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Occurrence and timely management of problems requiring prompt intervention among Indigenous compared with non-Indigenous Australian palliative care patients: a multijurisdictional cohort study

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ABSTRACT

Objectives Anticipation and prompt relief of symptoms among patients with a life-limiting illness is a core element of palliative care. Indigenous Australians commonly encounter cultural barriers in healthcare that may impair outcomes. The Palliative Care Outcomes Collaboration collects patient care data for the purposes of continuous quality improvement and benchmarking, with each recorded care episode divided into phases that reflect a patient's condition. We aimed to investigate differences between Indigenous and non-Indigenous patients in the occurrence and duration of 'unstable' phases (which indicate unanticipated deterioration in a patient's condition or circumstances), and determine attainment of the relevant benchmark (resolution of unstable phases in ≤3 days in 90% of cases) for both groups.

Design Cohort study.

Setting Australia-wide hospital-based and community-based specialist palliative care (1 January 2010 to 30 June 2015).

Participants 139 556 (1502 Indigenous and 138 054 non-Indigenous) adult patients.

Outcome measures Indigenous and non-Indigenous patients were compared on (1) the risk of a phase being categorised as unstable, (2) the duration of unstable phases, and (3) the risk of unstable phases being prolonged (>3 days). Crude and adjusted estimates were produced from three-level robust Poisson regression and complementary log-log discrete time survival models.

Results Unstable phases occurred with similar frequency overall among Indigenous and non-Indigenous patients (adjusted relative risks 1.06; 95% CI 1.00 to 1.11; not significant after correction for multiple comparisons). The duration and risk of prolongation of unstable phases were similar in both patient groups, with no significant differences evident among subgroups. The benchmark was not met for either Indigenous or non-Indigenous patients (unstable phase duration >3 days in 24.3% vs 25.5%; p=0.398).

Conclusions Despite well-documented shortcomings of healthcare for Indigenous Australians, there is no clear evidence of greater occurrence or prolongation of unanticipated problems among Indigenous patients accessing specialist palliative care services in hospital or the community.

Strengths and limitations of this study

► The study is based on a large multijurisdictional data set that provides detailed information on patients with a broad range of life-limiting illnesses and who have been cared for in diverse settings.
► The analysis incorporated multiple regression methods accounting for the three-level structure of the data and the discrete basis for time measurement.
► The data are not entirely representative of specialist palliative care services across Australia.
► There is the potential for bias in the timeliness with which the onset of unanticipated problems has been ascertained.
► Further, there is the potential for residual confounding by the type and stage of disease, although not in a manner likely to cast doubt on the conclusions.

INTRODUCTION

A principal aim of palliative care is the prevention and alleviation of suffering among persons who have a life-limiting illness.[1] Accordingly, a core task of palliative care clinicians is anticipation of new, unanticipated problems such as 'breakthrough' symptoms in order to reduce their occurrence when possible, along with early detection and prompt intervention to curtail and minimise the impact of such problems when they occur. The course of a life-limiting illness, including the occurrence of unpredicted events, is potentially influenced by the quality of care as well as by the nature of the underlying

disease, comorbidities and attributes of the patient in her or his social context.[2–4] In turn, the effectiveness of care is dependent on timely access to appropriate services and the skills of clinicians. The quality of communication between clinicians and patients along with their carers is of particular importance.[5]

In Australia, Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) people experience life-limiting illnesses at younger average ages than other Australians. Furthermore, Indigenous people more often encounter logistical and cultural barriers to high-quality healthcare.[6–8] Ineffective communications between health service providers and Indigenous patients may impair healthcare intervention and health outcomes.[9 10] Importantly, personal or collective historical adverse healthcare experiences may engender reluctance among Indigenous patients to disclose symptoms such as pain.[11] Although there is a growing literature on the particular needs and experiences of Indigenous Australians with life-limiting illnesses,[12 13] there have been no large-scale studies of healthcare system performance in addressing unanticipated problems in the palliative care context.

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national continuous quality improvement initiative funded by the Commonwealth Department of Health.[14] The Collaboration collects standardised patient care data from participating palliative care services for the purposes of analysis and regular reporting, benchmarking and research.[14 15] Established in 2005, PCOC collected data from services accounting for about 80% of specialist palliative care provision nationwide when data for the current study were collected. (The purview has since expanded to encompass non-specialist services providing palliative care.) The PCOC data set is structured hierarchically, comprising the records of one or more 'episodes' of care provided to each patient by a participating service, with each episode made up of one or more 'phases' that are categorised to delineate a patient's changing condition and care needs.[15 16] An 'unstable' phase is defined by the recognition of either an unanticipated problem or an unanticipated worsening of a patient's condition or circumstances (eg, family/carer issues impacting on care) that requires an urgent intervention or change in the management plan. The resolution of an unstable phase is defined by the institution of a care plan to deal with the unanticipated problem or when death is likely within days.[15] One of the PCOC quality-of-care benchmarks addresses timeliness of intervention in such circumstances, stipulating that '90% of unstable phases must last for 3 days or less'.[15]

The current study was conducted as part of a research project using the multijurisdictional PCOC data set to investigate the quality of care provided to Indigenous Australians with life-limiting illnesses, with a particular focus on the PCOC benchmarks.[15] We hypothesised that inequity in the care of Indigenous compared with non-Indigenous patients may be reflected in differences between the two groups in the occurrence and resolution of unstable phases. Our specific objectives were to compare Indigenous with non-Indigenous patients with respect to (1) the proportion of phases that were unstable, (2) the duration of unstable phases, and (3) the proportion of unstable phases that were prolonged (ie, >3 days), reflecting comparative attainment of the benchmark.

