Understanding end-of-life care in Australian hospitals

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Abstract.

Objective. To explore end-of-life care in the ward and intensive care unit (ICU) environment in nine Australian hospitals in a retrospective observational study.

Methods. In total, 1693 in-hospital deaths, 356 in ICU, were reviewed, including patient demographics, advance care plans, life-sustaining treatments, recognition of dying by clinicians and evidence of the palliative approach to patient care.

Results. Most patients (n = 1430, 84%) were aged ≥ 60 years, with a low percentage (n = 208, 12%) having an end-of-life care plan on admission. Following admission, 82% (n = 1391) of patients were recognised as dying, but the time between recognition of dying to death was short (ICU (staying 4–48 h) median 0.34 days (first quartile (Q1), third quartile (Q3): 0.16, 0.72); Ward (staying more than 48 h) median 2.1 days (Q1, Q3: 0.96, 4.3)). Although 41% (n = 621) patients were referred for specialist palliative care, most referrals were within the last few days of life (2.3 days (0.88, 5.9)) and 62% of patients (n = 1047) experienced active intervention in their final 48 h.

Conclusions. Late recognition of dying can expose patients to active interventions and minimises timely palliative care. To attain alignment to the National Consensus Statement to improve experiences of end-of-life care, a nationally coordinated approach is needed.

What is known about the topic? The majority of Australian patient deaths occur in hospitals whose care needs to align to the Australian Commission on Safety and Quality in Health Care's National Consensus Statement, essential elements of safe and high-quality end-of-life care.

What does this paper add? The largest Australian study of hospital deaths reveals only 12% of patients have existing advance care plans, recognition of death is predominantly within the last 48 h of life, with 60% receiving investigations and interventions during this time with late symptom relief.

What are the implications for practitioners? Given the poor alignment with the National Consensus Statement, a nationally coordinated approach would improve the patient experience of end-of-life care.

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Introduction

Despite data suggesting preferences to the contrary, ¹ most deaths occur in acute hospitals. ² Providing optimal end-of-life care in such settings is challenging. ³ A complex range of factors contribute to suboptimal end-of-life care, including failure to identify patients in their last months of life, ⁴ poor communication regarding prognosis with patients and families, ⁵ and failure to establish clear goals of care between members of professional teams, ⁶ which gives rise to inadequate provision of palliative interventions such as pain relief, ⁷ and delivery of inappropriate and futile investigations and treatments. ⁸

The Australian Commission on Safety and Quality in Health Care undertook a program of work reviewing the safety and quality of end-of-life care in acute hospitals. This led to the development of a *National consensus statement: essential elements of safe and high-quality end-of-life care* (Consensus Statement) in 2015,⁹ which describes the essential elements required to provide safe and high-quality end-of-life care in acute hospitals in Australia. For end-of-life care in acute hospitals to align with the Consensus Statement, clinicians may need to adjust current processes. Data describing clinicians' perceptions of end-of-life care¹⁰ and current processes¹¹ high-light gaps between current and desired practice.

There have been some initial analyses describing current end-of-life care provision in one Australian city, ¹¹ with similar findings internationally. ^{12,13} Given prior research has identified difficulties in providing optimal end-of-life care, the aim of the current study is to explore end-of-life care provided in the ward and intensive care unit (ICU) environment, using the main elements of the Consensus Statement in a broader range of acute Australian hospitals.

Methods

Design

Following a pilot of an audit tool in several disciplines within one hospital, ¹⁴ a retrospective medical record audit of inhospital deaths was undertaken in nine acute-care hospitals, chosen to reflect a range of public and private facilities, tertiary and metropolitan organisations in five Australian states. The audit was designed to assess the extent to which current practice aligns with elements of the Consensus Statement about processes of care. Specifically, the five elements included: (1) patient-centred communication and shared-decision-making; (2) teamwork and coordination of care; (3) goals of care; (4) use of triggers to recognise patients approaching the end of life; and (5) response to concerns.

