

SPIRITUALITY & Aboriginal Palliative Care

**SPIRITUALITY: IT'S CONNECTION WITH ABORIGINAL PALLIATIVE
CARE & PALLIATIVE CARE VOLUNTEERING**

DEFINING SPIRITUALITY

To define spirituality is a difficult task. There are many definitions available to us, but there is no 'one size fits all' approach to an individual's unique understanding or interpretation.

In a Western based culture, there is a tendency to embrace spirituality soon after the diagnosis of a terminal illness, in the need of hope; whereas, in the eyes of the Aboriginal community western medicalisation poses the risk of taking away the very essence of their spirituality.

ABORIGINAL SPIRITUALITY

‘Spirituality is a feeling, with a base in connectedness to the past, ancestors, and the values that they represent, for example, respect for elders, a moral/ethical path. It is about being in an Aboriginal cultural space, experiencing community and connectedness with land and nature including proper nutrition and shelter. Feeling good about oneself, proud of being an Aboriginal person. It is a state of being that includes knowledge, calmness, acceptance and tolerance, balance and focus, inner strength, cleansing and inner peace, feeling whole, an understanding of cultural roots and ‘deep wellbeing’ (Grievess 2006a:52).

‘Aboriginal spirituality is defined as at the core of Aboriginal being, their very identity. It gives meaning to all aspects of life including relationships with one another and the environment. All objects are living and share the same soul and spirit as Aboriginals. There is a kinship with the environment. Aboriginal spirituality can be expressed visually, musically and ceremonially’ (Grant 2004:8–9).

RECOGNITION OF THE NEED FOR ABORIGINAL PALLIATIVE CARE VOLUNTEERS

The WHO (World Health Organization) defines palliative care as;

‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO, 2015).

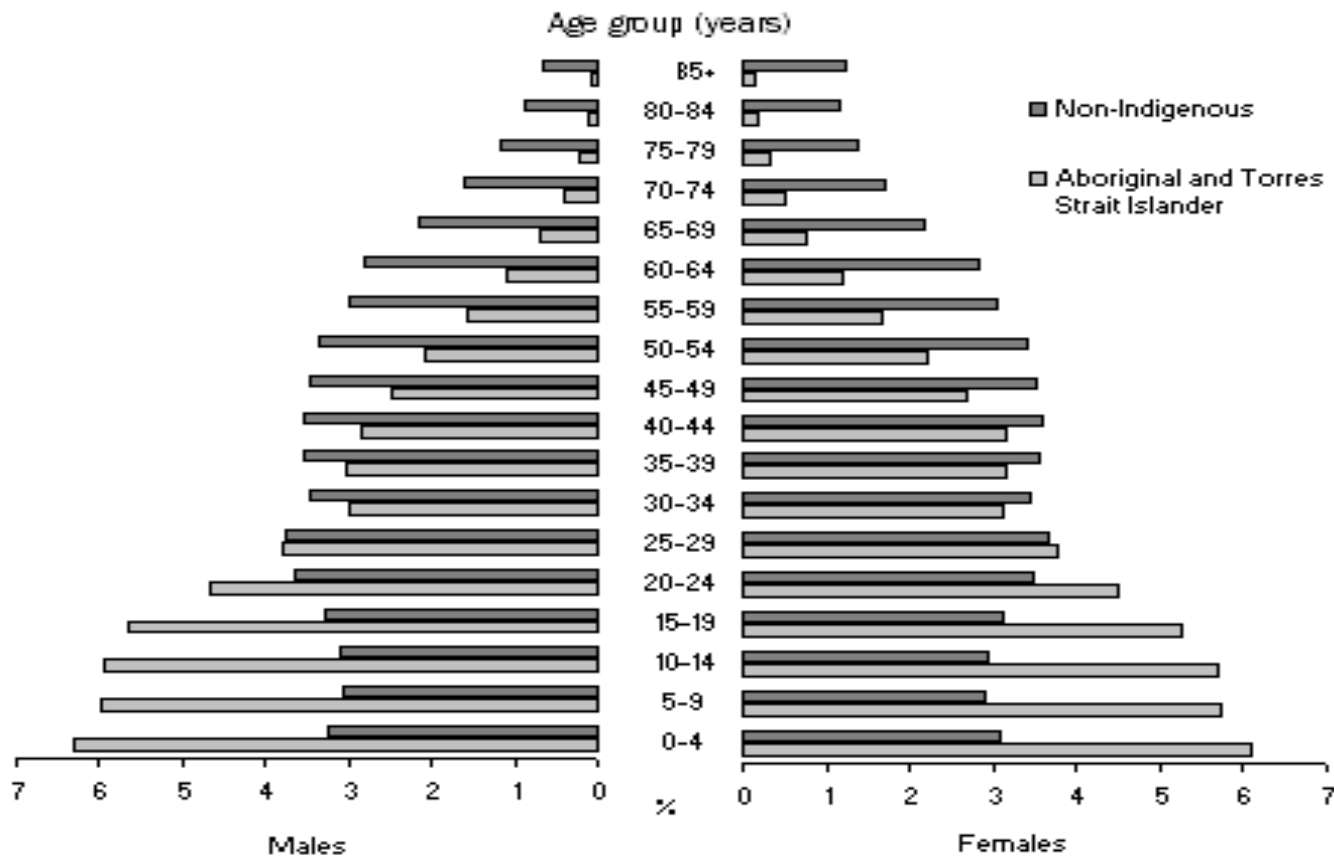
There are certainly barriers to **culturally appropriate** palliative care for Aboriginals. However, the need for palliative care is undoubtedly substantial.

