

Indigenous palliative care poster project

Andrew Taylor, Palliative Care Council of South Australia, **Fiona Coulthard**, Pika Wiya Health Service, South Australia

WHAT EXACTLY IS PALLIATIVE CARE

Palliative care is caring for a loved one who has a terminal illness.

Palliative care is the support of people who are suffering from an illness from which no cure can be anticipated. The aim of palliative care is to maximise the quality of the person's life. This is achieved by co-ordinating and delivering a range of services in response to the individual needs of the person being cared for and the caregiver.

It is recognised that a range of problems, including physical, emotional, social and spiritual may need attention.

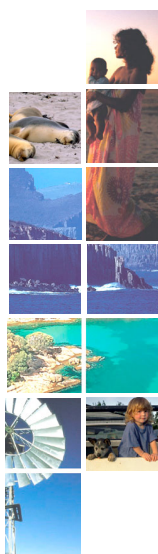
Discussing death and dying

While Australia is a death denying society, to discuss death and bereavement even more difficult for Indigenous Australians.

Discussing death in any community is hard as it initiates feelings of angst, pain and a sense of loss. Talking about death in Aboriginal communities is a very difficult thing to achieve, there are various factors that need to be considered when discussing death such as: cultural beliefs, extended family, and the taboo nature of discussion, which can initiate a sense of helplessness relating to the spiritual beliefs and customs that overarch Aboriginal communities.

To effectively illustrate and provide you with an insight into how Aboriginal people and communities deal with issues relating to grief and loss.

- Aboriginal people have larger family connections than ordinary Australians. The notion of Extended Families is a major focus on the overall social perspective of Aboriginal community. This means that families consist of several mothers, fathers, brothers and sisters.
- In circumstances where family members have been told that they are extremely ill and only have short period to live the grief and loss process is almost instant. Sympathy, empathy and memory begins to occur during this period.
- Aboriginal people especially health workers have a community obligation to provide assistance in periods of grief and loss. Some of this assistance includes: delivering food; clothing; transport; and providing financial assistance.
- Aboriginal people have a strong affinity with the land, especially their "homeland" during periods of grief and loss this sense and feeling is twice as strong. This is also the same as their home.



Problems we face as a Aboriginal community dealing with grief.

- Aboriginal communities grieve at the same time and visiting the terminally ill person to say “goodbye” is important for every member of the “family” – so there are restrictions already as people will come and go.
- Aboriginal people want to die in their own surroundings and want to be visited by their own kin, so they want to go home, and when this is requested, mainstream services look upon this as a futile and unnecessary act ie: all services are here, why do they want to go away. This can lead to further feelings of grief, pain and loss particularly for the dying, as not only do they have to deal with being in another environment, they have to deal with pain from illness as well as being apart from their family.

After the person has passed on:

- Sorrow camps are assembled. These “camps” differ from Aboriginal group to group as not all groups have designated area’s. Some groups shift house, and assemble at the home of a sister/brother or another family member.
- The hospital room or that house where a person has died is no longer a place that we can enter. If a person has died at home, the family moves. If a person has died in a hospital room, that room is “taboo”.
- The deceased person’s name is no longer mentioned in a lot of groups. In some the name cannot be mentioned for 12 months, in others, that person’s name is never mentioned again. This differs from group to group.
- Some groups have re-burials, 12 months after the initial funeral so that the husband/family can move on, and get on with their lives.

Spiritual beliefs also differ from group to group.

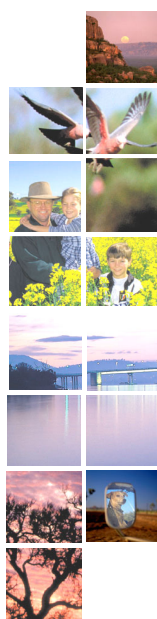
Two of my own group’s beliefs, for example, are that:

- there is always rain after a death, because God is washing the dead persons footprints from this earth
- another is that of the South wind, which is the Angels coming to collect the spirits of the sea.

INDIGENOUS PALLIATIVE CARE INFORMATION

We needed to be able to find a way for Palliative Care to be able to help Aboriginal people and to be able to deal with a sensitive issue in a more sensitive way.

The basis of the project was a desire to increase awareness of palliative care among Indigenous Australians. We were aware from surveys of community awareness of palliative care, that awareness of palliative care in SA was only 52% and much less than this for marginalised groups.