Multi-site ethics approval and a waiver of consent was granted by the Hunter New England Human Research Ethics Committee (approval reference: HREC/16/HNE/350). All study hospitals and the academic coordinating centre received additional specific site ethics approval. Patient privacy and confidentiality were maintained as no identifying information was provided to team members external to hospitals.

Participants

Patients who died between 1 July 2015 and 30 June 2016 were identified from hospital administrative data. Patients were eligible for inclusion if they were an in-patient at one of the participating hospitals and died at least 4 h after admission. Patients were excluded from the study if one or more of the following criteria applied: aged <18 years, died <4 h after hospital admission, in-patient but residing at home (e.g. receiving care

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through a hospital in-home service, or if they died in one of four settings likely to reflect a sudden death rather than a period of dying (i.e. death in the emergency department, operating theatre, adult mental health unit or delivery suite)). Four groups of patients were identified *a priori* for inclusion as they were considered to potentially reflect different modes of care:

- patients who died on an in-patient ward with a hospital admission from 4 to 48 h.
- patients who died on an in-patient ward with a hospital admission of >48 h.
- patients who died in intensive care (ICU) with a hospital admission from 4 to 48 h.
- patients who died in ICU with a hospital admission of >48 h.

For each hospital, a random sample of patient records was selected, using computer-generated random numbers, from each of the four patient groups. Each study hospital was requested to select 100 patients up to a maximum 200 patients, divided equally between the four cohorts, to provide adequate precision for measures of interest.

Data collection

Based on the processes of care (i.e. patient-centred care, teamwork, goals of care, using triggers, responding to concerns) outlined in the Consensus Statement, data collected included hospital and patient demographic data, information pertaining to advance care and resuscitation plans, life sustaining treatments, whether clinicians recognised the patient was dying and the type, if any, of palliative approach to patient care (See Supplementary Material S1).

Statistical methods

Data were entered into a collection tool, checked for inconsistencies and logical errors, and combined for all hospitals for analysis. Categorical data are presented as frequencies and percentages. Duration of time for processes of care were calculated as time between date and time of relevant process of care (e.g. recognising dying) and time of death in minutes and then converted to days (or proportion thereof). Due to skewed distribution of duration variables, summary statistics are presented as median and first (Q1) and third (Q3) quartiles.

The total number of admissions varied substantially across hospitals, as well as between the four patient categories, whereas the number of records selected for review was similar. Thus, the proportion of eligible records included in the study varied among the hospitals and patient groups, such that the distribution of records within the sample differed to the distribution in the population. To ensure results correctly reflect population distribution of categories, all data except for duration (time) variables were weighted to reflect sampling strategy. Within each hospital, weights were calculated for each patient group, as the proportion of all eligible patients in the group, divided by the proportion of the number of records sampled that were in that patient group. For example, if a hospital had 500 eligible patients of whom 100 had died in ICU within 4-48 h, and 50 patients were sampled in each of the four groups (200 in total), then the weight for the group who died in ICU within 4-48 h for that hospital would be (100/500) / (50/200), or 0.8. Each observation is multiplied by the relevant weight in the analysis. A weight <1 reduces the weight (impact) of the observation to account for over-sampling, whereas a weight >1 increases the weight (impact) of the observation to account for under-sampling.1

Results

Hospital demographics

Seven of the nine acute care hospitals were public and principal referral hospitals admitting between 5300 to almost 44 000 patients annually. All hospitals had a Medical Emergency Team (MET) and all but one site (which had a palliative care consultation service offsite) had a specialist palliative care service and one site had no intensive care unit (Table 1).

