a recommendation appearing in many allied research papers pertaining to indigenous Australians', is to employ Aboriginal and Torres Strait Islander staff.

The third enabler focuses on the all-important financial support and resourcing, Specific funding and resourcing needs are summarised in the following three points:

- *Ensure palliative care funding models are flexible to allow delivery of person-centred palliative care*
- *Improve the alignment of the relevant funding systems (including NDIS, aged care, primary and other health care) to support seamless transitions.*
- *Fund community-based/populationspecific approaches to palliative care, including establishment and maintenance of collaborative arrangements<sup>4</sup>*

Research, evaluation and monitoring is the final enabler and this is the foundation stone, as it were, of any strategies and plans relating to any interventions by society into the indigenous communities generally. What is often overlooked is the necessity to take a long hard look at any interventions, especially with regards to those relating to palliative care. It is logical that a key feedback loop is in place thereby ensuring that interventions, at whatever stage, are constantly evaluated and improved. The following approaches, based on such an evaluation loop, indicate that appropriate palliative care for indigenous Australians is at least heading in the right direction.

1. Ibid, page 13

2. Ibid page 8

3. Ibid, page 23

4. Ibid page 23

## Identification of Effective Approaches in the Delivery of Palliative Care to the Indigenous Communities'

1. Community awareness-raising
2. Engagement between services and communities
3. Recruitment of Aboriginal and Torres Strait Islander staff
4. Culturally-appropriate and translated resources
5. Culturally-appropriate engagement with individuals and families
6. Access to appropriate professional interpreting services
7. Training for professional interpreters (in palliative care concepts and terminology)
8. Community capacity-building (for palliative care provision and support)
9. Cultural competence within services
10. Trauma-informed approaches to care
11. Patient navigator initiative

It is all very well defining such effective approaches in the Delivery of Palliative Care to the Indigenous Communities' but the question needs to be asked, 'Do such approaches accurately reflect the issues faced by the indigenous communities?'

In September of 2003 Ian Maddocks and Robert G Rayner published an article in the Medical Journal of Australia under the title 'Issues in palliative care for Indigenous communities' <sup>1</sup>. Before examining the key issues facing the indigenous communities vis-à-vis palliative care both writers remind us (and it is worth recording entire quote at this juncture):

**During the 20th century, many Indigenous people also lost their knowledge of family, and their recognised place within it, through the forced removal of children from their parents to placement in institutions or adopting white families. Family strength remains one of the outstanding characteristics of Indigenous life, and a loss of identification with family surely underlies much of the dysfunction of Indigenous society. Deep emotional scars affect many Indigenous individuals and groups.<sup>2</sup>**

The first two key issues identified relate to the demography and epidemiology of the Australian indigenous peoples. Although many of us are familiar with the socio-economic status of such communities it really does resonate when the writers point out that our indigenous communities have a demonstrably close association with death and dying. Why? In part, this is because death rates for Indigenous Australians are among the highest in the world. This is particularly so in the -45–25 year age range, where death rates are 8–5 times those of non-Indigenous Australians, leading to a life expectancy up to 19 years less than non-Indigenous Australians. The next key issue addresses the issue of appropriate health services. It is quite astounding to discover that 'until recently, public hospital accommodation was segregated' <sup>3</sup> and, therefore, the health care provided was not only inadequate but also did not take into account 'the associated poor health status of indigenous people'<sup>4</sup>. It is interesting to note that according to the writers' findings, the services offered by Indigenous healthcare providers often have no link with mainstream services.