METHODS

Study design and patient population

This was a retrospective cohort study using the longitudinal, hierarchically structured PCOC data set (details available at https://ahsri.uow.edu.au/pcoc/ 4researchers/dataset/index.html). Palliative care phase was the unit of observation and the Indigenous identifier of the patient was the principal explanatory variable of interest. The study comprised the phase records (n=448 799) from all episodes of care provided to adult patients (>18 years at entry to care) during the period 1 January 2010 to 30 June 2015.

Definition of palliative care phase as the unit of observation

In PCOC data, palliative care phases experienced by patients are categorised non-sequentially as stable, unstable, deteriorating or terminal.[15] For the present study, phase types were recoded in binary form as 'unstable' or 'other', following exclusion of the 2.6% of records representing bereavement care for the family or carers after a patient's death and the 0.01% of records with a missing value for phase type. The PCOC data set includes start and end dates for each phase, allowing phase length calculation in days but not hours.

Study measures

The three primary outcome measures examined were the occurrence of unstable phases (as a proportion of all phases), unstable phase duration and the proportion of unstable phases that were prolonged. The relevant PCOC benchmark, based on 'time in the unstable phase',[15] was operationalised by defining a prolonged unstable phase as one lasting >3 days.

The main exposure variable investigated was the Indigenous identifier of patients, categorised in binary form as follows. Any patient identified as Aboriginal, Torres Strait Islander or both at entry to care was categorised as Indigenous. All other patients with a value recorded for this variable were categorised as non-Indigenous. The remaining patients (n=4980; 3.5%) with a missing value for the Indigenous identifier were excluded from the analyses.

In order to rule out biases arising from differences between Indigenous and non-Indigenous patients in episode structure (type and order of phases), we investigated the proportion of phase types in both patient groups, both overall and immediately preceding and following unstable phases.

Other covariates from PCOC data included in the analysis were sex, age in years at episode start, principal diagnosis, remoteness of residence, care setting, year of occurrence (recorded at phase onset) and selected clinical status indicators. PCOC categorises patient diagnoses according to 29 organ/system-specific codes,[15] which are grouped into the binary categories 'cancer' or 'other'. This binary grouping of principal diagnosis was adopted for the analysis because protocols for high-quality palliative care for patients with non-neoplastic life-limiting illnesses are less firmly established than for those with cancer.[17] Remoteness of a patient's residence at entry to care is categorised according to the five-tiered Australian Statistical Geography Standard.[18] For the current study the five categories were collapsed into three: (1) major cities; (2) inner regional; and (3) outer regional, remote or very remote. The setting in which an episode of care is provided is categorised as (1) overnight hospital/palliative care service admission, (2) hospital day admission/outpatient attendance, or (3) community. Validated clinical status indicators considered for the analyses were (1) the Australia-modified Karnofsky Performance Status (AKPS) scale, a clinician-rated assessment of a patient's physical abilities,[19] and (2) the Symptom Assessment Scale (SAS), which comprises symptom-related distress scores from seven domains (breathing, bowel problems, appetite problems, pain, insomnia, nausea and fatigue) rated by the patient (or by the carer if the patient is unable).[20] These clinical status indicators, recorded at the start of each phase, were modelled as numeric variables with each of the seven SAS items modelled as a separate covariate. Finally, the study period (during which substantial improvement in benchmark attainment was evident from preliminary inspection) was divided into two equal intervals: first half (1 January 2010 to 30 September 2012) and second half (1 October 2012 to 30 June 2015).

Statistical analysis

Approach to missing data

Comprehensive data quality assessment and cleaning for the research project instituted prior to the study incorporated the recoding of a small number of implausible values as missing.[21] Analytical results are based on records with non-missing values across all modelled covariates. Among included records (with a non-missing patient Indigenous identifier), the proportion of records with at least one missing value was ~14%, falling to ~3% when clinical status indicator scores were disregarded (online supplemental table 1). The main analyses therefore excluded the clinical status indicators, with sensitivity analyses that included these indicators undertaken for selected models to evaluate the potential impact of their exclusion.

Characteristics of patients and their care

Selected characteristics of Indigenous and non-Indigenous patients and their care were compared.

Also investigated was the potential for bias arising from differences between the two groups in the structure of patients' 'journeys of care' (number of care episodes experienced, number of phases, mix of phase types overall and immediately preceding and following an unstable phase).