Patient demographic characteristics

During the study period, 5963 eligible deaths were reported by all hospitals, of which 1324 (22%) were in ICU. Overall, 1695 records were audited, with the number of records audited within hospitals ranging from 99 (11% of eligible records) to 398 (88% of eligible records; Table 1). The number of records a hospital audited may have varied among patient groups due to missing records, because the number of eligible records within a

Table 1. Hospital characteristics FTE, Full-time equivalent; n/a, not applicable

Hospital	A	В	С	D	Е	F	G	Н	I
Hospital classification	Public	Public	Public	Public	Public	Public	Private	Public	Private
Allied health staff FTE	445	123	396	486	584	604	29	427	20
Specialists FTE	280	177	262	718	330	504	9	55	32
Junior medical officers FTE	417	439	750	77	710	699	6	320	n/a
Nursing staff FTE	1975	1459	2616	2251	2491	1611	151	1098	1014
Rapid response team	Yes	Yes	Yes						
Palliative care service	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Number of deaths	771	767	686	1116	911	908	411	501	452
Number of deaths audited	200	174	208	213	100	99	100	201	398
Percentage of eligible deaths audited	26	23	30	19	11	11	24	40	88
Number of admissions ^A	43 963	41 498	43 077	38 992	33 538		5273	6795	18 632

^AData were not available for all hospitals.

particular group was less than the requested number, or greater than initially counted; one hospital chose to audit approximately double the recommended maximum number of records. Two records were excluded due to missing/ineligible age, providing a final sample of 1693. Most patients (n = 1430, 84%) were aged ≥ 60 years, with one-third aged ≥ 85 years (n = 594, 35%). Almost three-quarters of all patients (n = 1242, 73%) and 84% (n = 298) of those who died in ICU (n = 356) were admitted from home. A previous hospital admission was common, with more than one-quarter (n = 389, 26%) of all patients having been admitted three or more times in the previous 12 months (Table 2).

Evidence of recognition of dying (Consensus Statement Element 4)

Most patients (n = 1391, 82%) were recognised to be dying by a clinician before death. The duration of time between recognition of dying to death was short: median 0.34 days (Q1, Q3: 0.16, 0.72) for patients dying in ICU within 4–48 h of hospital admission and median 2.1 days (Q1, Q3: 0.96, 4.3) for patients dying on the ward staying longer than 48 h in hospital (Table 3).

Advance care plans and resuscitation plans (Consensus Statement Elements 1, 3)

A low percentage (n=208, 12%) of patients had evidence of a written advance care plan (ACP) or equivalent before hospital admission, and only 3% (n=12) for those who died in ICU. Almost all patients (n=1508, 89%) had a documented resuscitation plan during their hospital admission, which was documented as being discussed with 77% (n=1154) of patients/family/their surrogate decision-maker (Table 4). The home team was involved in documenting the resuscitation plan 32% (n=489) of the time; otherwise, emergency doctors (n=216, 14%), ICU doctors (n=288, 19%), or admitting medical or surgical registrars (n=283, 19%) documented the resuscitation plan. The duration of time from first resuscitation plan to death was short (1.8 days (0.76, 6.1), Table 4).

Palliative care plans (Consensus Statement Elements 1, 2, 3) Less than half (n = 621, 41%) the patients were referred to a specialist palliative care team and for those patients who died in ICU, very few were referred (n = 16, 5%) (Table 5). In contrast, three-quarters of patients (n = 1308, 77%) did have a palliative care approach to care documented at some time

Table 2. Patient demographic and admission details by cohort

Numbers and percentages weighted for sampling scheme. Numbers may not add up to the total sample size due to missing values and/or weighting