Other approaches to this task:

- we provided a simple pamphlet in English “What exactly is Palliative Care?” to Nunkuwarrin Yunti in Adelaide
- the translation of information in to aboriginal languages. Rejected as too difficult as a national concept, due to the numerous language groups
- the “Bessie’s Story” booklet from Broome. Accepted well throughout Australia, with some concerns that the language is a bit condescending
- the “Many Ways of Caring” posters from Central Australia. Highly regarded in Central Australia, but not accepted in Darwin because they are too area-specific.

Research on means of providing palliative care information to Indigenous people led to discussions with Pika Wiya Health Service in Port Augusta.

Development of the poster

We discussed various ways in which we thought our message about Palliative Care could be more “user friendly” and came up with the idea of a poster.

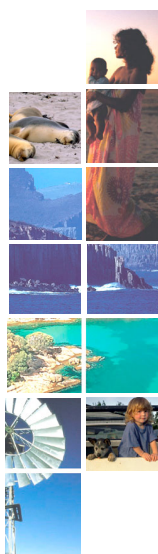
Reasoning’s behind this were:

- targeting groups across the board and not only making Palliative Care known to the elderly but also to young people
- we know that posters are used as a form of decoration in people’s homes
- we could provide more pictorial information as well as written
- we wanted to make it visually appealing.

A draft version of the poster was developed. This featured a stunning painting by artist Gordon Wayne, depicting a person going through their last journey from this life on earth, watched over by members of his family and community. A second painting by Audrey Wintinna provided the background. Small illustrations from Audrey’s painting told the story in dot point style, to go with the wording, which had been adapted from the pamphlet “What exactly is Palliative Care?”

Sensitive issues

The staff at Pika Wiya loved this design. Gordon’s work is painted in a European style, which should be universally accepted, but I envisaged that Audrey’s small illustrations might not be accepted interstate. Community consultation was undertaken with aborigines from Victoria and the Northern Territory, working at Nunkuwarrin Yunti. They advised that Gordon’s painting was very good, but that Audrey’s small paintings were of “another tribe’s language” and should not be used nationally, as they would not be understood or accepted by other tribal groups. A second version for use interstate was then developed, replacing Audrey’s dot point illustrations with circles containing similar wording under the headings RELIEF, COMFORT and SUPPORT.



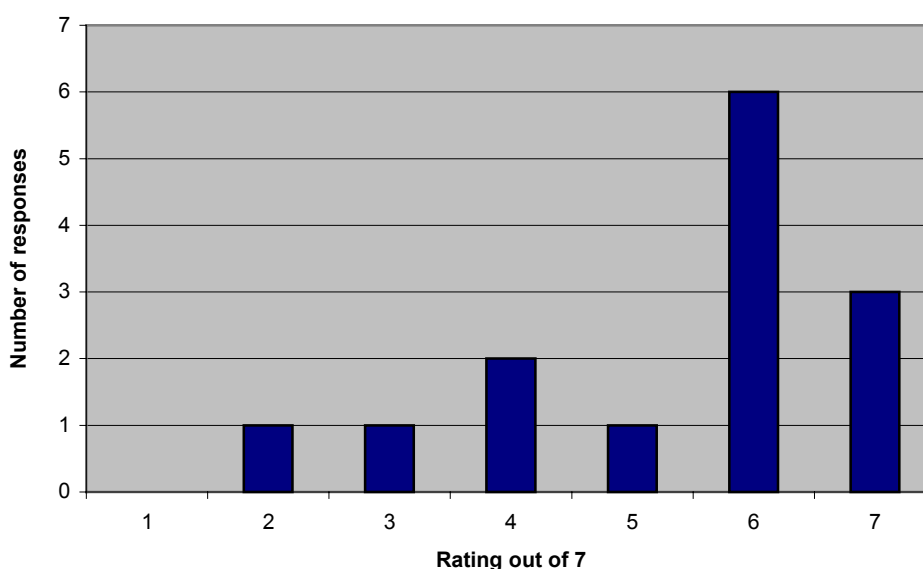
- We printed 1000 of the South Australian version and circulated to 53 SA Indigenous organisations; including health services, plus SA palliative care services.
- 4000 of the interstate version were printed, with primary distribution to 187 aboriginal health services listed on the OATSIH web site
<http://www.health.gov.au/oatsih/cont.htm>
- A small number of posters were also sent to state palliative care organisations, sufficient to provide one poster to all palliative care services in Australia.