Analyses of unstable phase occurrence

Unstable phase occurrence among Indigenous compared with non-Indigenous patients was investigated in three-level (patient, episode and phase) random intercept models, with relative risks (RR) and 95% CIs estimated using Poisson regression with robust variance structure.[22 23] Given that occurrence of an unexpected event (resulting in recording of an unstable phase) at the outset of a care episode may influence the setting of care, we undertook separate analyses for first and subsequent phases. Crude and adjusted estimates of RR were calculated. Adjusted model 1a incorporated the following covariates: age (modelled as a continuous variable), sex, principal diagnosis (modelled in binary form; ie, cancer vs other), remoteness and calendar year. Model 1b (subsequent phases only) comprised all covariates listed for model 1a plus setting. Finally, subgroup analyses were undertaken to estimate adjusted RRs for the Indigenous identifier across each stratum of the other covariates.

Analyses of phase duration

Time-to-event analyses were performed in order to investigate overall differences between Indigenous and non-Indigenous patients in the duration of each unstable phase (ie, the time from the phase start date until the phase end date (indicating institution of the care plan)). Software constraints precluded extension of the Cox proportional hazards model to three-level hierarchical data nesting,[24] and the hazard function assumptions of multilevel parametric (eg, Weibull distribution) survival models could not be fitted to the data.[25] Further, considering that unstable phase duration in PCOC data is ascertainable only from discretised start and end dates, it was not appropriate to model time as a continuous variable.[26] Accordingly, the time-to-event analyses were based on multilevel discrete time survival models incorporating a complementary log-log link to estimate the log hazard.[26] Unstable phases ending in death (3.6%: Indigenous 2.7%, non-Indigenous 3.6%) were right censored.[27] A further small minority of unstable phases of extreme duration (>30 days: 1.2% of phases from both Indigenous and non-Indigenous patient groups) prevented model convergence and were excluded. Violation of the proportional hazards assumption by covariates considered for multivariable regression modelling was investigated by preliminary modelling of interactions between the time variable and each covariate. Covariates demonstrated to have duration-dependent effects were stratified in subgroup analyses rather than incorporated into the regression models.

Analyses of unstable phase prolongation

Unstable phases that ended in death (n=3543 (3.6% of total; 2.7% of those of Indigenous patients and 3.6% of non-Indigenous)) were excluded from analyses of prolongation. In order to investigate the achievement of the PCOC benchmark, raw percentages of unstable phases that were prolonged (>3 days) were calculated for the total sample as well as Indigenous and non-Indigenous patients separately. Further, as with the analysis of unstable phase occurrence and duration (above), RRs of prolongation were estimated in three-level robust Poisson models for each independent variable: Indigenous identifier, age group (dichotomised as <65 years vs ≥65 years), sex, principal diagnosis, remoteness, setting and calendar year. For the Indigenous identifier, adjusted RRs were also estimated. The principal adjusted model incorporated the following covariates: age (modelled as a continuous variable), sex, principal diagnosis (modelled in binary form; ie, cancer vs other), remoteness, calendar year and setting. A sensitivity analysis comprised all covariates listed for the principal model plus the clinical indicators (ie, AKPS and the seven SAS domains). Finally, subgroup analyses were undertaken to estimate adjusted RRs for the Indigenous identifier for each stratum of the other model 1 covariates.

Additionally, crude differences in occurrence and prolongation of unstable phases were examined in relation to the setting of care and calendar time, in order to contextualise the comparisons between the phases of Indigenous and non-Indigenous patients.

P values were corrected for false discovery rate using the Benjamini-Hochberg method[28] applied across all 46 analyses in the study, with a corrected value p<0.0022 considered statistically significant. All analyses were conducted using Stata V.15.1 (StataCorp, College Station, Texas, USA).

Patient and public involvement

This research was done without patient involvement. Patients were not invited to comment on the study design and were not consulted to develop patient-relevant outcomes or interpret the results. Patients were not invited to contribute to the writing or editing of this document for readability or accuracy.

RESULTS
Study population

The sample comprised 139 556 patients, 1502 Indigenous and 138 054 non-Indigenous (table 1), with a further 4980 patients lacking an Indigenous identifier excluded from the study. Indigenous patients were a decade younger on average at entry to palliative care than non-Indigenous patients (63.3 vs 73.0 years), and a higher proportion were female (51.5% vs 46.4%). Similar proportions of patients in both groups had a cancer as the principal diagnosis (78.2% vs 78.9%). Indigenous patients more often resided outside major cities at entry to care (46.1% vs 23.0%),

Table 1 Characteristics of patients and their episodes and phases, by Indigenous identifier

