

**Improving end-of-life care for  
Indigenous Australians: an  
evaluation of The Program of  
Experience in the Palliative  
Approach(PEPA) on Indigenous  
participants and their  
contributions to end-of-life care**

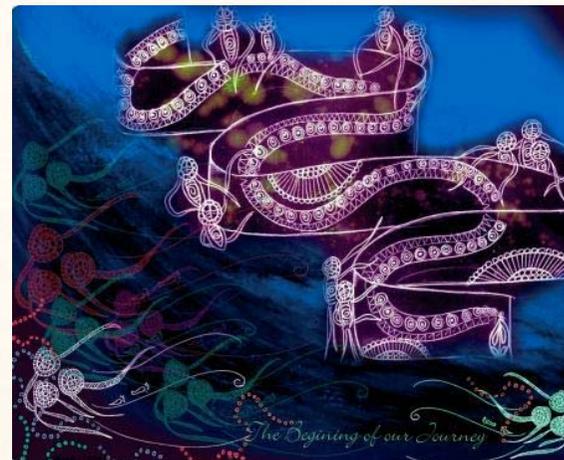


Western Australian Centre for Rural Health

# Palliative care and Aboriginal and Torres Strait Islander people

- The palliative approach aims to reduce unnecessary suffering experienced at the end of life
- Palliative care is a low priority for Aboriginal and Torres Strait Islander people due to:
  - Lack of understanding of the role of palliative care
  - Poor availability of services
  - Large burden of chronic disease seen as priority

The Beginning of our Journey  
Artist: Kahli Luttrell, Yorta Yorta  
descent of the Northern Country  
Victoria



# Services

- Indigenous peoples end-of-life decision making impacted by:
  - Poor availability of services
  - Lack of culturally safe services
  - Lack of understanding of palliative care
  - Lack of trained specialists to deal with Indigenous issues



# Program of Experience in the Palliative Approach (PEPA)

- Started in 2003
- To improve the quality, availability and access to palliative care for people with life-limiting illness
- improve skills, knowledge and confidence of palliative care providers across the continuum
- The Indigenous PEPA component commenced in 2007
  - To address the needs of Aboriginal and Torres Strait Islander patients and their families



# The Indigenous component of PEPA

Offers:

- A flexible, clinical learning experience
- An approach and delivery that is culturally sensitive
- Meets the needs of Indigenous Health Workers (IHWs), Liaison Officers, Community and Care Workers
- No cost
- Travel and accommodation assistance



# Evaluation

- 2 Phases
- Phase 1 examined the history and processes
- Phase 2 evaluated the impact of PEPA participation on Indigenous Health Workers (IHWs) and the communities within which they work

**Aim: to explore how PEPA influenced Indigenous participants and contributed to their provision of culturally appropriate end of life care for Indigenous people and to make recommendations for improvements**



# Program Differences

PROGRAM DIFFERENCES								
Organisational	ACT	NT	NSW	Queensland	SA	Tasmania	Victoria	WA
PEPA Manager employed	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
FTE	0.8	1.0	1.0	1.0	1.0	0.8	1.0	1.0
PEPA based with	Calvary Health Care	NT Department of Health	New South Wales Health Department	Queensland Health	Palliative Care Council (PCC), SA	Department of Health and Human Services	Department of Health , Victoria	Cancer Council, WA
Indigenous PEPA Project Officer	No	Yes	Yes-on secondment at time of interviews	Yes	Yes (partially supported by PCC,SA)	No	Yes-VACCHO employee	No
Aboriginal consultant	Yes- ALO	NA	NA	NA	NA	Yes-	NA	Yes- APO
FTE	0	1	unknown	0.5	1	0	unspecified	0
Program Facilitator/educator	No	No	Yes	No	Yes -PCC SA	No	Yes - contractual	No
Reverse PEPA placements offered	No	Yes	No	Yes(recently )	Yes	No	Yes	No
Indigenous PEPA outreach workshops	N/A	Yes - remote	Yes- remote	Yes- remote	Yes- remote	No	Yes- rural	No