Feedback

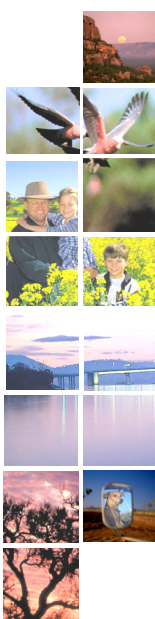
Enclosed with the posters was an Evaluation Sheet.

We stated our first objective for the posters as being to increase awareness among Indigenous Australians, of the existence of palliative care services, and asked “How well do the posters achieve this objective?” The response was variable, but mostly very positive.

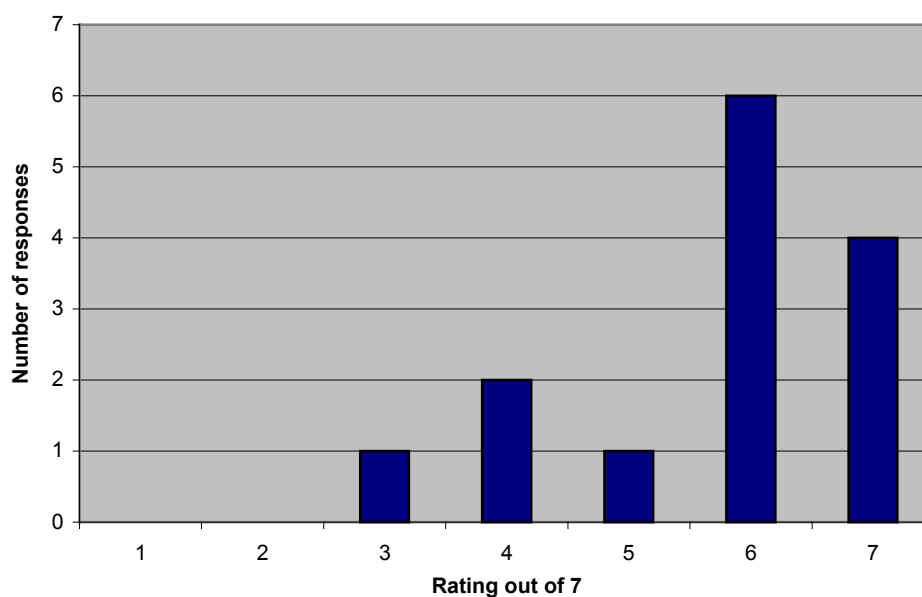
To increase awareness of palliative care among Indigenous Australians



We stated our second objective as aiming to be culturally sensitive, and asked “How well is this objective achieved?” The average response was 5.7 out of 7.



To be culturally sensitive



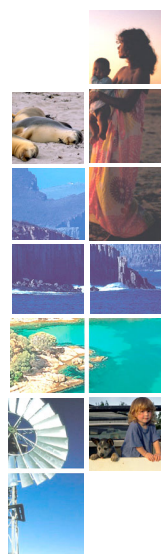
We then asked for any comments regarding the posters. Most answers were very positive, such as:

- Great, Very informative. Excellent picture.
- Excellent presentation of a dying person's last journey.
- Quite visually appealing.
- Culturally appropriate. Colourful, understandable.
- I think the posters look great, very eye catching.
- The information that it portrays is very relevant and culturally appropriate.
- All health workers and doctors were keen to put up in their rooms; always a good sign
- Very colourful
- Just well done!!

Three responses were more negative:

- Writing too small
- Too much writing. If you couldn't read you would not understand what the poster was about. Brighter colours.
- The poster reflects Aboriginal culture only. Torres Strait Islander people and culture are not reflected in the poster.

We also asked: "Do you have any suggestions for further palliative care information for Indigenous Australians?"



Six services suggested pamphlets, some with additional advice on format, such as:

- explaining what palliative care is about
- information on local council areas and agencies
- putting words into your own language besides the English version.
- Torres Strait Islander information must recognise Torres Strait Islander people and culture. Use of TSI flag, colours, language and art work.

Other suggestions were:

- A durable (ie not flimsy) picture book story. This can cross language barriers and be understood by everyone – literate or not.
- Maybe something on simple screening to help prevent cancer and on simple techniques to help patients with cancer eg pain management. Information on what to expect from chemotherapy and radiotherapy
- Bigger writing
- Terminology – What is it?

We then asked: “Do you have any suggestions regarding the training of individuals delivering palliative care to Indigenous Australians?”