		Patient cohort				
		Died in ward 4 h to 48 h n (%)	Died in ward $>48 \text{ h } n \text{ (\%)}$	Died in ICU 4 to 48 h n (%)	Died in ICU >48 h <i>n</i> (%)	Total n (%)
Number of patients		281	1055	107	249	1692
Sex (female)		127 (45)	483 (46)	38 (36)	97 (39)	745 (44)
Age (years)	18-59	26 (9)	109 (10)	44 (42)	83 (33)	263 (16)
	60-74	54 (19)	248 (24)	32 (30)	100 (40)	435 (26)
	75–84	72 (25)	258 (24)	22 (21)	49 (20)	401 (24)
	85+	130 (46)	439 (42)	8 (7)	17 (7)	594 (35)
Source of hospital admission	Home	179 (64)	765 (73)	82 (78)	216 (87)	1242 (73)
_	Residential care facility	79 (28)	172 (16)	2(2)	5 (2)	257 (15)
	Supported living	5 (2)	37 (4)	1(1)	2(1)	44 (3)
	Other	19 (7)	81 (8)	22 (20)	27 (11)	149 (9)
Number of hospital admissions in previous 12 months	0	86 (33)	309 (33)	54 (61)	114 (50)	563 (38)
	1-2	110 (43)	344 (37)	24 (27)	71 (31)	549 (37)
	3–5	37 (14)	184 (20)	6 (6)	29 (13)	256 (17)
	>5	25 (10)	90 (10)	5 (5)	13 (6)	133 (9)

Table 3. Recognition of dying by cohort

Numbers and percentages weighted for sampling scheme, except for duration variables, which are unweighted. Numbers may not add up to the total sample size due to missing values and/or weighting. Q1, Quartile 1; Q3, Quartile 3

	Patient cohort				
	Died in ward 4–48 h, <i>n</i> (%)	Died in ward $>48 \text{ h}, n \text{ (\%)}$	Died in ICU 4–48 h, <i>n</i> (%)	Died in ICU >48 h, <i>n</i> (%)	Total <i>n</i> (%)
Number of patients	281	1055	107	249	1692
Recognition of dying	221 (79)	851 (81)	92 (86)	227 (91)	1391 (82)
Time from recognition of dying to death ^A :	248 0.5	391 2.1	188 0.34	233 0.69	1060 0.79
N Median (days) [Q1, Q3]	[0.21, 0.88]	[0.96, 4.3]	[0.16, 0.72]	[0.16, 1.8]	[0.25, 2.0]

^AOnly includes those with documented indication that the patient was dying.

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Table 4. Advance care plans and resuscitation plans

Numbers and percentages weighted for sampling scheme, except for duration variables, which are unweighted. Numbers may not add up to the total sample size due to missing values and/or weighting. Q1, Quartile 1; Q3, Quartile 3

		Patient cohort				
		Died in ward 4–48 h, <i>n</i> (%)	Died in ward $>48 \text{ h}, n \text{ (\%)}$	Died in ICU 4–48 h, <i>n</i> (%)	Died in ICU >48 h, n (%)	Total <i>n</i> (%)
Number of patie	ents	281	1055	107	249	1692
Evidence pre-ac	lmission advance care plan	49 (17)	148 (14)	3 (3)	8 (3)	208 (12)
Inpatient resusc	itation plan	245 (87)	999 (95)	63 (60)	200 (80)	1508 (89)
Resuscitation plan discussed with patient/ family/surrogate decision-maker ^A		197 (81)	782 (78)	41 (65)	134 (67)	1154 (77)
Resuscitation	Emergency Department	74 (30)	134 (13)	4(7)	4(2)	216 (14)
plan	Admitting registrar	69 (28)	198 (20)	4 (6)	12 (6)	282 (19)
documented	Admitting team junior doctor	38 (15)	229 (23)	2(3)	17 (8)	285 (19)
by	Admitting team senior doctor	30 (1)	165 (17)	3 (5)	7 (3)	204 (14)
,	Specialist palliative care doctor	14 (6)	100 (10)	0 (0)	1 (0.4)	115 (8)
	Emergency Team doctor	4(2)	18 (2)	0 (0)	5 (2)	27 (2)
	ICU doctor	7(3)	82 (8)	48 (76)	151 (75)	288 (19)
	Other	10 (4)	74 (7)	2(3)	5 (2)	91 (6)
death (days) ^A	en first resuscitation plan and ays) [Q1, Q3]	243 0.96 [0.54, 1.4]	397 5.9 [3.0, 12.1]	` '	199 2.17 [0.97, 5.4)	` '

^AOnly includes those with a documented resuscitation plan.