There are huge disparities when comparing palliative care service delivery between urban and rural areas in general.

Statistically, between 2007 – 2011, almost a third (29.1%) of all Aboriginal loss of life occurred between the age bracket of 60-74. However, a more striking factor is that the life expectancy for Aboriginals is approximately 10.6 years less than all other Australians. From 2010-2012 Aboriginal life expectancy was 69.1 and 73.7 for men and women respectively (AIHW, 2015).

DEMOGRAPHICS SUGGEST...

The Aboriginal demographic strongly suggests that the need for Palliative Care in the future will be far greater for Aboriginal and Torres Strait Islanders. As you can see, a significant portion of the population is between 0-29 years of age.



NORTHERN TERRITORY ABORIGINAL PALLIATIVE CARE MODEL - Bev Derschow.



NORTHERN TERRITORY ABORIGINAL PALLIATIVE CARE MODEL

Section 1 – Palliative Care focus on family is just as important as the Aboriginal client. Both impact on each other.

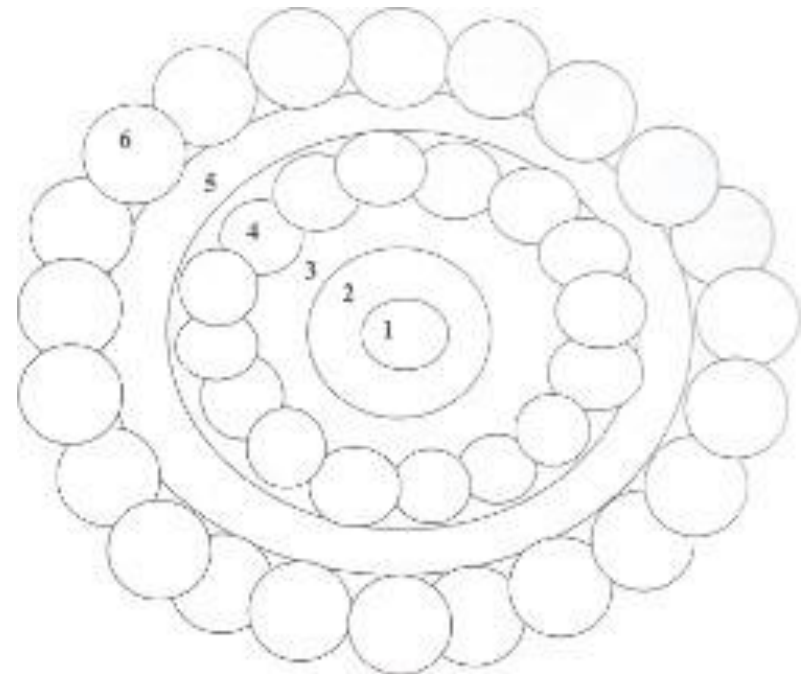
Section 2 – Culture, kinship and country are priorities for Aboriginal people. Understanding of the importance of these is the basis of providing culturally appropriate care.