Patients	Indigenous	Non-Indigenous
	n=1502	**n=138 054**
Baseline characteristics		
Age (years) at entry to care, mean (SD)	63.3 (14.3)	73.0 (13.6)
Age group at entry, n (%)		
<65 years	801 (53.3)	34 520 (25.0)
≥65 years	698 (46.5)	103 452 (74.9)
Sex, n (%)		
Female	773 (51.5)	64 038 (46.4)
Male	726 (48.3)	73 955 (53.6)
Principal diagnosis, n (%)		
Cancer	1174 (78.2)	108 921 (78.9)
Other	304 (20.2)	27 424 (19.9)
Remoteness of residence at entry, n (%)		
Major cities	809 (53.9)	106 361 (77.0)
Inner regional	337 (22.4)	21 965 (15.9)
Outer regional	242 (16.1)	6963 (5.0)
Remote/very remote	88 (5.9)	654 (0.5)
Episodes	**Indigenous**	**Non-Indigenous**
	n=2258	**n=191 784**
Setting of care, n (% by setting)		
Inpatient overnight admission	1423 (63.0)	110 930 (57.8)
Hospital ambulatory (day admission, OP)	67 (3.0)	2916 (1.5)
Community	768 (34.0)	77 938 (40.6)
Phases	**Indigenous**	**Non-Indigenous**
	n=4878	**n=443 921**
Phase type, n (% by type)		
Stable	1509 (30.9)	136 454 (30.7)
Unstable	1156 (23.7)	96 776 (21.8)
Deteriorating	1568 (32.1)	148 802 (33.5)
Terminal	645 (13.2)	61 889 (13.9)
Study period of phase start date, n (% within half)		
Earlier half (1 January 2010 to 30 September 2012)	2015 (41.3)	176 234 (39.7)
Later half (1 October 2012 to 30 June 2015)	2863 (58.7)	267 687 (60.3)

Percentage totals may not add up to 100% due to missing data.
OP, outpatient.

and more often received their care as inpatients admitted overnight (63.0% vs 57.8%). The proportion of Indigenous patients entering care over the study period did not change significantly while the proportion of patients with a missing identifier diminished progressively from 4.9%

(2010) to 2.0% (2015). The proportions of phase categories among Indigenous and non-Indigenous patients were similar (table 1).

The number of care episodes, phases overall and of each type of phase was similar among Indigenous and non-Indigenous patients (online supplemental table 2a). Further, the mix of phase types was similar in the two patient groups, both immediately preceding and immediately following unstable phases (online supplemental table 2b, c).

Outcomes among Indigenous compared with non-Indigenous patients

Occurrence of unstable phases

Overall, phases were less often categorised as unstable when care was provided in hospital day admission/outpatient settings (crude RR 0.82; 95% CI 0.78 to 0.86) and community settings (crude RR 0.52; 95% CI 0.51 to 0.52) compared with inpatient settings. Differences between settings in unstable phase occurrence varied with the phase sequence within an episode of care. First phases were less often categorised as unstable when care was provided in hospital day admission/outpatient settings or community settings compared with inpatient settings, with crude RRs respectively 0.47 (95% CI 0.44 to 0.50) and 0.20 (95% CI 0.19 to 0.20). The associations were reversed among subsequent phases, which were more often categorised as unstable when care was provided in hospital day admission/outpatient settings (crude RR 1.85; 95% CI 1.69 to 2.01) and community settings (crude RR 1.34; 95% CI 1.31 to 1.37) compared with inpatient settings. The occurrence of unstable phases diminished during the study period; phases were less often categorised as unstable during the second half of the study period (1 October 2012 to 30 June 2015) compared with the first half (1 January 2010 to 30 September 2012) (crude RR 0.79; 95% CI 0.78 to 0.80).

The crude RR of a phase being unstable versus all other types of phase was significantly higher among Indigenous compared with non-Indigenous patients even after correction for multiple comparisons (RR 1.09, p=0.002, 95% CI 1.03 to 1.15) (table 2). However, there were no significant crude differences between phases of the two patient groups when phases were stratified by order within an episode as either first or subsequent. After adjustment and correction for multiple comparisons, there were no significant differences across the total sample in RRs of a phase being unstable versus all other types of phase among Indigenous compared with non-Indigenous patients. In the subgroup analyses, the adjusted RR of a phase being unstable among Indigenous compared with non-Indigenous patients was significantly different (after correction) only in patients living in major cities (RR 1.13, p<0.001, 95% CI 1.05 to 1.20).

Duration and prolongation of unstable phases

Unstable phases more often had a duration of greater than 3 days when care was provided in hospital day

Table 2 Relative risks for unstable phase occurrence according to Indigenous identifier, overall and by sequence within an episode of care and subgroups

	RR	P value	95% CI
Crude estimates			
All phases	1.09	0.002*	1.03 to 1.15
First phases	1.08	0.031	1.01 to 1.16
Subsequent phases	1.04	0.404	0.95 to 1.14
Adjusted estimates: total sample			
Model 1a† all phases	1.06	0.038	1.00 to 1.11
Model 1a† first phases	1.08	0.038	1.00 to 1.15
Model 1a† subsequent phases	1.00	0.971	0.92 to 1.10
Model 1b‡ (subsequent phases only)	1.02	0.732	0.93 to 1.12
Adjusted§ estimates: selected subgroups			
Age group			
<65 years at episode start	1.04	0.269	0.97 to 1.11
≥65 years at episode start	1.11	0.008	1.03 to 1.20
Principal diagnosis category			
Cancer	1.08	0.005	1.02 to 1.14
Other	0.83	0.091	0.67 to 1.03
Remoteness			
Major cities	1.13	<0.001*	1.05 to 1.20
Inner regional	1.01	0.794	0.92 to 1.12
Outer regional/remote/very remote	0.87	0.052	0.75 to 1.00
Care setting¶			
Inpatient	1.06	0.020	1.01 to 1.11
Community	0.92	0.175	0.81 to 1.04
Study period			
First half (1 January 2010 to 30 September 2012)	1.06	0.075	0.99 to 1.14
Second half (1 October 2012 to 30 June 2015)	1.05	0.211	0.97 to 1.13

