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Published

2023

Journal Title

Australian Health Review

Version

Accepted Manuscript (AM)

DOI

[10.1071/ah23160](https://doi.org/10.1071/ah23160)

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The role of law in end-of-life decision-making in Emergency Departments and Intensive Care Units: A retrospective review of current practice in a Queensland health service.

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Acknowledgements: The research team acknowledge Ms Lucy Tripp and Ms Therese Gardiner for the research assistance they provided on this project. We also acknowledge Dr Kerina Denny for the helpful feedback provided on a draft of the manuscript.

Key Words: End-of-life decision-making, Medical Record Audit, Withholding treatment, Advance Health Directive, Substitute decision-makers.

CRediT author Statement:

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Ethical Approval: The study was approved by the Human Research Ethics Committees at Gold Coast Health (LNR/2021/QGC/72854), Griffith University (2021/193), Queensland University of Technology (2021000261), Bond University (LNR/2021/QGC/72854) and Southern Cross University (2021/042).

Declaration of Interests: Professor Lindy Willmott and Professor Ben White are funded by the Commonwealth Department of Health to deliver a training program to clinicians entitled 'End of life Law for Clinicians'. There are no other conflicts of interest to declare.

Declaration of Funding: This study was supported by a Gold Coast Health Collaborative Research Grant (RGS2020-044)

Data Availability Statement: The data that support this research will be shared upon reasonable request to the corresponding author.

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A retrospective review of current practice in a Queensland health service.**

ABSTRACT

Objective: There is limited evidence about how legal frameworks that underpin end-of-life decisions are applied in practice. This study aimed to identify how end-of-life decisions are made and documented in Emergency Departments and Intensive Care Units. The secondary aim was to explore the extent to which the legal processes featured in these decisions.

Methods: A retrospective chart audit of 85 adult patients who died in the Emergency Departments and Intensive Care Units of a Queensland health service was undertaken. Quantitative data were analysed and reported using descriptive statistics. Qualitative textual data were analysed using inductive content analysis.

Results: Nearly all admissions were unplanned (97.6%), and most patients (74.1%) were admitted from home. Only one patient had an Advance Health Directive, although all had an eligible substitute decision-maker. The qualitative analysis revealed two main concepts – ‘healthcare professionals choreograph the end of life’, and ‘patients and families are carried on an unplanned journey’.

Conclusions: There was limited documentation related to the application of the legal framework in these decisions. Healthcare professionals relied on their clinical judgment about what was in the best interest of the patient. It was common for there to be a substantial effort to achieve consensus in decision-making which coincidentally complied with the law.

Introduction

Hospital Emergency Departments (ED) and Intensive Care Units (ICU) employ skilled staff and resources that are typically directed toward sustaining life. However, ED and ICU staff also care for patients approaching the end of life for whom life-sustaining treatment is not appropriate. In all Australian states, legal frameworks govern health-related decision-making where adults lack decision-making capacity. This includes decisions to withdraw or withhold life-sustaining treatment (end-of-life decisions).¹

Working within the law is a central element of quality end-of-life care. Recent literature demonstrates gaps in healthcare professionals’ knowledge of the law about end-of-life decision-making.² While training, education, or support have been developed to address this,^{3,4} knowing the

law is not the same as applying the law, and there is limited evidence about how legal frameworks relating to end-of-life decisions are applied in practice.

The aim of this study was to identify how end-of-life decisions are made and documented in ED and ICU. The secondary aim was to explore the extent to which legal processes featured in these decisions. We defined end-of-life care to include physical, spiritual and psychosocial care, and treatment delivered by health professionals to a person who is at the end of life.⁵ An end-of-life decision relates to this care, and because it includes decisions to limit or withdraw active treatment may shorten life.⁶ 'Family' refers to those 'closest to the patient in knowledge, care, and affection,'⁵ p.33 noting that a legal decision-maker for an adult patient who lacks decision-making capacity may be their spouse, a carer, a close friend or relation, or another person nominated by the patient.⁷

Methods

The study was undertaken at the two EDs and two ICUs of one health service in Southeast Queensland, Australia. Approval was obtained from the Human Research Ethics Committees at Gold Coast Health (LNR/2021/QGC/72854), Griffith University (2021/193), Queensland University of Technology (2021000261), Bond University (LNR/2021/QGC/72854) and Southern Cross University (2021/042). A waiver of consent was granted as data collected were from deceased patients which made it impossible to obtain their consent and impracticable to obtain consent from another party.