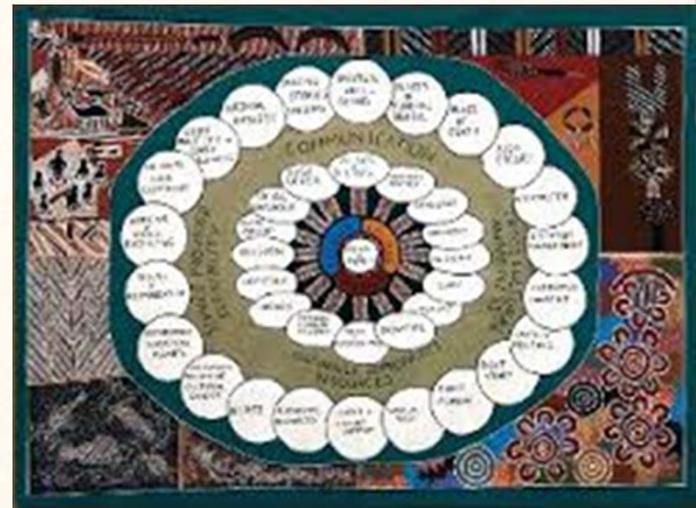
# Program Differences

- PEPA is delivered by the State or Territory Department of Health in five states and territories Qld, NT, Vic, NSW, Tas
- SA-Palliative Care Council SA & WA-Cancer Council WA
- Management roles were similar across jurisdictions and were primarily administrative
- The role of the IPO/Advisor differed across jurisdictions
  - Played a vital role in linking PEPA into the communities and building relationships with key stakeholders
- *So really, my role has been a facilitation role around cultural facilitation... making sure that Aboriginal workers have a safe spiritual, emotional well-being area that- because you know talking about death and dying is not easy for our people.*  
(IPO)



# The Program

- Aims to provide a supportive learning opportunity  
Offers combination of learning experiences:
  - workshops,
  - clinical placements,
  - reverse PEPA placements
  - An electronic self-directed learning guide



# Workshops

- Run by palliative care health professional
- Informal format with less structured content
- “Yarning” workshops worked well

## What we found

- Need to be flexible
- Adapted for participants
- Require a skilled facilitator
- Consider 2 day workshop



- *It was open to everyone but it was predominantly Indigenous Health Workers about 80% and other health workers that worked with Indigenous clients. I found it a really useful forum because it's very laidback. It's working with the people and what they want to get out of it. It was very workshop like and groups putting ideas together...*

(Non-Indigenous workshop participant)



# Community Outreach Workshop

- A tailored workshop for Indigenous communities
- Developed in the NT to service remote communities
- Flexible structure
- Aimed at IHW, community workers, ILO, and community elders and carers
- includes anyone working with Indigenous patients
- *What we worked on was communication between health professionals, access for clients to cancer and palliative care services... so it was quite an overview at a level that was appropriate to everyone.* (Workshop participant)



# Community Outreach Workshop

## What we found

- ideal for Indigenous communities, remote clinics and Aboriginal Community Controlled Health Services
- opportunity for 2 way learning



# Clinical Placements

- Provide opportunity to develop skills in the palliative approach
- Usually at a palliative care specialist service
- 3-5 days
- Placement sites pre-selected
- Site suitability for participant's needs
- 245 Indigenous participants to mid 2014

Going home to country



Walking on country



*Images by C Holloway*



# Reverse PEPA Placements

- Palliative care specialist works as a PEPA mentor on site
- Opportunity for the local service to learn about palliative care
- Placements - 2-5 days
- Tailored to the needs of the community
- Increases opportunity for IHW participation
- Ideal for rural & remote



## Impact on Participants

- Indigenous Health Workers were empowered to help their patients understand and cope with the dying process
- *One of the things about hospital that people don't like-no windows, no real air-recycled air. You're seeing a lot of strangers who are making decisions about you and you don't know them. You know that they're doing the right thing or they're doing their job, but it makes a world of difference see a black face, another Indigenous person working in the area, and prepared to work with you. (IHW participant)*



## Impact on Community

- IHW able to visit patients in their homes
- Gained confidence in explaining end of life processes
- Less overwhelming for patients and their families
- *I could see that they were sort of a bit overwhelmed. I said that I'll catch up to him at home, and we did, we caught up and talked one to one, man to man about things. I couldn't have done that without having done PEPA training, a bit of confidence to let you know its ok to talk about dying!* (Placement participant)



# Making a difference

## “A good death”

*One of my cousins passed away about two months ago and during her journey we would go and visit her and at the end of her journey she said a big thank you to us. And it was really good to hear that from a sick person, thanking us so much and I said “no its alright because this is what we do, we help people”. Yes it was very rewarding for us all. Its good to hear from people who are leaving us and the care they have got and I say to myself at least we are appreciated (IHW)*



# Lessons learned

- A dedicated Indigenous Project Officer is essential
- Training is particularly valuable in communities that have no visiting palliative care services
- Outreach Workshops are a good model for remote
- Mixed yarning & outreach workshops - valuable in building cross-cultural knowledge

The remote community of Tjuntjuntjara in Western Australia



# Future possibilities

- Employ a dedicated IPO / IEO in each jurisdiction
- Palliative care information sessions for community
- Engage health centre managers
- Develop local educational material in easily understood language
- Dedicated session on Advance Care Planning.
- Extended workshop model to include understanding cancer
- Longer workshops such as the “yarning” and Outreach Workshops to allow for discussion and storytelling
- Possible accreditation of the PEPA as a Certificate IV unit



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