PROVIDING PALLIATIVE CARE TO REMOTE ABORIGINAL PATIENTS
- A CASE SERIES

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From existing knowledge - what are some barriers:

- Multiple care providers with variable palliative care experience
- Scarce resources
- Difficulties with travel and escalating care
- Large proportion of care resides with family, carers and remote health clinics
- Limited support or respite services
- Cultural relationship rules determine who can be involved in physical care
- Cultural practices and obligations around dying, bereavement and grief
- Social, emotional, economic and infrastructure barriers – such as overcrowding, poverty, involvement of young children
Study method

- Retrospective non-consecutive case series (purposive sample)

- Ethics approval has been gained through the Central Australian Human Research Ethics Committee

- The Territory Palliative Care – Australia team members agreed to be part of an expert reference group to analyse the data.

- Thanks to the Territory Palliative Care - Central Australia team and my supervisor, Dr Fariba Nadimi
In the two-year study period the palliative care service had sixteen remote patients die at home addresses in remote communities.

I would like to describe two out of the three journeys in our study …
CASE 1
Case 1 - John

- 55 year old Aboriginal man from community with extensive SCC of the nasal cavity
- Transfer to hospital for diagnosis and treatment of severe secondary infection, returned home for end of life care

- Community - 325km from hospital / palliative care service
- Lived in aged care facility - staff (1) during day; granddaughter overnight
- Clinic staff - 2 Nurses; 1 Aboriginal health practitioner; Doctor 5 days/month
- Equipment utilised - Shower chair, wheelchair, tent, fly-net with hat
Case 2 - Sarah

- 60 year old Aboriginal woman with end stage renal failure, living in Alice Springs for last two years for renal replacement therapy
- Sarah decided to cease dialysis and return to community for end of life care
- Community - 275km from hospital; 600km from palliative care service
- Lived in sons house - son, daughter-in-law and husband initial carers; granddaughter carer for end of life care (no support services available)
- Clinic staff - 1 Nurse; 1 Aboriginal health practitioner; Doctor 5 days/month
- Equipment utilised - Shower chair, wheelchair
These cases highlight the complex interplay between patients, their family and service providers in providing supported end of life care in remote communities ....
ENABLERS TO SERVICE DELIVERY
Enabler – family and patient

It is an ‘individual discussion with each family’
Enabler – cultural safety

- Recognition of the ‘two world views about health’
- Large role for Aboriginal health workers, traditional healers and interpreters
- Advocacy to support a culturally competent service
Enabler – service coordination

- Early assessment, defined roles and planning
- Empowering the patient and family
- Realistic goals
- Create network to ‘troubleshoot’ issues
Enabler – service capacity building

- Timely transport
- Appropriate infrastructure
- Building staff capacity
- The ability to have ‘back up’ by the palliative care team is crucial
Enabler - relationships

- Need a ‘champion at the community level’
- Advocacy
- Flexibility in service delivered
- Need to create formalised pathways
Future direction

- Continued research
- Formalised pathways
- Advocacy to provide a more culturally safe service
- Advocacy to strengthen aged care, support and respite services to remote communities
THANK YOU VERY MUCH!
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