Table 5. Referral to specialist palliative care

Numbers and percentages weighted for sampling scheme, except for duration variables, which are unweighted. Numbers may not add up to the total sample size due to missing values and/or weighting. Q1, Quartile 1; Q3, Quartile 3

	Patient cohort					
	In patient ward 4–48 h, <i>n</i> (%)	In-patient ward $>48 \text{ h}, n \text{ (\%)}$	ICU 4–48 h, <i>n</i> (%)	ICU >48 h, n (%)	Total n (%)	
Number of patients	281	1055	107	249	1692	
Referral to specialist palliative care	65 (26)	540 (58)	1(1)	14 (6)	621 (41)	
Review by specialist palliative care nurse	32 (13)	396 (42)	1(1)	7 (3)	435 (29)	
Review by specialist palliative care doctor	48 (19)	492 (53)	1(1)	11 (5)	552 (36)	
Palliative/comfort care ONLY plan at any time during admission?	199 (71)	858 (81)	61 (58)	190 (76)	1308 (77)	
Palliative/comfort care plan communicated to patient and/or family? ^A	190 (97)	829 (98)	60 (98)	188 (99)	1266 (98)	
Time from palliative care referral to death (Days) ^B N Median [Q1, Q3]	54 0.85 [0.42, 1.4]	225 3.4 [1.4, 7.8]	4 0.27 [0.16, 0.54]	12 1.1 [0.62, 1.7]	295 2.3 [0.88, 5.9]	
Time from initiation of palliative care to death (Days) ^A N Median [Q1, Q3]	225 0.50 [0.20, 0.89]	418 2.2 [0.76, 4.7]	135 0.19 [0.08, 0.44]	201 0.24 [0.09, 0.87]	979 0.67 [0.19, 2.0]	

^AOnly includes those with a palliative care plan.

during their admission. In most cases (n = 1266, 98%) this was communicated to the patient or family. Most referrals to specialist palliative care were made within the last few days of life (2.3 days (0.88, 5.9), Table 5). The duration of time a patient received a palliative care approach before death was short (0.69 days), but this varied across patient cohorts (0.19 days for patients dying in the ICU within 4–48 h of hospital admission, 2.2 days for patients dying on the ward staying >48 h in hospital).

Non-beneficial investigations and treatments (Consensus Statement Elements 3, 4)

Almost one-third of patients (n = 482, 30%) had an ICU admission before death and 71% (n = 341) of these were invasively ventilated. Over one-third of all patients (n = 562, 35%) underwent one or more MET reviews before their death. Of those undergoing a MET review, 15% (n = 83) died at the time of MET review and an additional 37% (n = 207) had a new treatment limitation placed.

^BOnly includes those referred to specialist palliative care.

Table 6. Non-beneficial investigations and treatment in the final 48 h before death by cohort

Numbers and percentages weighted for sampling scheme. Numbers may not add up to the total sample size due to missing values and/or weighting