Section 3 – Artwork depicts the links between traditional Aboriginal culture, kinship and country.

Section 4 – Consideration of traditional cultural practices and personal western influences on an Aboriginal person and their family helps the service provider to better assess, identify and address needs with appropriate resources and support.

Section 5 – Service providers need to reflect on how they communicate, ensuring there is cross cultural awareness, using culturally appropriate resources and enabling service provider flexibility to engage Aboriginal people and their family to make informed choices.

Section 6 – Aspects of the two key areas of spiritual and practical need to be considered by the service provider. Both are closely interwoven and there is often no clear delineation between them.



ROLE OF THE CARER

“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 the patients, to which the services are being provided” (Willis, 2010).

The six practice principles that are listed below were developed in collaboration with Palliative Care providers, Indigenous people and their communities.

- **Spiritual,**
- **Emotional.**
- **Social,**
- **Physical**
- **Psychological and**
- **Economic.**

They encapsulate a holistic approach, which ensures not only cultural appropriateness, but addresses first and foremost the fact that spirituality is of paramount importance for the patient.

SOME BARRIERS TO PROVIDING PALLIATIVE CARE

Palliative Care is still recognised as mainstream care. Moreover, it is still strongly considered to be a Western style of care, without a great deal of emphasis (if any) placed on one's **spirituality**.

There are **barriers** on both sides of the equation; clinicians and patients alike. Examples of these barriers include (but are not limited to):

Shame (on behalf of the patient): This is experienced through the loss of an extended version of one's self. Their **spirituality** is compromised. This can affect health and health care outcomes.

Lack of cultural understanding (on behalf of the clinician): As there are currently very few Aboriginal's utilising Palliative Care Services, there is minimal opportunity to better understand and appropriately treat them in accordance with their spirituality, beliefs and practices surrounding 'Sorry Business'.

Social and Economic factors: Poverty and long term unemployment can be detrimental in terms of affording medication or equipment required to treat their condition.

BARRIERS CONTINUED

Location: Many Aboriginals experience first hand, the barrier of distance in gaining both adequate and appropriate healthcare. Relocation is often suggested, but this causes severe trauma to the patient, who have in the past reportedly felt overwhelmed, isolated and frightened (Willis, 2010).

Resistance: 'Many Aboriginal peoples and Torres Strait Islander peoples hold strong spiritual and cultural beliefs about the cause of serious illness, which may conflict with the medical explanation. By demonstrating respect for diversity in the sick person's cultural and spiritual beliefs, a relationship of trust and rapport can be built' (PEPA, 2014). In short, Aboriginals feel that there is no great need to be 'medicalised'.

Lack of AHW's: AHW's are Aboriginal Health Workers. For more information please follow this link:
<http://cdm.ahpa.com.au/HealthcareProfessionals/AlliedHealthProfessionals/AboriginalHealthWorkers/tabid/148/Default.aspx>

Lack of access for families: Many Aboriginals choose to stay at home with their families, as there is no alternative offered for their families to come with them to the hospital (or other locations) when they are sick.

ALTERNATIVES TO PATIENT RELOCATION

Temporary relocation of Aboriginal healthcare workers to the patient.

In doing this, there is a larger chance of cultural sensitivity is recognised. And, to some extent, a bridging of the gap between mainstream and Aboriginal health systems.

To ensure **continuity** of care, there may need to be **relocation and/or adequate distribution of resources**. For example, ensuring there will be adequate prescribed medicine available when the patients are discharged from hospital or other facilities to go home. Also 'telehealth' can positively impact those in rural areas.