A retrospective audit of the medical record of 85 adult patients who died in either of the two EDs or two ICUs between May 2019 and September 2021 was undertaken. Based on similar studies,⁸ this sample size was assessed as large enough to extract meaningful data and answer the research questions. Medical records were stratified according to the hospital and clinical area (ED or ICU), and consecutive sampling was used to include records of decedents. A data collection tool was developed in REDCap,⁹ based on the Australian Commission on Safety and Quality in Health Care End of Life Care Audit Tool.¹⁰ Patient demographic characteristics, data about hospital admission, date and time of death, relevant clinical information, presence of an advance health directive (AHD) and other enduring documents or information related to goals of care were extracted and entered directly into the REDCap database. Entries documented by clinicians that related to end-of-life decision-making, such as the goals/purpose of care, treatment options and limitations, and communication with patients and/or families, were also collected.

To ensure the accuracy and reliability of the data, a data dictionary provided definitions and examples of the variables collected. The tool was piloted by XX and YY who independently collected data from the same 10 electronic medical records to assess face validity and inter-assessor

reliability. Using IBM SPSS Statistics for Windows v28 (IBM Corp: Armonk, NY), ¹¹ Cohen's Kappa was run on a sample of 10 medical records to determine the extent of agreement between the two data collectors. ¹² The mean Kappa coefficient of 0.8266 indicates strong agreement between them.

Quantitative data were analysed and reported using descriptive statistics. Qualitative textual data were analysed using Kyngäs et al's ¹³ inductive content analysis approach where abstracted data were reduced to codes and then grouped into sub-concepts by comparing similarities and differences between them. Sub-concepts are grouped into concepts, and in the final step, concepts are grouped into main concepts to address the study aims.

Findings

Most patients who died in ED or ICU had been admitted from home (n=63, 74.1%) and over three-quarters (n= 65, 76.5%) died within 5 days of admission. A Glasgow Coma Scale (GCS) score was reported on 71 occasions (83.5%). Twenty-seven patients had a GCS of 3-5 suggesting that decision-making capacity was limited. Twenty-six patients were recorded as having a GCS of 15 and would be presumed to have decision-making capacity for some decisions.

Patients' presumed preferences for treatment were documented in 41.2% of cases. Four medical records (4.8%) included statements of choices, however, completion of the statutory options for substitute decision-making was limited. Only one patient had an AHD documented, but this was incomplete and not accessed by healthcare professionals. Eleven patients (11.8%) had appointed a person to act as their substitute decision-maker, known in Queensland as an Enduring Power of Attorney. In most cases (>95%), there was a person eligible to act as a statutory health attorney (SHA). Health Department-based acute resuscitation plans (ARP) also document patients' presumed preferences for end-of-life care. An ARP was discussed during the patient's admission in 36 cases (42.4%) and completed in 23 of these 36 medical records.

Seven concepts, distilled into two main concepts, were construed from the qualitative data. Four concepts relate to healthcare professionals and three to family and patient. Figures 1 and 2 depict the main concept, the headings in the text boxes are the concepts, and the text is the associated sub-concepts.

Main Concept 1. Healthcare professionals choreograph the end of life.

FIGURE 1

Concept 1: *confronting the inevitability of death*. HCPs use their knowledge, skills, and resources to diagnose and prognosticate about failing bodies and the likelihood of making a meaningful recovery. Decisions made based on these assessments were frequently documented in the medical records.

This is a terminal event. Respiratory arrest imminent [H1_ED_21]

Recognising the patient's death was imminent, or inevitable, the focus of care changed from seeking to actively reverse the cause of the physiological failure to minimising harm and suffering.

...given the extent of his burns and an inability to graft this is a nonsurvivable injury – ongoing support is futile and potentially harmful [H1_ICU_19]

Family in agreement that we should make sure he doesn't suffer any more [H1_ICU_6]

Concept 2: *making the right decision*. Medical records show end-of-life decisions were rarely made in isolation; consultation with medical colleagues was common.

...NOT for CPR / antibiotics or any other escalation of care. Ask for pal care input. Prioritise comfort at all times Dr [name] consulted Dr [name], who agrees with the assessment
[H2_ICU_17]

Having reached a consensus among medical colleagues, seeking agreement from those close to the patient was sometimes documented.

Following further discussion with [patient's brother] today, everyone in agreement to switch to comfort measures, [H2_ICU_23] and son in agreeable [sic] with plan to palliate
[H1_ED_21]

Conversations previously held and documented about possible limits to treatment seem to relieve some decision-making burden, although in some cases, the benefit of an ARP may be perceived as negligible if doctors believe they have the authority to make these decisions.

