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# **ORIGINAL RESEARCH**

# End-of-life issues: Withdrawal and withholding of life-sustaining healthcare in the emergency department: A comparison between emergency physicians and emergency registrars: A sub-study

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# Abstract

**Objective:** We investigated and compared the importance of the considerations and discussions when withdrawing and withholding life-sustaining healthcare between emergency physicians (EP) and emergency registrars (ER).

*Methods*: This was a sub-study of a prospective cross-sectional questionnaire-based case series conducted in six EDs. Primary outcomes were, which of the discussion and considerations, were rated most important by EP and ER in the decision-making process.

**Results:** We studied responses relating to the care of 320 patients, of which 49.4% were women and the median age was 83 (interquartile range [IQR] 72–88). EP and ER were sole decision-makers in 185 (39.7%) and 135 (30.0%) of cases, respectively. Treatment was withdrawn or withheld in 72.0 and 90.6% of all deaths by EP and ER, respectively (P < 0.001). EP and ER provided full treatment in 88 (34%) and 19 (12.7%) of cases, respectively (P < 0.05). The consideration rated most important was prognosis: 165 (90.2%, confidence interval: 85.0-93.7) and 121 (90.3%, confidence interval: 84.1-94.2) for EP and ER, respectively. ER rated comorbidities and age more important than did EP (P < 0.05). Both rated discussions with family as very important. EP and ER referred 6.0% versus 11.9% patients to palliative care services, respectively. The proportion of patients taking longer than 24 h to die was higher for ER compared with that for EP (14.1% vs 4.9%, P < 0.05).

*Conclusion:* We found that ER were more likely to withdraw/withhold life-sustaining healthcare, provide partial treatment, rate different considerations as important and their patients took longer to die than that of EP. Focused education and

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#### Key findings

- Majority of deaths in the ED involve a decision to withdraw/withhold life-sustaining healthcare.
- At the time of this study less than 12% of patients dying in the ED were referred to a palliative care service.
- There are differences between emergency physicians and emergency registrars when making end-of-life decisions.

training might improve decisionmaking consistency between physicians and training registrars.

**Key words:** *death, emergency department, end-of-life care.* 

#### Introduction

We are strangers to our patients, and yet, we are often the first to teach them the intimate truths about life and death

– Monica Williams-Murphy

The ED is a clinical setting where critical life-saving interventions are initiated by emergency clinicians with various levels of experience and training. There is an expectation that care will be provided immediately and a presumption that life-sustaining healthcare would be desired.<sup>1,2</sup> Although it is recognised

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that the ED might not be the most appropriate place to give end-of-life care, the fact patients die in the ED is not surprising given that this is where emergency care is primarily delivered for a range of lifethreatening presentations.3 Deaths will occur unexpectedly in previously well individuals, despite attempts at full resuscitation, and also in patients with acute episodes of chronic illness.<sup>4</sup> At times emergency clinicians will institute invasive treatments near death in absence of information around end-of-life wishes, which subsequently may be withdrawn.<sup>1,2</sup>

There are more than 7.3 million presentations to Australian EDs and approximately 10 000 patients a year will die in the ED, which is approximately 0.14% of all presentations.<sup>5</sup> The incidence is predicted to increase with an ageing population.<sup>6,7</sup>

In Australasia, there are approximately 1810 registered fellows and 2276 registrars/trainees registered with the Australasian College for Emergency Medicine.8 Ideally emergency physicians (EP) are involved in all decisions relating to the withdrawal and/or withholding lifehealthcare. Although sustaining emergency registrars (ER) are required to work in a supervised environment, in most EDs in Australasia, ER are the most senior clinician in the ED after-hours between 2400 and 0700 h.

There have been few studies that describe the process relating to withdrawal of treatment and subsequent death that occurs in the ED. Those in Australasia have all been surveys of hypothetical clinical scenarios.9-12 Internationally three prospective observational studies all have limitations and the primary purpose of the two most recent studies were to describe the characteristics of patients who died in the ED and investigate the frequency of withdrawal.<sup>13-15</sup> There are no studies that have attempted to investigate and compare emergency consultants and training registrars when a decision is made to withdraw and/or withhold life-sustaining healthcare.

We aim to investigate and describe any differences in the importance of the considerations and discussions that took place when EP and ER made a decision to withdraw and/or withhold life-sustaining healthcare in the ED.