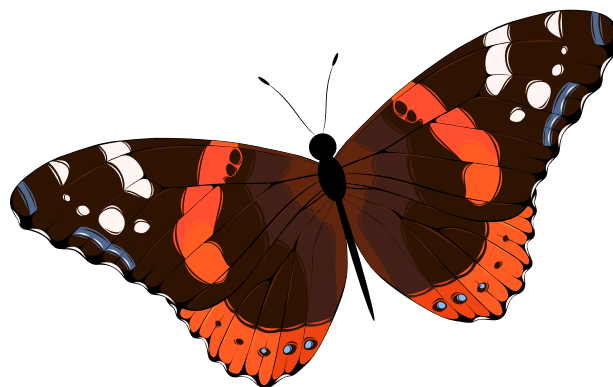
1. MJA Vol 15 179 September 2003

2. Ibid page 17

3. It is important to note this 'segregation' issue referred to a period prior to 2003.

4. Op.Cit. page 17

Similarly, mainstream providers may have little awareness either of the special needs of Indigenous patients or the services, networks and cultural supports available to them. Furthermore that, 'in many communities, Indigenous people have not accessed palliative care services to any great extent [and] many have not heard of palliative care, or associate it only with inpatient care and cancer.<sup>1</sup> Of course, the issue of communication is well documented and is of particularly relevance to the culturally-appropriate delivery of palliative care in the indigenous community. The following table of communication issues needs to be factored in by both medical professionals and allied health workers.



## FOR EXAMPLE:

- It may be considered impolite or offensive to look directly at an Indigenous person.
- It will be difficult for an Indigenous person to question a doctor's management, even if it is clearly impractical.
- Health decisions tend to be a family or community affair.
- Family structure is complex and governed by recognised obligations and cultural rules.
- Gender issues are important, with "women's business" and "men's busyness" being defined and held separate.
- Traditional healers have a good understanding of underlying beliefs about health, and may offer treatments with a greater authority than the white healthcare professional can command.

As is pointed out 'traditional medicines are used in many settings' and 'Indigenous health workers are now widely employed to help liaise with families who are trying to make best use of both traditional and modern medicine.'<sup>2</sup> One final point concerning 'issues. It would be remiss not to make reference to the complexity of decision-making processes in the indigenous community. As is emphasised 'the decision-making processes in Indigenous communities are collective and often protracted'.<sup>3</sup>

So, given that it is undeniable that the delivery of appropriate palliative care to the Australian indigenous community requires urgent redress the June 2003, Palliative Care Australia (PCA) released an outline ("a planning guide") of the population-based resources necessary to provide palliative care services in Australia. The following table presents us with the minimum requirements for an effective delivery of palliative care across the nation. In terms of the consideration of cultural diversity and special needs relating to the Australian indigenous community it is confirmed that 'populations with special needs, including children, Indigenous people and people with culturally and linguistically diverse backgrounds, were also considered' <sup>4</sup>.

1. Ibid page 17

2. Ibid page 18

3. Ibid page 18

4. A planning guide": developing a consensus document for palliative care service provision David C Currow and Ellen M Nightingale MJA 2005

**Estimated minimum staffing levels for professional support of interdisciplinary palliative care in the community, acute-care settings and palliative care units by discipline, expressed as full-time equivalent staff**

Discipline/staff category	Community-based services*	Acute-care hospital consultative service†	Designated palliative care beds‡
Palliative care specialist §	←—————	1.5	—————→
Registrar §	←—————	1.0	—————→
Resident medical officer	0	0	0.25
Liaison psychiatry	←—————	0.25	—————→
Clinical nurse consultant §	1.0	0.75	0
Registered and enrolled nurses §	0	0	6.5 hours per patient per day
Discharge liaison	0	0.25	0
Psychologist	0.25	0.1	0.1
Social work	0.5	0.25	0.25
Bereavement support	0.25	0.1	0.1
Pastoral care	0.25	0.25	0.25
Speech pathology	0.2	0.2	0.2
Dietitian	←—————	0.2	—————→
Physiotherapy	0.4	0.2	0.2
Occupational therapy	0.4	0.2	0.2
Pharmacist	0	0.25	0.1
Other therapies ¶	0.5	0	0.25

\* Full-time equivalent staff per 100 000 population served.