D/W [discussed with] regarding ARP, patient states wants to have some time to consider, but definitely would not like to be a 'vegetable'. I have left her as full resus at this point but have asked her to consider ceilings of care for her wellbeing, however decision for ceiling of care is still a medical decision. No ARP found on file, despite this initial discussion [H2_ICU_25].

Concept 3: *Preparing the family*. Obtaining family agreement and consent for an end-of-life decision can only occur if they are aware the patient is going to die, and decisions need to be made. Ensuring the patient's family was informed also meant signalling the patient was likely to die during the current hospital admission.

Family meeting via video conference with [patient's] sons and wife in the room...I have discussed his case with my other colleagues...and we believe that his prognosis is very poor. It is very likely that even if he survived this he will be severely debilitated and unlikely regain his previous function and QOL[quality of life] [H1_ICU_15]

While health professionals documented information about the patient, factors beyond the patient's immediate clinical needs were also considered.

Concept 4, *navigating healthcare regulation*, captures limits or ceilings of treatment, complying with legal processes, including coronial referrals and potential organ donation.

Active cares and treatments to facilitate family time to grieve...coroner's referral...not medically suitable/unsupportable for organ donation consideration of MOF/DIC [H1_ICU_9]

Main Concept 2. Patients and their families are carried along on an unplanned journey.

FIGURE 2

Concept 1: *coming to terms with the death*, and medical record documentation describes varied family responses to the patient's condition and prognosis.

Dtr [daughter] conveyed that patient's wishes were to die comfortably and that she would not like any life-prolonging treatment [H2_ED_6], and in contrast,

We believe that the prognosis is grim, and the likelihood of a meaningful outcome is extremely low. Brothers understand her issues. However, indicated that they believe in 'miracles' and have a close family member that 'recovered' from a brain injury after neurosurgery. [H1_ICU_17]

Concept 2: *Being with the patient who was dying*, reflected the importance that health professionals placed on ensuring the dying person was not alone and that family members had the opportunity to be present immediately before death.

[Son] appeared to prefer coming into hospital in the morning rather than overnight, but when reiterated her critical prognosis, he stated 'fine, I'll come in – give me half an hour' [H1_ED_23]

Concept 3: *doing what's best for the patient* captured efforts to ensure that the patient's wishes were carried out, and the most appropriate person was conveying these wishes.

Nil EPoA [enduring power of attorney]. Pt has requested that his partner is his NoK [next of kin]. Pt believes partner has knowledge of his core wishes as it pertains to his health [H2_ICU_1].

There was one exceptional case of a patient admitted to ICU with a severe head injury. Despite maximal medical therapy, the patient did not improve. On two occasions the family requested all treatment be discontinued. This request was made after they were informed that the most likely outcomes for the patient were death or severe disability. The medical team sought an independent opinion regarding this request. The consulting practitioner concluded that,

given the prognosis, the view of the family as regards withdrawing consent to further treatment is in my opinion reasonable on both ethical and legal grounds [H1_ICU_21].

Decisions to withdraw treatment generally required consensus among the medical team. This case was exceptional because the decision to withdraw treatment was initiated by the family who believed the patient would have an unacceptable quality of life. The family orchestrated their adult child's end-of-life journey and the change in decision-making dynamics caused the medical team to pause and take steps to reassure themselves that this was an ethically and legally sound decision.

Discussion

This study aimed to identify how end-of-life decisions are made and documented in ICU and ED and to explore the extent to which legal processes featured in these decisions. We found decisions about limiting or withdrawing treatment generally began with conversations led by doctors. Flannery et al report that in ICU, as doctors assume responsibility for treatment decisions, they are the most appropriate person to initiate end-of-life decisions.¹⁴ While the same applies in ED, ensuring that communication about the patient's condition and likely death was clear and concise was seen as important for the transition from active treatment to end-of-life care.¹⁵

Faced with inevitable or imminent death, the options for authentic shared decision-making were limited. Ackkermans et al report that, in their study, families usually remained passive and compliant as doctors informed them of the decision to be made.¹⁶ Conveying prognostic information helps doctors reach a shared understanding of the inevitable outcome with the patient and their family.¹⁷ Consensus building may also help family members avoid feeling as though they are 'stuck or saddled' with a decision.¹⁷ Consistent with the findings of Craig et al, efforts to reach a consensus were evident in our study, and understanding and fulfilling patients' wishes was an important part of the process.¹⁸ If consent was required for a decision, the process enacted by doctors may comply with

the underpinning legal framework, but our findings suggest this was coincidental and ancillary to reaching consensus about acting in accordance with a patient's end-of-life wishes.