*Significant after correction for multiple comparisons (Benjamini–Hochberg method).[28]
†Model 1a: adjusted for age (years: continuous/quadratic), sex, broad diagnosis, remoteness (three categories), calendar date (phase start: continuous/linear).
‡Model 1b (subsequent phases only): adjusted for setting in addition to the covariates listed for model 1a.
§Each subgroup analysis incorporated covariates from model 1a above other than the variable of stratification.
¶Hospital day admission/outpatient setting was excluded from stratification because small numbers interfered with model convergence.
RR, relative risk.

admission/outpatient settings (crude RR 2.11; 95% CI 1.99 to 2.15) and community settings (crude RR 1.57; 95% CI 1.53 to 1.61) compared with inpatient settings. Just as occurrence of unstable phases diminished across
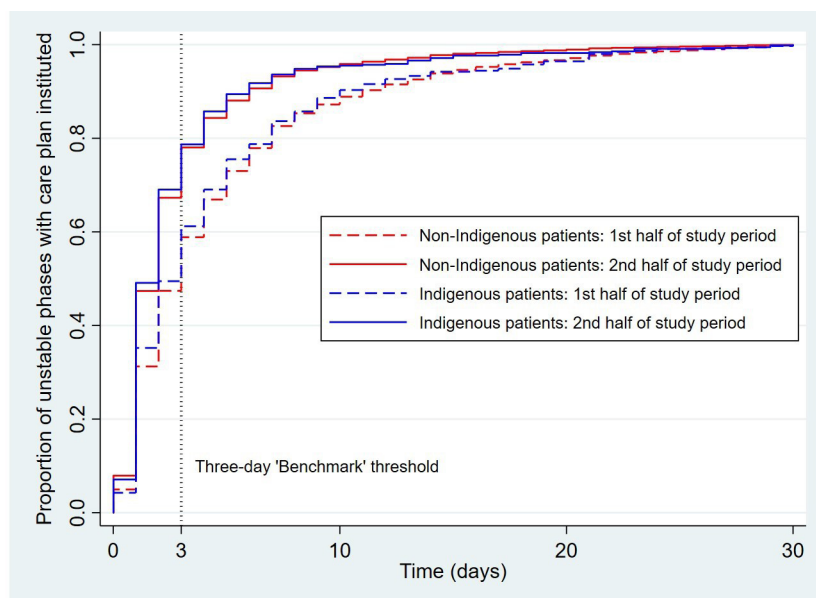
Figure 1 Crude time to completion of unstable phases among Indigenous compared with non-Indigenous patients, stratified by halves of study period. (Only unstable phases completed by institution of a care plan within 30 days are included. Phases ending in death were censored.)

the study period, so did prolongation of unstable phases (>3 days); phases were less often prolonged during the second half of the study period compared with the first half (crude RR 0.55; 95% CI 0.548 to 0.56).

There were no significant differences between the unstable phases of Indigenous and non-Indigenous in either the HR for duration or the RR of prolongation, in either crude estimates (figure 1) or adjusted estimates for the total sample or selected subgroups (table 3), after correction for multiple comparisons.

The benchmark of resolution of unstable phases (excluding those ending in death) in ≤3 days in 90% of instances was not achieved for either Indigenous (70.8% of unstable phases ≤3 days) or non-Indigenous patients (69.8%) (p=0.498). Despite some improvement over time, completion within 3 days during the second half of the study period (1 October 2012 to 30 June 2015) was still attained only in 78.2% and 78.0% of unstable phases experienced by Indigenous and non-Indigenous groups, respectively (p=0.945) (figure 1).

DISCUSSION

In this longitudinal, multijurisdictional study of unanticipated problems experienced by Indigenous compared with non-Indigenous Australian patients during specialist palliative care, we found no overall differences in the proportions of unstable palliative care phases or the proportion of unstable phases that were prolonged between the two groups, after appropriate adjustment. These generally null findings were robust to sensitivity analyses that compared exclusion with inclusion in regression models of the clinical status covariates, which had a substantial proportion of missing values. After correction for multiple comparisons, a significantly higher risk of

a phase being unstable among Indigenous patients was evident among those living in major cities but in no other subgroup. However, this association was not predicted a priori, was modest in magnitude and may have been influenced by unmeasured confounding. The pertinent PCOC benchmark stipulating that resolution of an unstable phase be attained within 3 days in ≥90% instances was not met for either patient group during the study period. However, there was progressive decrease across the study period in the occurrence of unstable phases and the proportion of these phases that were longer than 3 days.

