Characterisation of Indigenous and non-Indigenous patients accessing Palliative Care Services in Australia from July 2011 to June 2014

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Caveats

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- “Indigenous Australians” refers to Aboriginal and Torres Strait Islanders. It is acknowledged that these are two culturally different groups – the broader term is used throughout this presentation for brevity.

Indigenous Australians & Palliative Care

- Indigenous Australians are known to experience worse end of life health outcomes[1,2]
- Palliative Care is associated with better patient quality of life, reduced caregiver strain, and improved efficiency for health services [3-7]
- Two primary settings for palliative care in Australia
    - Community based palliative care
    - Inpatient palliative care

1. Australian Institute of Health and Welfare, *Australia's Health 2014. Australia's health series no. 14. Cat. no. AUS 178.* , AIHW, Editor 2014: Canberra.
2. World Health Organisation. WHO | WHO Definition of Palliative Care [Internet]. 2015. Available from: http://www.who.int/cancer/palliative/definition/en/.
3. Gomes, B., et al., *Effectiveness and cost-effectiveness of home-based palliative care services for adults with advanced illness and their caregivers.* Health, 2012.
4. Luckett, T., et al., *Elements of effective palliative care models: a rapid review.* BMC Health Services Research, 2014. **14**(1): p. 136.
5. Seow, H., et al., *Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis.* BMJ: British Medical Journal, 2014. **348**.
6. El-Jawahri, A., J.A. Greer, and J.S. Temel, *Does palliative care improve outcomes for patients with incurable illness? A review of the evidence.* The Journal of Supportive Oncology, 2011. **9**(3): p. 87-94.
7. Rabow, M., et al., *Moving upstream: a review of the evidence of the impact of outpatient palliative care.* Journal of Palliative Medicine, 2013. **16**(12): p. 1540-1549.

Indigenous Australians & Palliative Care

There is limited data available on Indigenous Australians' use of Palliative Care Services (PCSs) in Australia.

- From National reports, Indigenous Australians comprise:
    - 1.7% of patients accessing hospitals[1]
    - 1.1% of PCOC cohort[2]
- Indigenous population accessing PCSs described in one study Performed in NT[3]:
    - Found Indigenous patients were more likely to be:
        - Younger, female, living rurally, and to die at home

1. Palliative Care Outcomes Collaboration, *National Report on Patient Outcomes in Palliative Care in Australia July – December 2014*, 2014.
2. Australian Institute of Health and Welfare, *Palliative care services in Australia 2014*, 2014.
3. To, T. and M. Boughey, *Referral patterns to a palliative care service in rural Australia servicing indigenous Australians.* International Medical Journal, 2010. **40**(11): p. 772-6.

Research Aims

1. Describe and compare the demographic characteristics of Indigenous and non-Indigenous patients.

2. Describe and compare, by setting, the characteristics of the episodes of care received by Indigenous and non-Indigenous patients.

3. Determine whether clinical outcomes differ between Indigenous and non-Indigenous patients.

Methods: Data Source

- All information provided by PCOC
  palliative care
  outcomes collaboration

- PCOC data collection is part of routine service provision for participating PCSs

- Three levels: patient, episode and phase.

PCOC Dataset

PATIENT LEVEL

- Age
- Indigenous Status
- Diagnosis
- Country of Birth
- Preferred Language
- Sex
- State of Residence
- Distance
- Patient SEIFA

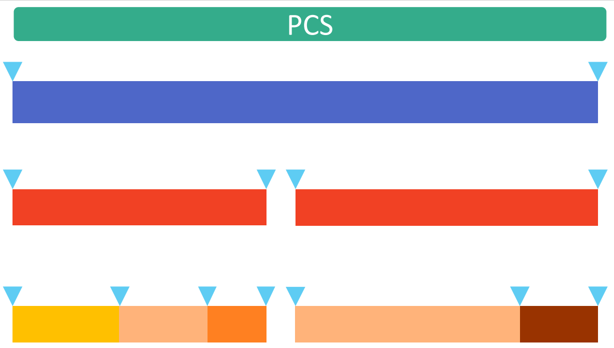
EPISODE LEVEL

- Date Episode Starts
- Date Episode Ends
- Episode Setting
- Start and End mode
- Referral Source
- Start and End Accommodation
- Service SEIFA

PHASE LEVEL

- Date Phase Starts and Ends
- Phase Length
- Phase End Reason
- Next Phase Type
- Clinical Characteristics
  - Palliative Care Problem Severity Score
  - Australian Karnofsky Performance Scale
  - Symptom Assessment Scales
  - Resource Utilisation Group – Activities Of Daily Living

Data Collection Example



KEY

Inpatient PCS	🟩	Stable Phase	🟧
Patient	🟦	Unstable Phase	🟨
Episode	🟥	Deteriorating Phase	🟧
Data Collected	▼	Terminal Phase	🟧
		Bereavement Phase	🟫

Methods: Study cohort

79,597 patients that accessed PCSs reporting to PCOC from July 2011 – June 2014

Excluded N= 3,277 patients
Did not have complete episode data:385
Did not have reliably reported data: 397
Did not have Indigenous status reported: 2,495

N = 76,320 patients included in descriptive analyses
894 Indigenous patients
75,426 non-Indigenous patients
104,611 episodes

Excluded N = 55,541 patients
84,913 episodes
Missing end of episode clinical outcome data: 55,541