- All aboriginal health workers, carers and volunteers should have some form of knowledge about palliative care, to assist their community members.
- Make sure you have people who are acceptable, compassionate to the whole person’s needs, and take an holistic approach not forgetting the carer
- There should be an elderly care steering committee – that steers the training providers in the right direction to what is needed out in community
- All individuals involved in palliative care for Torres Strait Islanders, should be trained in TSI culture and history.

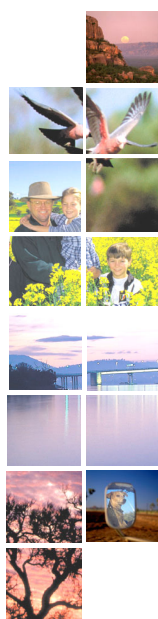
It was sad but not unexpected to have comments

- Well I don’t know of any so anything will be an improvement. Or if there is some training available improving access and knowledge about the training.
- Unsure of needs. Would be interested in what our service could provide or have access to.

I felt that one of the most useful comments was:

- The emphasis should be on culturally appropriate care, which will not always sit well inside a Euro Centric Medical Model of Care. (ie if that old person wants to be outside next to a fire with their dogs, then don’t insist that they stay inside in a “comfortable” bed.

Palliative care is delivered, where possible, where the person wants to be. So I think that palliative care teams are more in tune with the above concept than our general medical system is.



Finally, we asked: “What other palliative care assistance is required by Indigenous Australians and by people who are working with Indigenous Australians who are dying?”

The feedback ranged from:

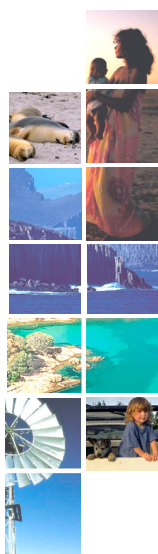
- In remote areas palliative care is almost non-existent.

to

- We care for our own immediate family member at home if resources are available, if not there is one palliative section at the district hospital, (which is) very supportive.

Additional assistance mentioned, included:

- Overnight care or 24 hour care.
- Family assistance.
- Counselling
- Respect for where they feel most comfortable during this time. Remember it is not my will but their will.
- There needs to be Aboriginal Health Workers in hospitals working with the people
- Improved support for relatives to help them understand the disease and that there is no blame to suffer from cancer and also how they can help and support the dying without feeling too scared.
- Family and Clinics across the lands need to be educated. Palliative Care is an acceptable option for people in remote regions. Currently there is no Palliative Care Service to cover the Remote Central Desert.
- Ensure that any palliative care given is done so in a culturally appropriate and sensitive manner and that it takes into account the cyclical concept of life-death-life for Indigenous Australians.
- The recognition and practice of Torres Strait Islanders culture is important to TSI people who are dying, especially for TSI residing on the mainland of Australia.



IN SUMMARY

The majority of respondents found that the posters did fulfil the primary objectives, which were:

- to increase awareness among Indigenous Australians, of the existence of palliative care services
- to be culturally sensitive.

Additional feedback was quite diverse, illustrating that some services had no idea of what palliative care was and how they might access it, through to others who praised their local palliative care service.



The concept of pamphlets, perhaps utilising the artwork from the poster, was suggested by several services. Community consultation would be necessary to ensure acceptability of the final product.

Respondents would welcome training for their own staff and people, plus training in cultural awareness for non-Indigenous health care workers.

Separate recognition of Torres Strait Islanders was requested.

CONCLUSIONS

- The original concept of producing posters has been vindicated by the feedback that the majority of respondents found that the posters did fulfil the primary objectives.
- There is a significant need to educate Indigenous Australians of the existence of palliative care and to enable remote communities access to this expertise.
- Current awareness of and access to palliative care is patchy.
- Cultural sensitivity is an important requirement of any programs designed to assist Indigenous Australians.
- Training of Indigenous health staff in palliative care is needed.
- Cultural awareness training of non-Indigenous health staff is needed.
- Some Indigenous services are keen to be involved in future similar projects, particularly to produce pamphlets.

RESOLUTION

That projects to produce and disseminate further culturally sensitive palliative care information to Aboriginal Medical Services be undertaken.

PRESENTER

Andrew Taylor is currently Executive Officer of the Palliative Care Council of South Australia and a member of the Council of Palliative Care Australia. He has had 30 years previous experience in pathology, including public relations and customer service. He is married, with three children, and is a keen Rotarian.