# Methods

## Study design and setting

This is a sub-study of a prospective, multicentre, cross-sectional questionnaire-based case series of deaths in the ED. It was intended to sub-analyse the data of the parent study to identify if there were any differences between EP and ER when withdrawing and/or withholding life-sustaining healthcare. The treating clinician completed a questionnaire in regard to the discussions and the considerations that had taken place prior to a decision to withdraw and/or withhold lifesustaining treatment. The study was conducted in six metropolitan EDs in five Australian states, with a combined annual census of more than 320 000. Five of the departments were tertiary referral departments including trauma (two were adultonly EDs and three mixed EDs). The remaining department was an adultonly teaching ED. The study was conducted between 2009 and 2011. Four of the departments collected data for 12 consecutive months and two departments for six consecutive months. The human research and ethics committees of each participating hospital approved the study.

## Selection of participants

Every adult or child who died in a participating ED was eligible for inclusion (main department or observation unit). Patients were excluded it they underwent full treatment without any withdrawal or withholding, if questionnaires were incomplete and if the decision was not made solely by either an EP or a ER.

# Data collection, questionnaire and processing

An original questionnaire was drafted and piloted by EP and ER before the actual study commenced to refine and identify any issues with its completion (Appendix S1). It includes questions relating the clinician decision-maker, level of treatment provided and if it was withdrawn. Clinicians were asked to rate on 5-point Likert scale (5 = veryimportant) the importance of 10 possible factors in the decision to withhold/ withdraw life-sustaining healthcare and any discussions that took place. Data was also collected from the medical record at a later date and included, age, sex and time to death.

Each treating clinician was given a coded questionnaire to complete within 72 h of the death, which was returned to the site coordinator. The questionnaire had no markings that identified who the decision-maker was and following return of the completed questionnaire the treating practitioner was then de-identified from the patient code.

# Definitions

Life-sustaining healthcare was defined as any form of advanced healthcare that if not provided would result in the death of a patient. Full treatment was defined as care without any limitations, including cardiopulmonary resuscitation, intubation and ventilation, inotropes and consideration for ICU admission. Partial treatment was defined as any treatment with specified limitations, for example noninvasive ventilation, or 'trial' of inotropes. Treatment commenced then withdrawn was defined as any kind of treatment (full or partial) that was commenced but later was withdrawn. No treatment was defined as absence of active treatment after ED arrival.

### Outcome measures

The co-primary outcomes of interest were which of the considerations and discussions were considered most often and rated most important in the decision-making process. Secondary outcomes included classification of decision-maker, level of treatment provided, incidence of withdrawal and/or withholding of treatment, referral or discussion with the coroner, referral to a palliative care service and time to death of the patient.

#### Primary data analysis

Descriptive statistics were used to describe the baseline characteristics of the study patient and the decisionmaker. Median and interquartile ranges (IQR) are reported for continuous variables. Percentages with 95% confidence intervals (CI) are reported for dichotomous variables, including the primary and secondary outcomes. Pearson  $\chi^2$ -test was used to compare the two groups. Analysis was performed using Statistical Package for Social Science (SPSS), version 20 (IBM, Armonk, NY, USA).

## Results

#### Characteristics of study subjects

A total of 466 deaths were identified. There were 146 exclusions leaving a final study sample of 320. Participant flow is summarised in Figure 1. Of the 320 deaths included in the analysis, demographics, triage category, cause of death and timing of death data were available for 299 (93.4%) patients. The median age was 83 years (IQR 72-88) and 49.4% were women. The most frequent causes of death were cardiac arrest (24.1%), intracranial haemorrhage (18.1%), respiratory failure (17.7%),sepsis (5.4%)and advanced cancer (5.4%). Patient characteristics with individual percentages for EP and ER are summarised in Table 1.

#### Main results

Treatment was withdrawn or withheld in 72.0% of deaths when that decision was made by a EP compared with 90.6% of deaths when that decision was made by a ER. Full treatment was provided by EP (34%) of the time compared with that by ER (12.1%, P < 0.001). EP were more likely to withdraw full treatment and ER were more likely provide partial treatment to (P < 0.05). The relative importance of the factors and discussions are summarised in Table 2. The



Withdrawn

n = 44 (32.6%)

Includes -Full

subsequently

Treatment:

withdrawn

n=4

treatment

Total Deaths = 466

Figure 1. Participant flow: Patients, emergency physicians and emergency registrars.