N=20,779 patients included in clinical outcome comparisons
23,930 episodes

Results: Patient Demographics

		Indigenous (N=894)	Non-Indigenous (N=75,426)
Age at episode start*		63.6±15.4	73±14.0
Gender*		47.9% Male	53.7% Male
Diagnosis		78.9% Cancer diagnosis 21.1% Non-cancer diagnosis	79.6% Cancer diagnosis 20.4% Non-cancer diagnosis
Distance between accommodation and PCS**		120.1±506.0 kms	29.0±237.4 kms
Patient socioeconomic status**		Low 34.7% Medium 42.6% High 22.7%	Low 21.6% Medium 36.8% High 41.6%
State of residence*	**NSW**	21.0%	22.8%
	VIC	15.7%	28.8%
	QLD	25.6%	20.9%
	SA	6.0%	7.7%
	WA	23.6%	15.0%
	TAS	7.8%	4.8%
Setting of care**		64.3% Inpatient setting 33.9% Community Setting	58.5% Inpatient setting 37.2% Community Setting

All categorical variables compared using chi square tests. All continuous variables compared using t-tests. *p<0.05. **p<0.001. N=patients

Results: The Average Inpatient Episode

N=842 Indigenous and N=60,253 non-Indigenous inpatient episodes

Lasted a median of 5(2-12) and 6(3-14) days

At the start of the average inpatient episode:

- Most frequently referred by a public hospital
  - 61.4% vs 51.3%
- or by themself / family / carer
  - 20.7% vs 21.3%
- And entered the service coming from accommodation,
  - 61.6% vs 62.8%
- or transferred from another hospital/ward.
  - 31.6% vs 33.8%
- First phase was most commonly unstable (deteriorating condition, no care plan in place)
  - 46.4% vs 45.3%
- or deteriorating (deteriorating condition, care plan in place)
  - 28.3% vs 28.6%

Results: The Average Inpatient Episode

N=842 Indigenous and N=60,253 non-Indigenous inpatient episodes

At the end of the average inpatient episode:

- Most commonly ended the episode in a stable phase (stable condition, care plan in place)
  - 36.6% vs 30.7%
- or terminal phase (death likely within days)
  - 34.7% vs 40.3%
- Indigenous patients admitted from accommodation most commonly returned to accommodation
  - 54.4% vs 44.2%

Results: The Average Community Episode

N=414 Indigenous and N=41,208 non-Indigenous inpatient episodes

Lasted a median of 28(8-70) and 26(8-70) days

At the start of the average community episode:

- Most frequently referred by a public hospital
  - 61.0% vs 51.7%
- or by a GP / Specialist
  - 19.6% vs 19.8%
- And entered the service coming from accommodation,
  - 65.9% vs 65.4%
- First phase was most commonly Stable (unchanging condition, care plan in place)
  - 42.8% vs 44.9%
- or deteriorating (deteriorating condition, care plan in place)
  - 42.5% vs 43.8%

Results: The Average Community Episode

N=414 Indigenous and N=41,208 non-Indigenous inpatient episodes

At the end of the average community episode:

- Most commonly ended the episode in a deteriorating phase (deteriorating condition, care plan in place)
  - 38.2% vs 41.5%
- or a stable phase (stable condition, care plan in place)
  - 35.0% vs 33.0%
- Both patient populations were most commonly discharged to continued care with a different service provider or palliative care service,
  - 50.8% vs 52.5%
- Or passed away
  - 30.5% vs 33.1%

Results: Clinical Outcomes

- Very few differences in initial and final Symptom Assessment Scores between Indigenous and non-Indigenous patients
  - Measured for symptom burden problems associated with Appetite, Bowels, Breathing, Fatigue, Insomnia, Nausea, and Pain.
    - If present, rated by patient on a scale of 1 – 10 for symptom distress.
- Average change in score was negative or zero across scales

Main Findings: Patient Demographics

- Similar demographics to those seen in To & Boughey's (2009) paper,[1] despite no coverage of NT in PCOC dataset
  - High proportion of males and cancer diagnoses
- High proportion of cancer diagnoses in Indigenous patients despite high non-cancer chronic disease[2]
- Residing further from PCSs in lower SES areas: out-of-pocket costs?

1. 10. To, T. and M. Boughey, *Referral patterns to a palliative care service in rural Australia servicing indigenous Australians.* International Medical Journal, 2010. **40**(11): p. 772-6.
2. Australian Institute of Health and Welfare, *Australia's Health 2014. Australia's health series no. 14. Cat. no. AUS 178.* , AIHW, 2014: Canberra.

Main Findings: Characteristics of Care

- In the inpatient setting, Indigenous patients had better outcomes if admitted from home
  - Despite worse patient outcomes compared to non-Indigenous Australians[1-4]

Main Findings: Clinical Outcomes

- Findings limited to patients with end of episode clinical information
  - Healthier patients/ lower needs
- Indicate these patients have similar outcomes

1. Australian Institute of Health and Welfare, *Australia's Health 2014. Australia's health series no. 14. Cat. no. AUS 178.* , AIHW, 2014: Canberra
2. Shahid, S., et al., *Identifying barriers and improving communication between cancer service providers and Aboriginal patients and their families: the perspective of service providers.* BMC Health Services Research, 2013. **13**(1): p. 460.
3. Cunningham, J., et al., *Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia.* The Lancet Oncology, 2008. **9**(6): p. 585-595.
4. Condon, J.R., et al., *Stage at diagnosis and cancer survival for Indigenous Australians in the Northern Territory.* Medical Journal of Australia, 2005. **182**(6): p. 277-80

Limitations

- Representativeness of PCOC cohort for Indigenous and non-Indigenous Australians
  - Generalizability of findings
- Reliability of Indigenous status
- Use of clinical scores limited by available data

Recommendations for future research

- Explore end-of-life care needed and received by patients with non-cancer diagnoses
- Investigate issues of equitable access regarding Indigenous patients' out-of-pocket costs when accessing PCSs
- Continue to nurture relationships with Indigenous Australian communities, to develop palliative evidence base to improve Indigenous Australians' end-of-life care

Questions?

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