Uncertainty contributes to distress and diminishes quality of life among people with life-limiting illnesses.[29] However, there has been little research specifically on the occurrence and timeliness of interventions to ameliorate unpredicted problems of palliative care patients or exploring these outcomes among patients from disadvantaged populations. PCOC data provide opportunity to investigate this topic on a large scale. Indigenous Australians experience disparities in health service provision and outcomes across their lives, and this is likely to occur within their journey with a life-limiting illness.[30 31] In the case of cancer (the principal diagnosis of the majority of patients receiving specialist palliative care), Indigenous Australians have lower uptake of screening,[32] and they commonly experience substantial delays in diagnosis.[33 34] Additionally, they have more limited access to definitive treatments,[32 35] have lower uptake of hospitalisations[36] and frequently have unmet supportive care needs.[37] A far lower proportion of Indigenous compared with non-Indigenous patients receive specialist palliative care at the end of life.[38] In contrast to these 'upstream' care disparities, the findings of the current study provide reassurance in relation to one important aspect of the care provided

Table 3 Comparisons by Indigenous identifier of unstable phase duration and prolongation (>3 days), overall and by subgroups

HRs for conclusion of unstable phase through institution of care plan

	HR	P value*	95% CI
Crude estimates			
Indigenous identifier	1.03	0.532	0.94 to 1.13
Adjusted estimates: Total sample (principal model)†			
	1.04	0.435	0.94 to 1.14
Adjusted estimates: Total sample (principal model+additional adjustment for baseline clinical status)‡			
	1.02	0.646	0.93 to 1.13
Adjusted estimates: Selected subgroups§			
Age group			
<65 years at episode start	1.03	0.686	0.90 to 1.17
≥65 years at episode start	1.05	0.495	0.91 to 1.21
Principal diagnosis category			
Cancer	1.03	0.589	0.93 to 1.13
Other	1.18	0.359	0.83 to 1.70
Remoteness			
Major cities	1.07	0.302	0.94 to 1.21
Inner regional	0.85	0.071	0.70 to 1.01
Outer regional/remote/very remote	1.12	0.351	0.88 to 1.42
Care setting¶			
Inpatient	1.12	0.024	1.02 to 1.25
Community	0.85	0.167	0.68 to 1.07
Study period			
First half (1 January 2010 to 30 September 2012)	1.09	0.236	0.95 to 1.24
Second half (1 October 2012 to 30 June 2015)	1.00	0.944	0.89 to 1.14

Relative risks for an unstable phase being prolonged >3 days

	RR	P value*	95% CI
Crude estimates			
Indigenous identifier	1.03	0.562	0.94 to 1.13
Adjusted estimates: Total sample (principal model)†			
	1.02	0.716	0.92 to 1.13
Adjusted estimates: Total sample (principal model+additional adjustment for baseline clinical status)‡			
	1.01	0.903	0.90 to 1.13
Adjusted estimates: (Selected subgroups)§			
Age group			
<65 years at episode start	1.04	0.583	0.91 to 1.19

Continued

Table 3 Continued

≥65 years at episode start	0.93	0.328	0.79 to 1.08
Principal diagnosis category			
Cancer	0.98	0.722	0.88 to 1.09
Other	1.07	0.739	0.71 to 1.61
Remoteness			
Major cities	1.00	0.952	0.89 to 1.13
Inner regional	1.09	0.368	0.91 to 1.31
Outer regional/remote/very remote	0.75	0.187	0.50 to 1.15
Care setting¶			
Inpatient	0.94	0.334	0.84 to 1.06
Community	1.12	0.237	0.93 to 1.34
Study period			
First half (1 January 2010 to 30 September 2012)	1.00	0.989	0.88 to 1.13
Second half (1 October 2012 to 30 June 2015)	1.04	0.650	0.88 to 1.22

*No p values were significant after correction for multiple comparisons (Benjamini–Hochberg method).[28]
†Principal model covariates: age (continuous, quadratic), sex, principal diagnosis category, setting, remoteness (three categories) and calendar date (phase start: continuous/linear).
‡Principal model plus additional covariates: start-of-phase Symptom Assessment Scale (seven domains; continuous); start-of-phase Australia-modified Karnofsky Performance Status scale (continuous).
§Each subgroup analysis incorporated covariates from model 1a above other than the variable of stratification. The following covariates violated the proportional hazards assumption: remoteness, care setting and study period. For correspondence with other results tabulated in the paper, the HR data were also subgrouped by age and principal diagnosis category.
¶Hospital day admission/outpatient setting was excluded from stratification because small numbers interfered with model convergence.
HR, hazard ratio; RR, relative risk.

to Indigenous patients who access specialist palliative care services.

Given the acknowledged importance of cultural competence of clinicians in dealing with patient symptoms[39] and findings from previous qualitative research that communication difficulties may disadvantage Indigenous patients in the context of life-limiting illness,[9 40] the near equivalence between the two groups across the measured outcomes is encouraging. It suggests that at least for those Indigenous patients accessing care in services that report data to PCOC, challenges in communication between them (or their carers) and service providers do not impact substantially on prevention of and intervention for unpredictable acute problems. These findings are particularly reassuring in consideration of the 10-year differential in average patient age (concordant with the well-known life expectancy gap), given that younger patients may present

distinctive challenges for services geared predominantly to dealing with older patients.[41]

It is a testament to PCOC as a large-scale continuous quality initiative that a consistent and substantial reduction occurred across the 5.5-year study period in both the occurrence of unstable phases (both at the outset and later during episodes of care) and their undue prolongation. Based on the summary data available in the PCOC's regular public domain reporting,[42] the trend has continued since the data for the present study were provided, reflecting ongoing efforts to address this important concern. This marked temporal trend in outcomes did not influence the similar outcomes among Indigenous and non-Indigenous patients, suggesting that both groups have benefited to a comparable extent from the progressive improvement.