TABLE 1.	Characteristics of the patients who died in the ED and the decision-
makers with	lrawing and/or withholding treatment

	Combined ( $n = 299$ from medical record†)	Registrars $(n = 121)$	Physicians $(n = 178)$
Median (IQR) age (years)	83 (72.0-88.0)	83 (76-89)	82 (70-86)
Women, no. (%)	149 (49.8)	65 (53.7)	84 (47.5)
Triage category, no. (%)			
1 and 2		108 (89.3)	157 (88.2)
3 and 4		13 (10.7)	21 (11.8)
Cause of death, no. (%)			
Cardiac arrest	72 (24.1)	27 (22.3)	45 (25.3)
Intracranial haemorrhage	54 (18.1)	21 (17.4)	33 (18.5)
Respiratory failure	55 (18.7)	24 (19.8)	31 (17.4)
Sepsis	19 (5.4)	10 (8.3)	9 (5.1)
Cancer advanced	19 (5.4)	9 (7.4)	10 (5.6)
Aortic aneurysm	14 (4.7)	6 (5.0)	8 (4.5)
Trauma	7 (2.3)	1 (0.8)	6 (3.4)
Other	59 (19.7)	23 (19.0)	36 (20.2)

†The medical record was not accessible for 21 patients. IQR, interquartile range.

Exclusions

No Treatment

after Arrival

n=21(15.6%)

at ED

\* Questionnaire not completed =2

Partial

Treatment

n=70(51.9%)

Withdrawn

n= 82 (44.3%)

Includes - Full

Treatment

withdrawn

n=16

subsequently

treatment

No Treatment

after Arrival

n=34 (18.4%)

at ED

Partial

Treatment

n=69(37.3%)

	Emergency physicians $(n = 185)$			Emergency registrars ( $n = 135$ )			
	Reported that it was considered (no. (%, 95% CI))	Reported as very important (no. (%, 95% CI))	Reported as not considered (no. (%, 95% CI))	Reported that it was considered (no. (%, 95% CI))	Reported as very important (no. (%, 95% CI))	Reported as not considered (no. (%, 95% CI))	P-value†
Factors‡							
Patients interests	129 (72.1%, 65 1–78 1)	121 (67.6%,	50 (27.9%, 21.9–34.9)	104 (80.6%, 73.0-86.5)	91 (70.5%, 62.2-77.7)	25 (19.4%, 13.5-27.1)	0.060
Patients wishes	107 (61.1%,	87 (49.7%,	68 (38.9%,	82 (65.1%,	63 (50.0%,	44 (34.9%,	0.589
Family wishes	53.8-68.1) 142 (78.5%,	42.4–37.1) 109 (60.2%,	32.0-46.2) 39 (21.6%,	56.4-72.9) 118 (90.1%,	41.4–38.6) 91 (69.5%,	27.2-43.6) 13 (9.9%,	0.025
Co-morbidities	71.9–83.8) 150	53.0–67.1) 117	16.2–28.1) 31	83.8–94.1) 122	61.1–76.7) 104	8.9–16.2) 11	
	(82.9%, 76.7–87.7)	(64.6%, 57.4–71.2)	(17.1%, 12.3–23.3)	(93.1%, 87.5–96.3)	(79.4%, 71.7–85.4)	(8.4%, 4.8–14.4)	0.023
Age	123 (68.3%, 61.2–74.7)	59 (32.8%, 26.3–39.9)	57 (31.7%, 25.3–38.8)	107 (81.7%, 74.2–87.4)	56 (42.8%, 34.6–51.3)	24 (18.3%, 12.6–25.8)	0.024
Prognosis	169 (92.4%, 87.6–95.4)	165 (90.2%, 85.0–93.7)	14 (7.7%, 4.6–12.4)	127 (94.8%, 89.6–97.7)	121 (90.3%, 84.1–94.2)	7 (5.2%, 2.3–10.4)	0.372
Futility	133 (72.7%, 65.8–78.6)	117 (63.9%, 56.8–70.5)	50 (27.3%, 21.4–34.2)	109 (83.9%, 76.6–89.2)	97 (74.6%, 66.5-81.3)	21 (16.2%, 10.8–23.4)	0.065
Advanced health directive	68 (39.3%, 32.3-46.7)	50 (28.9%, 22.7–36.1)	105 (60.7%, 53.3-67.7)	50 (40.0%, 31.8–48.8)	27 (21.6%, 15.3–29.6)	75 (60.0%, 51.2-68.2)	0.087
Organ donation	41 (23.2%, 17.6–29.9)	3 (1.7%, 0.6–4.7)	136 (76.8%, 70.1–82.4)	38 (30.4%, 23.0–39.0)	5 (4.0%, 1.7–9.0)	87 (69.6%, 61.1–77.0)	0.253
ICU bed availability	43 (24.3%, 18.6-31.1)	1 (0.6%, 0.1–3.1)	134 (75.7%, 68.9–81.4)	39 (31.7%, 24.1-40.4)	1 (0.8%, 0.1-4.5)	84 (68.3%, 59.6–75.9)	0.365
Discussions						, , , , ,	
Patients	49 (29.3%, 23.0–36.7)	33 (19.8%, 14.4–26.5)	118 (70.7%, 63.4–77.0)	43 (35.5%, 27.6–44.4)	33 (27.3%, 20.1–35.8)	78 (64.5%, 55.6–72.4)	0.323
Family	160 (87.4%, 81.6-91.5)	147 (80.3%, 74.0-85.4)	23 (12.6%, 8.5–18.1)	121 (91.7%, 85.7–95.3)	116 (87.9%, 81.2–92.4)	11 (8.3%, 4.7–14.3)	0.195