	Patients cohort							
	In patient ward 4–48 h, <i>n</i> (%)	In-patient ward $>48 \text{ h}$, $n \text{ (\%)}$	ICU 4–48 h, n (%)	ICU >48 h, n (%)	Total n (%)			
Number of patients	281	1055	107	249	1692			
Chemotherapy	1 (0.4)	2 (0.2)	0 (0)	1 (0.2)	4 (0.2)			
Radiotherapy	0 (0)	3 (0.3)	0 (0)	0 (0)	3 (0.3)			
Intubation/invasive ventilation	12 (4)	14 (1)	82 (77)	163 (66)	272 (16)			
Dialysis	1 (0.2)	19 (2)	5 (5)	44 (18)	69 (4)			
Non-invasive ventilation	20 (7)	34 (3)	10 (9)	34 (13)	97 (6)			
Vasoactive drugs	23 (8)	41 (4)	72 (68)	142 (57)	279 (16)			
CPR	17 (6)	28 (3)	20 (19)	21 (9)	87 (5)			
Anaesthetic/operation	8 (3)	10(1)	28 (26)	27 (11)	72 (4)			
IV antibiotics	98 (35)	236 (22)	51 (48)	163 (65)	547 (32)			
IV fluids	153 (54)	310 (29)	90 (85)	209 (84)	762 (45)			
Artificial nutrition	2(1)	42 (4)	13 (12)	123 (49)	180 (11)			
Blood tests	198 (70)	353 (33)	82 (77)	198 (79)	831 (49)			
Medical imaging	177 (63)	223 (21)	81 (76)	169 (68)	651 (38)			
Blood product transfusions	18 (6)	35 (3)	25 (23)	49 (20)	128 (8)			
Intra-aortic balloon pump	1 (0.2)	0 (0)	2(2)	4(1)	6 (0.4)			
Cardiac catheter	5 (2)	5 (0.5)	4 (4)	5 (2)	19(1)			
Others	37 (13)	98 (9)	21 (19)	34 (14)	190 (11)			
Any intervention	229 (81)	485 (46)	98 (92)	235 (94)	1047 (62)			

In the last 48 h of life, most (n = 332, 93%) patients dying in the ICU experienced an active intervention or investigation compared with 53% (n = 714) of patients dying on the ward (Table 6). Overall, the most common interventions and investigations were blood tests (n = 831 patients, 49%), IV fluids (n = 762, 45%), medical imaging (n = 651, 38%) and IV antibiotics (n = 547, 32%).

Discussion

The main finding in this retrospective audit of 1693 patients who died in acute care hospitals was the lack of consistency of alignment between the Consensus Statement and clinical practice. This was highlighted by the short length of time between recognition of dying and death (0.79 days (0.25, 2.0)); dying not recognised for almost 20% of patients; 62% of patients received a non-beneficial investigation or treatment in the last 48 h of life; 89% of patients having a resuscitation plan before death but disturbingly only 77% of these had been discussed with the patient/family/surrogate decision-maker; and although 62% patients had at least one admission in the previous 12 months and 26% had three or more, only 12% of patients had an advance care plan before admission.

These experiences are unlikely to exhibit high-quality end-of-life care, which requires earlier recognition of a patient approaching the last year of life. Delay in recognising dying is not unique to this study. A recent English audit of 9302 patients found 93% were recognised to be dying, but half were recognised to be dying in the last 34 h before death. ¹⁶ Existing research has also discussed ways in which this delay in recognition leads to invasive treatments that lack benefits for individuals in their last days of life. ¹⁷ Our findings extend on this research, demonstrating that such treatments – that do not meet the principles of the Consensus Statement – are widespread across Australian hospitals.

Despite 26% of patients had three or more admissions in the previous 12 months, a relatively low percentage of patients had an advance care plan. This (along with the late recognition of dying) suggests multiple lost opportunities for patients and families to experience high-quality end-of-life care. Similarly, low instances of an advance care plan have been found in an Australian study of intensive care patients ¹⁸ (9%), although our rates were higher than the recent UK audit ¹⁵ at 4%, but lower than a Canadian study ¹⁹ at 30.8% and an Australian study of older citizens (29.8%). ²⁰

In the absence of an advance care plan, patients, to some extent, are able to express dying wishes through resuscitation or goals of care plans. A high proportion of patients (89%) had a resuscitation plan in this study, which was similar to an Australian audit, ¹¹ a UK audit ¹⁶ and a Canadian study ¹⁹ (87.2%, 91% and 87.5% respectively). A critical step to aligning care with a dying patient's wishes is to engage in shared decision-making. ²¹ Discussing resuscitation plans with patients or families (as seen in 77% of cases in the current study) represents a step towards greater shared decision-making.