† Full-time equivalent staff per 125 hospital beds.

‡ Full-time equivalent staff per 6.7 beds, whether in an acute-care setting or in a freestanding palliative care unit or hospice (6.7 palliative care beds per 100 000 population would be needed).

§ Assumes that these roles in the community are consultative, with well resourced primary clinical care (general practitioners and community nurses)

¶ Includes combinations of music, art, complementary, narrative and diversional therapies.

In analysing the planning guide elements' David C Currow and Ellen M Nightingale, writing in the medical Journal of Australia pointed out that 'National scoping studies in palliative care provision, paediatric and Indigenous palliative care, and competency-based guidelines for providing palliative care' will inform future editions of the planning guide; <sup>1</sup> There is an indication that there are cross-overs from indigenous palliative care strategies to mainstream palliative care coping mechanisms. For example, as the writers suggest, 'complementary and diversional therapies, including art, music and narrative therapy, also have a role' <sup>2</sup>. The palliative care service in central Australia enabled the development and publication of a painting representing 'the complexities of end-of-life decision making for Aboriginal patients living in remote communities who must travel long distances for hospital care' <sup>3</sup>.

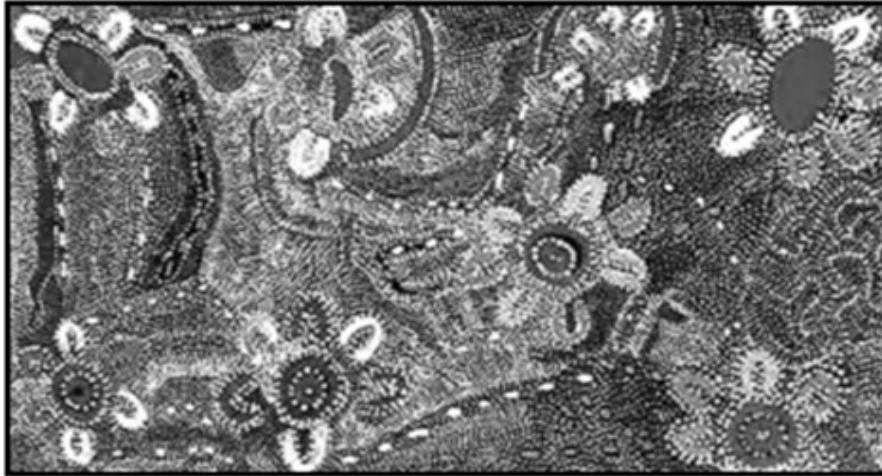
1. Ibid

2. Ibid

3. Issues in palliative care for Indigenous communities Ian Maddocks and Robert G Rayne



### **“Making the right decisions”**



*The palliative care service in central Australia created an Aboriginal art project to develop relevant teaching and learning tools. Aboriginal artists from different language and cultural groups were invited to paint their stories about “finishing up”. This painting, “Making the right decisions” by Kumantjay Miller, illustrates the complexities of end-of-life decision making for Aboriginal patients living in remote communities who must travel long distances for hospital care.<sup>9</sup>*

The palliative care service in central Australia created an Aboriginal art project to develop relevant teaching and learning tools. Aboriginal artists from different language and cultural groups were invited to paint their stories about “finishing up”.

This painting, “Making the right decisions” by Kumantjay Miller, illustrates the complexities of end-of-life decision making for Aboriginal patients living in remote communities who must travel long distances for hospital care.

So, in conclusion, what can be said about the current status of palliative care vis-à-vis the Australian indigenous communities? Issues have been identified, a range of needs analyses have taken place, and a planning framework has emerged. However, underpinning the successful implementation of palliative care strategies among the indigenous communities’ is the constantly repeated need for cultural sensitivity. As has been re-iterated in many studies pertaining to the Australian indigenous communities’, if there is a lack of both knowledge and understanding of the socio-economic plight of those communities’ then any palliative care interventions will have limited success.

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