PROVIDING PALLIATIVE CARE TO REMOTE ABORIGINAL PATIENTS - A CASE SERIES

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Glen Helen 98
Kings Canyon 283
Haasts Bluf 30


Timor Sea
Darwin
Ashmore and Cartier Islands (AUSTRALIA)
Katherine
Gulf of Carpentaria
Wyndham
Kununurra
INDIAN OCEAN
Coral Sea
Derby
Broome
Cairns
Normanton
Forsayth
Coral Sea Islands (AUSTRALIA)
Townsville
Charters Towers
Mount Isa
Port Hedland
Dampier
Yarrie
Karratha
Mackay
WESTERN
QUEENSLAND
Newman
Paraburdoo
Rockhampton
Yaraka
Bundaberg
AUSTRALIA
Carnarvon
Quilpie
Charleville
Maryborough
Meekatharra
SOUTH
Cunnamulla
Brisbane
Toowoomba
Gold Coast
Leonora
Coober Pedy
AUSTRALIA
Leigh Creek
Geraldton
Bourke
Lismore
Kalgoorlie
Broken Hill
NEW SOUTH
Coffs Harbour
WALES
Cobar
Port Macquarie
Dubbo
Perth
Fremantle
Ceduna
Port Augusta
Port Pirie
Orange
Newcastle
Bunbury
Esperance
Mildura
Sydney
Port Lincoln
Adelaide
Wollongong
Albany
Swan Hill
Canberra
Great Australian Bight
Melbourne
Australian Capital Territory
Mount Gambier
Ballarat
Geelong
Warrnambool
Bairnsdale
Bass Strait
Tasman Sea
Devonport
Launceston
TASMANIA
Hobart
Tasmania
INDIAN OCEAN
BARKLY REGION
TENNANT CREEK
ALICE SPRINGS
ALICE SPRINGS REGION
Australia
International boundary
State-level boundary
National capital
State-level capital
Railroad
Expressway


ON CALL
WELCOME

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

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

Analysis

These cases highlight the complex interplay between patients, their family and service providers in providing supported end of life care in remote communities ….


Year Planner 2014


CLINIC


AMBULANCE

Photo courtesy of ABC Alice Springs

ENABLERS TO SERVICE DELIVERY

Enabler – family and patient

It is an ‘individual discussion with each family’

Enabler – cultural safety

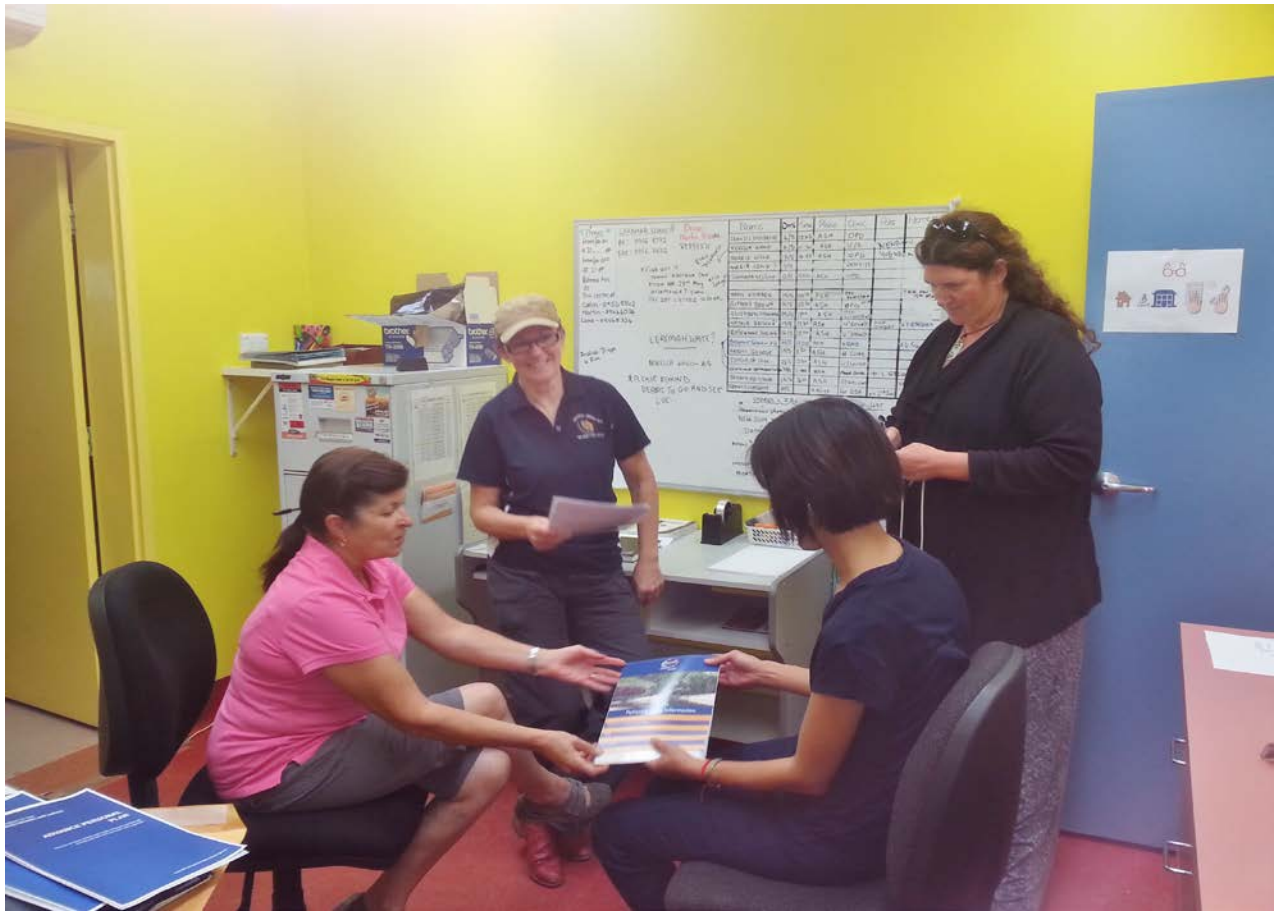
- Recognition of the ‘two world views about health’
- Large role for Aboriginal health workers, traditional healers and interpreters
- Advocacy to support a culturally competent service

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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