**TABLE 2.** Reported relative importance of factors and discussions in decision-making regarding withdrawal and/or withholding of treatment (n = 320)

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	Emergency physicians $(n = 185)$			Emergency registrars $(n = 135)$			
	Reported that it was considered (no. (%, 95% CI))	Reported as very important (no. (%, 95% CI))	Reported as not considered (no. (%, 95% CI))	Reported that it was considered (no. (%, 95% CI))	Reported as very important (no. (%, 95% CI))	Reported as not considered (no. (%, 95% CI))	P-value†
Inpatient team	93 (53.8%, 46.3–61.0)	58 (33.5%, 26.9–40.9)	80 (46.2%, 39.0–53.7)	87 (50.3%, 42.9–57.7)	52 (40.0%, 32.0-48.6)	43 (40.8%, 32.7-49.4)	0.065
ICU	62 (35.8%, 29.1–43.2)	25 (14.5%, 10.0–20.5)	111 (64.2%, 56.8–70.9)	45 (36.3%, 28.4–45.1)	16 (12.9%, 8.1–19.9)	79 (63.7%, 55.0–71.6)	0.879

*†P*-value compares 'Reported as very important' columns. *‡Decision-makers* who did not respond have not been included. CI, confidence interval.

consideration rated most important by both EP and ER was prognosis. ER considered co-morbidities and age more often and rated them more important than did EP (P < 0.05). The least important considerations were ICU bed availability and organ donation. Discussions with families were rated very important by both EP and ER. Physicians and registrars referred 11 (6.0%, 95% CI: 3.4-10.3) and 16 (11.9%, 95% CI: 7.4–18.4) patients to palliative care services, respectively. Rates of referral to the coroner was 45 (24.3%, 95% CI: 18.7-31.0) for EP and 23 (17%, 95% CI: 11.6-24.3) for ER. Time to death was obtained through the medical record of the patients in whom EP withdrew or withheld treatment: 111 (60.1%, 95% CI: 52.8-66.8) died within 4 h and nine (4.9%, 95% CI: 2.6-9.0) died after 24 h. In patients in whom ER withdrew or withheld treatment, 64 (47.4%, 95% CI: 39.2-55.8) died within 4 h and 19 (14.1%, 95% CI: 9.2–20.9) died after 24 h (P < 0.05).

#### Discussion

To our knowledge this is the first prospective multicentre study to investigate and compare the importance of considerations and discussions that EP and ER took into account when withdrawing and/or withholding life-sustaining health-care in the ED.

This was a sub-study of a parent study that reported the overall findings of the group of patients who had life-sustaining healthcare withdrawn and/or withheld. This study examined further the clinician groups by comparing the responses of the decision-makers to the questionnaire that they completed.

We found EP and ER made a decision relating to withdrawal or withholding in 72.0 and 90.6% of patients, respectively. We also found that EP were more likely to provide and withdraw full treatment than did ER, who conversely were more likely to provide partial treatment. These differences could be explained by clinician experience and confidence, where a more senior/experienced clinician is willing to provide full treatment, not seeing it as a barrier to later withdrawal, depending on the clinical response or obtaining additional information. This of approach is consistent with the reported concept that time is invaluable in determining effects of treatment or obtaining more certain objective information about futility.16

We found that the most important consideration taken into account by EP and ER was prognosis, with ER also considering co-morbidities and age more often and rating them more important than did EP. This could be explained by more experienced clinicians focusing on the reversibility of a patient's condition in the first instance, rather than on their age or pre-existing conditions. Organ donation and ICU bed availability were essentially irrelevant considerations for both groups.

