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Title:

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

Date:

2016-12-01

Citation:

Richardson, P. G., Greenslade, J., Isoardi, J., Davey, M., Gillett, M., Tucker, A., Klim, S., Kelly, A. M. & Abdelmehmoud, I. (2016). 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. *EMA Emergency Medicine Australasia*, 28 (6), pp.684-690. <https://doi.org/10.1111/1742-6723.12684>.

Persistent Link:

<https://hdl.handle.net/11343/291816>

Abstract

Objective: We investigated and compared the importance of the considerations and discussions when withdrawing and withholding life sustaining health care 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 Emergency Departments (ED). 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, 49.4% were woman and the median age was 83 (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 Treatment was withdrawn or withheld in 72.0% and 90.6% of all deaths by EP and ER respectively ($p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%, CI; 85.0-93.7) and 121 (90.3%, CI; 84.1-94.2) for EP and EM respectively. ER rated co morbidities and age more important than EP ($p<0.05$). Both rated discussions with family as very important. EP and ER referred 6.0% v 11.9% patients to palliative care services respectively. The proportion of patients taking longer than 24-hours to die was higher for ER compared to EP (14.1% v 4.9%, $p<0.05$)

Conclusion: We found that ER were more likely to withdraw/withhold life sustaining health care, provide partial treatment, rate different considerations as important and

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi:

10.1111/1742-6723.12684

Key Words Death, Emergency Departments, End of Life Care

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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 emergency department (ED) is a clinical setting where critical lifesaving 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 health care would be desired.^{1,2} While it is recognised 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 life threatening 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.⁴ At times emergency clinicians will institute invasive treatments near death in absence of information around end-of-life wishes which subsequently may be withdrawn.^{1,2}

There are more than 7.3million presentations to Australian EDs and approximately 10,000 patients a year will die in the ED, which is approximately 0.14% of all presentations.⁶ The incidence is predicted to increase with an aging population.^{7,8}

In Australasia there are approximately 1810 registered fellows and 2276 registrars/trainees registered with the Australasian College for Emergency Medicine.⁵ Ideally EP are involved in all decisions relating to the withdrawal and/or withholding life sustaining health care. Although 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 2400-0700.

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.^{9,10,11,12} 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.^{13,14,15} 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 health care.

We aim to investigate and describe any differences in the importance of the considerations and discussions that took place when emergency physicians and training registrars made a decision to withdraw and/or withhold life sustaining health care in the ED.

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METHODS

Study Design and Setting

This is a sub-study of a prospective, multicenter, 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 health care. 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 life sustaining treatment. The study was conducted in 6 metropolitan EDs in 5 Australian States, with a combined annual census of more than 320,000. Five of the departments were tertiary referral departments including trauma, (2 were adult-only EDs and 3 mixed EDs). The remaining department was an adult only teaching ED. The study was conducted between 2009 and 2011. Four of the departments collected data for 12 consecutive months and 2 departments for 6 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 if 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. This is available as on-line appendix A. 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 scales (5=very important) the importance of 10 possible factors in the decision to withhold/withdraw life sustaining health care and any discussions that took place. Data was also collected from the medical record at a later date and included, age, gender and time to death.

Each treating clinician was given a coded questionnaire to complete within 72-hours 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 health care was defined as any form of advanced health care 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 Intensive Care Unit (ICU) admission. Partial treatment was defined as any treatment with specified limitations e.g. non invasive 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.

Outcomes 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 decision maker. Median and interquartile ranges, are reported for continuous variables. Percentages with 95% confidence intervals are reported for dichotomous variables including the primary and secondary outcomes. Pearson chi-square 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 summarized in Figure 1. Of the 320 deaths included

in the analysis, demographics, triage category, cause of death and timing of death data was available for 299 (93.4%) patients. The median age was 83 years (IQR 72-88), 49.4% were female. 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 summarized in Table 1.

Main Results

Treatment was withdrawn or withheld in 72.0% of deaths when that decision was made by a EP compared to 90.6% of deaths when that decision was made by a ER. Full treatment was provided by EP 34% of the time compared to 12.1% for ER ($p<0.001$). EP were more likely to withdraw full treatment and ER were more likely to provide partial treatment ($p<0.05$). The relative importance of the factors and discussions are summarized in Table 2. The 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 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-hours and 9 (4.9% 95% CI; 2.6-9.0) died after 24-hours. In patients whom ER withdrew or withheld treatment 64 (47.4%, 95% CI; 39.2-55.8) died within 4-hours and 19 (14.1%, 95% CI; 9.2-20.9) died after 24-hours ($p<0.05$).

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DISCUSSION

To our knowledge this is the first prospective multicenter 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 health care 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 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 clinical response or the obtaining of additional information. This approach is consistent with the reported concept that time is invaluable in determining effects of treatment or obtaining more certain objective information about futility or not.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 physicians. This could be explained by more experienced clinicians focusing on the reversibility of a patient's condition in the first instance, rather than 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 was there 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 EP and rated it more important as well. This could be explained by a less paternalistic approach by ER by involving patients themselves which maybe reflective of changes to undergraduate training.

This studied showed that trauma, intracranial hemorrhage 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.^{14,17} While 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.^{17,18} It is recognized that doctors are poor at predicting when death will occur and we found that deaths were significantly prolonged for the registrar group.^{19,20} The significance of this finding is not fully explained given the acuity and diagnoses of the patients managed by EP and ER was very similar. We also found that EP referred fewer patients than ER to a palliative care service 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 (ACP) 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.^{21,22} Education of doctors about ACP and end of life care is not only important because it will improve compliance with patient's wishes but also because ACP has been shown to improve end of life experience for patients and their families.²³

The ED has been advocated as the ideal environment for difficult conversations regarding withholding of treatment that on retrospect might be judged futile and emergency clinicians are potential reformists because they have become the defacto experts on end of life decision making.^{24,25} If this is the case this would need to be reflected in the training curriculum and post fellowship education programs 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. It also showed that ER made a significant number of end of life decisions on their own. Focused education and training may improve decision making consistency between EP and ER.

LIMITATIONS

This study has limitations. Firstly, the study only involved 6 EDs, all in metropolitan areas; there were no rural or regional ED included. Secondly, there is a small amount of missing demographic information, but this does not impact on the information obtained from the questionnaire. Thirdly 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. Fourthly, there may have been a Hawthorne effect with a change to considerations and discussions undertaken if clinicians completed the questionnaire more than once. Fifthly, the 2 groups could not be formally randomized, 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 2 groups. Sixthly, 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 of the differences might be explained. Finally, it would have been preferable to include questions about previous training in end-of-life care.

Acknowledgments: The authors thank all staff at participating sites who contributed.

Competing Interests: The authors have stated that the study was supported by a grant from the Queensland Emergency Medicine Research Foundation. AK is a member of the editorial board of EMA.

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Title Page

End-of-life-issues. Withdrawal and withholding of life sustaining health care in the Emergency Department: A comparison between Emergency Physicians and Emergency Registrars. A sub-study

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Grant

Supported by a grant from the Queensland Emergency Medicine Research Foundation.

Conflicts

All authors have completed a ICJME conflict form- and no conflicts have been noted

Word Count

2296

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 and JG and IM analyzed the data. PGR drafted the manuscript and all authors contributed to the final article. AK reviewed and made major contributions to subsequent drafts. PGR takes responsibility for the paper as a whole.

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