Patients can express end-of-life wishes through an AHD. However, despite significant efforts to promote their completion,¹⁹ we found only one medical record with an AHD. This low prevalence reflects the findings of other studies²⁰ and may confirm shortcomings associated with anticipating future health states and treatment needs.²¹ Where patients' wishes are not documented, then healthcare professionals try and ascertain their values and align them with the potential options for treatment or end-of-life care. In the limited time available in ED, this can be challenging.²²

In the absence of documented wishes, end-of-life decisions initiated by doctors may be recorded in an ARP.²³ While the number of ARPs completed was still relatively low, they were more common than AHDs which may reflect doctors' initiation of end-of-life discussions. In Queensland, decisions to withhold life-sustaining treatment from a patient lacking decision-making capacity require consent.¹ Clinical Guidance states that ARP completion does not constitute legal consent, and there is no requirement for a substitute decision-maker to sign the ARP form.²³ Instead, doctors are directed to document discussions around consent on the ARP, and for this to be cross-referenced in the medical record. Consent was recorded in all ARPs, but whether this reflected agreement with the recommendations of the treating medical team or an expression of patient preferences for treatment is uncertain. Recent research reveals that Australians may have limited knowledge about the role of substitute decision-makers and access minimal support when making challenging medical decisions.²⁴ In the emotional setting of end-of-life, potential substitute decision-makers may feel unprepared to assume a decision-making role, preferring instead to follow the lead of others.²⁵ However, this assumes that those charged with leading the process are aware of the law, but this may not always be the case.²⁶ To begin to address these areas of uncertainty, we make the following recommendations.

Figure 3 - Recommendations

Limitations

A study limitation was reliance on a retrospective audit of medical records. It is likely that prognostic discussions between members of the healthcare team, or others invited to consult were not captured in the medical record. This study was conducted at one health service, and there may be

variations in processes between this setting and others, so findings may not be generalisable to other settings.

Conclusions

End-of-life decision-making is complex and challenging. Our study found there was limited documentation about the application of the law in these decisions. Instead, reflecting existing literature, healthcare professionals relied on their clinical judgment about what was in the best interests of the patient. It was common for there to be substantial effort to achieve consensus in decision-making which coincidentally complied with the law.

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Figure 1: Main Concept 1, Concepts and Sub-concepts that were construed from the data.

Figure 2: Main Concept 2, Concepts and Sub-concepts that were construed from the data.

Figure 3: Recommendations

Table 1 Patient demographic characteristics, admission data, and end-of-life decision-making

Patient Demographic Characteristics, Admission Data, and End-of-life Decision-making	
Demographics (n=85)	
Age on admission (years) Median (Inter-Quartile Range) Range	67.4 (55.5-82.0) 18 - 93
Gender* Male	45 (52.9%)
Admission data	
Admission type Planned Unplanned	2 (2.4%) 83 (97.6%)
Admitted from Home Residential Aged Care Another acute hospital No fixed address	63 (74.1%) 11 (12.9%) 10 (11.8%) 1 (1.2%)
No of days from admission to death 0 1-5 6-10 11-20 21-30 >30	32 (37.6%) 33 (38.9%) 7 (8.3%) 6 (7.2%) 3 (3.6%) 4 (4.8%)
Neurological assessment Neurological assessment documented on admission. GCS documented on admission.	85 (100%) 71 (83.5%)
End-of-life decision-making	
Patient presumed preferences for care	
Reference to patients' presumed preferences documented.	35 (41.2%)
Statement of choices	
No. of patients with a statement of choices, form used for people who have decision-making capacity.	2 (2.4%)
No. of patients with a statement of choices, form used for persons who lack decision-making capacity.	2 (2.4%)
Tribunal Appointed guardian	
No. of patients with a tribunal-appointed guardian.	Nil
Enduring Power of Attorney for health matters	
No. of patients where an enduring power of attorney was documented in the medical record.	10 (11.8%)
Statutory Health Attorney	
No. of patients for whom a person was able to act as the statutory health attorney (SHA). **	81 (95.1%)
Acute Resuscitation Plan	
No. of patients for whom an ARP was discussed during the admission.	36 (42.4%)

No. of completed ARPs during the admission.	23 (27.1%)
Consent obtained for ARP.	23 (27.1%)
The person who provided consent	
○ Patient with decision-making capacity	2 (8.7%)
○ Person identified by a medical practitioner as the Enduring Power of Attorney	3 (13.0%)
○ Person identified by a medical practitioner as SHA	18 (78.3%)
* The computer system that collects patient demographic data permits only biological sex, not gender, to be recorded.	
** We note that where a person has a valid Enduring Power of Attorney the SHA will not have legal decision-making power.	