The lower proportion of unstable phases in outpatient and community settings compared with inpatient setting as the reference was accentuated in first phases and reversed in subsequent phases (table 2), vindicating our stratification of occurrence by phase order. From the unadjusted models, care provided in inpatient hospital settings was associated with a much higher risk of unstable phases at the commencement of a care episode, with second and subsequent unstable phases more common in outpatient and community settings. These findings are unsurprising as identification of unanticipated or increasingly complex problems (corresponding with recognition of an unstable phase) in community settings frequently results in an inpatient admission. Conversely, clinical monitoring of patients is likely to be reduced in outpatient and community settings, where it may rely more on proactive communication from patients and their families.

Strengths and limitations

PCOC has assembled an information-rich longitudinal data set that allows for large-scale investigation of health service quality in Australian palliative care, including studies of care equity. For the small subgroup of Indigenous patients receiving care, we used several complementary modelling strategies to deal with the limitations of available information.

The timing of onset of unstable phases will likely be influenced by clinicians' recognition of 'unanticipated problems' and clinician–patient (or clinician–carer) communication. Therefore, there is a potential for a varying 'lag' period in recognition of an unanticipated problem, which might plausibly differ on average among Indigenous compared with non-Indigenous patients. Such a lag is not inherently ascertainable from the recorded start-of-phase date. However, we reasoned that delays in detection may be reflected in heightened problem severity at phase start as perceived by the patient and/or by greater deterioration in functional status, and thereby may be captured indirectly in start-of-phase responses to the SAS or AKPS questionnaires, respectively. In this regard, our unstable phase duration models incorporated modelling with and without these items as covariates.

However, we recognise that patients' responses to the SAS items may be culturally modulated and could find no evidence that the SAS has been specifically validated for use by Indigenous Australians, raising the possibility of differential under-reporting of symptom severity between the two patient groups.

Despite adjustment in multiple regression models to account for the diverse natural histories of underlying principal diagnoses, some degree of residual confounding by disease process may have occurred, particularly as the data did not include stage of disease at entry to care. Indigenous compared with non-Indigenous Australians experiencing a life-limiting illness tend (particularly in the case of cancers) to be diagnosed at a later stage, and with a disease type having an inherently poorer prognosis,[43] and are also more likely to have comorbidities.[44] Consequently, any residual confounding by disease stage or aggressiveness would be expected to increase the occurrence and duration of unanticipated problems among Indigenous patients. Therefore, confounding on this basis is unlikely to account for unstable phase occurrence and duration being no greater than among non-Indigenous patients. Although most specialist palliative care services nationwide provided data to PCOC throughout the study period, differential participation inevitably means that results are not representative of all services, with some having better or poorer performance than those that participated. No services from the Northern Territory provided PCOC data during our study time frame[38] (although several have since become involved).[45] This jurisdiction is home to an estimated 9% of Indigenous Australians,[46] a high proportion of whom live in remote or very remote areas, and many preferentially speak an Indigenous language rather than English. Consequently, the study excluded a subgroup of Indigenous patients at risk of especially heightened barriers to high-quality healthcare. Further, linkage of data from individuals cared for by more than one participating service or with other health data sets was not available so it was not possible to identify patients who received care from more than one service, or to incorporate external information such as cancer registry data on date and stage of diagnosis.[47] Finally, the data did not permit direct investigation of cultural safety (and how this may have influenced the outcomes) or of care appraisal from an Indigenous worldviews perspective, both of which are critical to improving health service performance for Indigenous people.[48 49] Incorporation of a cultural appraisal tool[50] into PCOC data collection for Indigenous patients would be an innovation worthy of consideration.

CONCLUSION

Australian Indigenous patients receiving specialist palliative care do not experience unanticipated problems or undue prolongation of such problems substantially more often than do non-Indigenous patients. While these findings are encouraging, caution is required in their interpretation. Future refinement of design and analytical methods through data linkage may offer opportunities for further systematically exploring palliative care outcomes and provide greater

insights into the experiences of Indigenous patients receiving palliative care.