Specialist palliative care addresses patients' physical, emotional and spiritual needs during their end-of-life care, particularly if their care is complex. In this study, 41% of patients were referred to specialist palliative care teams, which is higher than an Australian study from two sites in one city, ¹¹ and higher than seen in the UK audit ¹⁶ and the Canadian study ¹⁹ (31.8%, 31% and 25.7% respectively). The overall late referral (especially for the site that did not have an onsite specialist palliative care team) does not allow patients to be afforded the benefits of timely referral to specialist palliative care. ⁵

Implications

The Consensus Statement provides a framework for delivery of high-quality and safe end-of-life care for patients in acute 546 Australian Health Review I. Mitchell et al.

hospitals. Our study demonstrates areas that need improvement, namely setting early goals of care, using clear triggers to facilitate recognition of dying, the seemingly poor team work and engagement with specialist palliative care and potentially poor response to patient's concerns with the late initiation of a palliative care approach and an associated high use of non-beneficial interventions and investigations in the last 48 h of life.

To facilitate some of these challenges, advance care planning has been demonstrated to improve end-of-life care and patient and family satisfaction.²² The low uptake of advance care planning may be due to the reluctance to discuss end-of-life issues, or the lack of infrastructure or coordinated approach to promote and assist with advance care plans. As a start, families need to have an understanding of each other's wishes through a verbal discussion, which can allow for 'in the moment' decisionmaking.²³ Additionally, if caring healthcare teams were prompted to recognise dying earlier through trigger tools (such as the Supportive and Palliative Care Indicators Tool; SPICT),²⁴ patients might benefit from earlier supportive and palliative care assessment and care planning. Although instruments such as the SPICT lack a combined high sensitivity and specificity for identifying patients dying within 12 months, ²⁴ they do provide reminders patients are closer to dying than many other patients.

Strengths and limitations

This study is the largest to have examined the end-of-life care of patients dying in Australian hospitals. The study describes the current gaps in care when reviewing practice against the National Consensus Statement⁹ and allows Australian hospitals to determine what strategies need to be put in place to ensure compliance with the Australian Commission for Safety and Quality in Health Care's National Quality Standards for Hospitals.

There are limitations to the study. First, this retrospective study required an in-depth chart review, which required not only processes of care to be documented but also interpretation by the research teams. Each hospital had their own research team, but a study data dictionary was provided to try and minimise differences in interpretation, particularly given how palliative approaches are documented (see Supplementary Material S1). Second, there was no attempt to describe the patients' or families' experience, which is of paramount importance going into the future. Third, there was no distinction between those patients who did or did not die unexpectedly. A pragmatic decision was made to paint an overall Australian picture of patients dying in hospitals. Fourth, it is possible the nine hospitals do not reflect all Australian hospitals despite them representing a wide mix and geographical spread of Australian hospitals. Fifth, it is important to note in some groups the number of records audited is larger than the original number identified by the hospitals: this could be due to patients being incorrectly classified initially. Sixth, the five elements of the Consensus Statement are not easily mapped to accessible data in patient's charts, which reduces the accuracy of mapping of the Consensus Statement particularly to element 5 (response to concerns). Finally, our data were collected up to 5 years ago, when the Consensus Statement was relatively new. However, analysis of more recent data suggests that the essential elements of the statement are still not being met.¹¹

Conclusion

The National consensus statement: essential elements of safe and high-quality end-of-life care facilitates healthcare organisations to identify areas of practice improvement in end-of-life care. The study findings highlight a lack of alignment between the consensus statement and practice in nine public and private Australian hospitals across five states. Despite national funding and a national campaign to raise awareness of advance care planning, the low prevalence of ACPs in our study suggests a potential need for the wider community to engage in talking about what will be important to them in their dying days. To reduce variability in end-of-life care and greater alignment with the Consensus Statement, a nationally coordinated approach is needed. In turn, this will improve the patient and family experience at such an important time in their lives.

Competing interests

The authors declare no competing interests.

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