Discharge planning strategies. Talking to the patients family members regarding end of life scenarios, so that they are aware of what to expect in the stages leading up to their loved one passing.

Ensuring adequate communication throughout. The role of the AHW is exercised in these instances. For family and patients alike the AHW aids

- Medicalised jargon,
- Culturally sensitive questions,
- Advance care directives.

REFLECTIVE PRACTICE

“Critically examining your own beliefs and taking the trouble to understand your patients’ lives will assist in resolving many of the ethical dilemmas that arise from cross cultural work and will provide the basis for human service” (Fried, 2000).

Aboriginal culture is not static. No culture is! The nature of the work will continually change. Everyone’s view on what **spirituality** means will differ. Clinicians and patients need to be actively involved in reflective practice! It is important to engage in:

- ***Technical reflection***, rational deductive thinking about clinical procedures.
- ***Practical reflection***, how one interprets their experience and explains the human interaction involved.
- ***Emancipatory reflection***, review of the entire practice, with a particular focus on whether power relationships or other constraints are present.

POSITIVE REFLECTIVE PRACTICE

Aboriginal Health Workers have been quoted as saying:

"I am able to talk to our G.P. about the need for medication."

Noticed improved symptom management;

"Given me time to listen to each individual's needs and listening to family members; confidence in communicating and delivering quality service to our clients."

Noticed improved psychosocial support;

"It will help with Palliative care in the remote community, PEPA placement was very helpful. Know who to ring a palliative care, for information about palliative care clients".

Noticed improved networks.

PALLIATIVE CARE VOLUNTEERS FROM VARYING CULTURES

“Power imbalances can occur in health care settings. The key to balance is to enable a safe friendly environment, engage people to become partners and to participate in decisions about their health care plans”. (PEPA, 2014).

It is imperative that we address the needs of each individual person, and recognise that each situation is unique. A person’s spirituality and belief’s are unique to not only themselves, but also their given situation. Consequently, their care should be catered for with these considerations in mind. Power imbalances create negativity, and perpetuate power relationships which are not favourable for the patient. It is **not** up to a volunteer to question a patients spirituality – it **is** up to them to non-judgmentally converse with the patient about their journey.

USEFUL LINKS

PEPA – Program of Experience in the Palliative Approach.

<http://www.pepaeducation.com/>

<http://www.pepaeducation.com/health-professionals/aboriginal-and-torres-strait-islander-health-professionals.aspx>

http://www.healthinonet.ecu.edu.au/uploads/resources/20453_20453.pdf

<http://cdm.ahpa.com.au/HealthcareProfessionals/AlliedHealthProfessionals/AboriginalHealthWorkers/tabid/148/Default.aspx>

<http://palliativecarenswh.org.au/site/about-palliative-care/information-for-health-professionals/>

<http://ruralhealth.org.au/sites/default/files/publications/fact-sheet-34-palliative-care-rural-and-remote-areas.pdf>

<http://www.palliativecarebridge.com.au/>

REFERENCES:

- AIHW, 2015. <http://www.aihw.gov.au/deaths/life-expectancy/>
- Grant, E. K. 2004, *Unseen, Unheard, Unspoken: Exploring the Relationship Between Aboriginal Spirituality & Community Development*, Thesis, University of South Australia.
- Fried, O. 2000, 'Providing palliative care for Aboriginal patients', *Australian Family Physician*, Vol. 29(11).
- Grieves, V. 2006a, *Indigenous Wellbeing: A Framework for Governments' Cultural Heritage Activities*, NSW Department of Environment and Conservation, Sydney. Accessed on 31 January 2007 at: <<http://www.environment.nsw.gov.au/conservation/IndigenousWellbeingFramework.htm>>
- PEPA Project team (2014) *PEPA Cultural Considerations Providing end of life care for Aboriginal people and Torres Strait Islander people*
- Willis, J. 1999, 'Dying in country: Implications of culture in the delivery of palliative care in indigenous Australian communities', *Anthropology & Medicine*, vol. 6(3), pp. 423-435, DOI: 10.1080/13648470.1999.996459