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Supplemental material

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Supplemental Tables:

Occurrence and timely management of problems requiring prompt intervention among Indigenous compared with non-Indigenous Australian palliative care patients: a multi-jurisdictional cohort study

John A Woods, Judith M Katzenellenbogen, Kevin Murray, Claire E Johnson and Sandra C Thompson

Supplemental Table 1: Missing values, by patient group and variable

	Variable	Observations missing	Observations not missing	Percent Missing
Variables ascertained for each patient at entry to care by a service				
All patients	**Sex**	64	139,492	0.0
	Diagnosis	1,733	137,823	1.2
	Remoteness	2,137	137,419	1.5
		Data complete for 97.3% of patients		
Indigenous patients	**Sex**	3	1,499	0.2
	Diagnosis	24	1,478	1.6
	Remoteness	26	1,476	1.7
		Data complete for 96.5% of patients		
Non-indigenous patients	**Sex**	61	137,993	0.0
	Diagnosis	1,709	136,345	1.2
	Remoteness	2,111	135,943	1.5
		Data complete for 97.3% of patients		
Variables ascertained at commencement of each episode of care				
All patients	**Age**	128	193,914	0.1
	Setting	0	194,042	0.0
		Data complete for 99.9% of patients		
Indigenous patients	**Age**	3	2,255	0.1
	Setting	0	2,258	0.0
		Data complete for 99.9% of patients		
Non-indigenous patients	**Age**	125	191,659	0.1
	Setting	0	2,258	0.0
		Data complete for 99.9% of patients		
Variables ascertained at commencement of each clinical phase (i) All phases				
All patients	**Phase type**	49	448,799	<0.1
		Data complete for ~100.0% of patients		
Indigenous patients	**Phase type**	0	4878	0.0
		Data complete for 100.0% of patients		
Non-indigenous patients	**Phase type**	49	443,921	<0.1
		Data complete for ~100.0% of patients		

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Variables ascertained at commencement of each clinical phase (ii) Unstable phases only

All patients	Start date	0	97,932	0.0
	End date	0	97,932	0.0
	SAS Pain score	6,277	91,655	6.4
	SAS Nausea score	6,789	91,143	6.9
	SAS Breathing	6,926	91,006	7.1
	SAS Bowel score	7,361	90,571	7.5
	SAS Insomnia score	8,259	89,673	8.4
	SAS Appetite score	7,279	90,653	7.4
	SAS Fatigue score	6,777	91,155	6.9
	AKPS	6,144	91,788	6.3
	Data complete for 85.8% of patients			
Indigenous patients	Start date	0	1,156	0.0
	End date	0	1,156	0.0
	Start date	76	1,080	6.6
	End date	79	1,077	6.8
	SAS Pain score	80	1,076	6.9
	SAS Nausea score	84	1,072	7.3
	SAS Breathing	88	1,068	7.6
	SAS Bowel score	81	1,075	7.0
	SAS Insomnia score	82	1,074	7.1
	SAS Appetite score	103	1,053	8.9
	Data complete for 84.3% of patients			
Non-indigenous patients	Start date	0	96,776	0.0
	End date	0	96,776	0.0
	Start date	6,201	90,575	6.4
	End date	6,710	90,066	6.9
	SAS Pain score	6,846	89,930	7.1
	SAS Nausea score	7,277	89,499	7.5
	SAS Breathing	8,171	88,605	8.4
	SAS Bowel score	7,198	89,578	7.4
	SAS Insomnia score	6,695	90,081	6.9
	SAS Appetite score	6,041	90,735	6.2
	Data complete for 85.8% of patients			

Supplemental Table 2:

Evidence of similar structure of Indigenous and non-Indigenous patients' journeys of care

2a. Episodes and phases within a patient's journey of care, by Indigenous identifier

	Indigenous	Non-Indigenous
Number of episodes & phases within a patient's journey of care, mean (median, IQR, range)		
Episodes per patient	1.50 (1, 1–2, 1–16)	1.39 (1, 1–1, 1–44)
Phases per patient	3.25 (2, 1–4, 1–31)	3.22 (2, 1–4, 1–145)
Phases per episode	2.16 (2, 1–2, 1–31)	2.31 (2, 1–3, 1–139)
Number of phases of each type within a patient's journey of care, mean (median, IQR, range)		
Phase type		
Stable	1.00 (1, 0–1, 1–14)	0.99 (1, 0–1, 1–71)
Unstable	0.77 (0, 0–1, 1–11)	0.70 (0, 0–1, 1–32)
Deteriorating	1.04 (1, 0–1, 1–13)	1.08 (1, 0–1, 1–71)
Terminal	0.43 (0, 0–1, 1–3)	0.45 (0, 0–1, 1–13)

2b. Phase types immediately preceding an unstable phase: Number and percentage of all phases

Preceding Phase type	Phases of non-Indigenous patients	Phases of Indigenous patients	Total
Nil (First phases)	58,260	740	59,000
	60.2%	64.0%	60.3%
Stable	25,738	286	26,024
	26.6%	24.7%	26.6%
Deteriorating	12,290	127	12,417
	12.7%	11.0%	12.7%
Terminal	258	3	261
	0.3%	0.3%	0.3%
Missing phase record	230	0	230
	0.2%	0.0%	0.2%
Total	96,776	1,156	97,932
	100%	100%	100%

2c. Phase types immediately following an unstable phase: Number and percentage of all phases

Following Phase type	Phases of non-Indigenous patients	Phases of Indigenous patients	Total
Stable	41,431	515	41,946
	42.8%	44.6%	42.8%
Deteriorating	33,406	377	33,783
	34.5%	32.6%	34.5%
Terminal	4,684	52	4,736
	4.8%	4.5%	4.8%
Missing phase record (majority due to death)	17255	212	17467
	17.8%	18.3%	17.8%
Total	96,776	1,156	97,932
	100.0%	100.0%	100.0%