We found that EP and ER discussed decisions in almost all cases with families; in less than 12.5% of decisions there was no discussion. The family discussions were rated very important by both groups. We also found that ER considered discussions with the patient more often than did EP and rated it more important as well. This could be explained by a less paternalistic approach by ER by involving patients themselves, which might be reflective of changes to undergraduate training.

This study showed that trauma, intracranial haemorrhage and cardiac arrest accounted for less than 50% of deaths, and 5.4% of deaths occurred in patients with advanced malignancy, with an uncertain number of deaths relating to advanced non-cancer chronic illness. As reported by other studies, patients with non-cancer advanced chronic illness present and die within the ED.<sup>14,17</sup> Although this can suggest late referral or difficulty accessing

palliative care services, it is also reported that limits of futility are very individual, with cancer patients willing to accept treatments for what some medical professionals would consider offer only small benefits.<sup>17,18</sup> It is recognised that doctors are poor at predicting when death will occur and we found that deaths were significantly prolonged for the registrar group.<sup>19,20</sup> The significance of this finding is not fully explained, given the acuity and diagnoses of the patients managed by EP and ER were very similar. We also found that EP referred fewer patients to a palliative care service than did ER, but a greater proportion of their patients died earlier. We found referral to the coroner was low at less than 25%, which may reflect the relative aged population and the differentiated cause of death by the time this occurred rather than clinicians not being aware of their legal obligations in relation to reporting. This may warrant further investigation.

Decisions relating to withdrawal and/or withholding can be complex, but they are a reality of emergency medicine practice. Training in the area of end of life could provide emergency clinicians better understanding as to why certain patients may not have advanced care planning in place and why they present to the ED for what many clinicians would consider to be futile treatment. It could also improve consistency in decision-making in the ED and provide a better understanding that uncertain time courses mandate either closer palliative care service partnerships or specific training in this area of end-of-life care. This is supported by recent research relating to the management of patients with advanced cancer and emergency staff perspectives in the provision of palliative care in the ED.<sup>21,22</sup> Education of doctors about advanced care planning and end-of-life care is not only important because it will improve compliance with patient's wishes but also because it has been shown to improve end-of-life experience for patients and their families.<sup>23</sup>

The ED has been advocated as the ideal environment for difficult



**Figure 2.** *Time to death: For patients following decision to withdraw/withhold treat-ment.* (**■**), *Consultants;* (**■**), *registrars.* 

conversations regarding withholding of treatment that on retrospect might be judged futile, and emergency clinicians are potential reformists because they have become the de facto experts on end-of-life decision-making.<sup>24,25</sup> If this is the case, this would need to be reflected in the training curriculum and post-fellowship education programmes available to ER and EP.

This study has shown that there are differences between EP and ER in the level of treatment provided, rates of withdrawal, the considerations that were rated important and the time to death for patients (Fig. 2). It also showed that ER made a significant number of end-oflife decisions on their own. Focused education and training may improve decision-making consistency between EP and ER.

#### Limitations

This study has limitations. First, the study involved only six EDs, all in metropolitan areas; there were no rural or regional ED included. Second, there is a small amount of missing demographic information, but this does not impact on the information obtained from the questionnaire. Third, although we attempted to make clinicians feel they could be honest and candid in their responses,

it is possible that some answered in a way they thought would be expected or acceptable rather than reflecting reality. Fourth, there may have been a Hawthorne effect with a change to considerations and discussions undertaken if clinicians completed the questionnaire more than once. Fifth, the two groups could not be formally randomised, and although acuity and cause of death were similar for both groups, this needs to be taken into consideration when evaluating the differences between the two groups. Sixth, it is possible that if additional data was available for analysis, for example on such variables as mode of arrival, usual residence and time of death, that some differences might of the be explained. Last, it would have been preferable to include questions about previous training in end-of-life care.

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#### Author contributions

PGR designed the study and enlisted the additional sites and facilitated

ethics approval at each site. PGR, MD, AT, SK, JI and MG recruited patients at each site and supervised completion of questionnaires and data collection. JG performed a data audit. JG and IA analysed the data. PGR drafted the manuscript and all authors contributed to the final article. AMK reviewed and made major contributions to subsequent drafts. PGR took responsibility for the paper as a whole.

#### **Competing interests**

AMK is a member of the editorial board of *Emergency Medicine Australasia*.

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## Supporting information

Additional supporting information may be found in the online version of this article at the publisher's web site:

**Appendix S1.** End-of-life issues – Withdrawal of life-sustaining healthcare: Decision not to treat and/or withdraw treatment in the ED: A prospective multicentre review.