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# End-of-life decisions, nurses, and the law (Editorial)

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**End-of-life decisions, nurses, and the law**

## Introduction

Among the many decisions made and implemented in the intensive care unit (ICU), are those about where and when treatment limits should apply. As these decisions often foreshadow the end of life, they are conceptually different to those made with the aim of maintaining and restoring health and life. While nurses do not bear ultimate responsibility for making these decisions, they are often the ones who action them. Nurses must, therefore, be confident that the decision was made in line with best practice, and this includes ensuring that it accords with the law. However, research demonstrates that there are significant gaps in nurses' knowledge and understanding of the law that applies in these circumstances, leading to poorer patient outcomes, and potential legal risk. In this editorial, I argue that nurses' legal knowledge is constitutive of professional nursing practice, and can improve end-of-life decision-making for patients in ICU.

## The intersection of healthcare and law

Critical care nursing involves making decisions based on unique nursing knowledge and clinical expertise to achieve the best possible patient outcomes.[1] Nurses are frequently also required to implement decisions made by others, including medical practitioners. While many of these decisions are directed to improving health outcomes, others are about limiting care. Decisions about withdrawal of care are conceptually different from treatment decisions and have ramifications beyond those traditionally based on practitioner-patient relationships. For example, the State has an inherent interest in the preserving life of its citizens and ensuring their death is not intentionally hastened. This is why in certain circumstances, it criminalises actions that cause death.[2] Critical care nurses frequently find themselves working in the liminal space between life and death. It is imperative, therefore, that they know where the boundary between lawful actions and those that contravene the law lie.

Laws that operate around end-of-life decision-making stipulate a process to be followed, or set out who is authorised to decide. They reflect current societal norms and give primacy to the ethical principle of autonomy. The laws enable individuals to decide about the type of treatment that is or is not, acceptable to them. If an adult has decision-making capacity, this includes refusing treatment that others might consider to be in their best interest and/or essential to save or sustain their life.[3] Whether or not an adult has decision-making capacity, therefore, is a threshold question. If an adult lacks decision-making capacity, State or Territory-based legal frameworks set out who can act as their substitute decision-maker and consent to or refuse healthcare treatment.[4]

## Providing non-beneficial care

The legal frameworks that underpin decision-making, including decisions to limit or refuse treatment, are closely aligned with shared or patient-centred care. These approaches emphasise the importance of communication for shared and collaborative decision-making rather than traditional unilateral paternalistic approaches.[5] They have been shown to result in improved patient outcomes and overall satisfaction with care.[6] However, patient or family participation in shared decision-making frequently relies on the information provided, or recommendations made, by medical practitioners.

Medical practitioners have a professional obligation to ensure that any treatment they recommend responds to an identified therapeutic need, has a reasonable expectation of clinical efficacy, and benefit for the patient.[7] Despite this, there is substantial variation in treatment offered to patients in

intensive care, which at times includes recommending treatment with negligible benefit.[8] Recent Australian research has demonstrated that more than ten per cent of ICU admissions involve the provision of treatment deemed futile and did not improve overall survival rates or quality of life.[9] Furthermore, the treatment may not reflect the patient's preferences toward the end of life.[10]

The reasons that futile or non-beneficial care is offered and provided are multifactorial. They include practitioners feeling underprepared to have difficult conversations about end of life, and the perceived legal risk associated with withdrawing or withholding care.[11] These factors are amplified in circumstances where there are different points of view within families about care for the dying patient, or if a family member disagrees with a healthcare practitioner about the decision.[11] As a consequence, some patients experience extended ICU admissions that ultimately prolong the process of dying.

**What this means for nurses**

End-of-life decision-making is complex and can be challenging, but the decision to avoid making a decision can also be harmful. Patients can experience loss of dignity and increased suffering as a result of receiving unwanted or non-beneficial medical treatment.[12] There is also a substantial financial cost incurred by the patient, their family, or the State.[13] As nurses are intimately engaged in the provision of all aspects of end-of-life care they are more likely to recognise the point at which patient treatment is futile and can experience moral distress as a result of providing this care.[14]

Strategies designed to improve interdisciplinary end-of-life care can also minimise the provision of non-beneficial treatment. For example, the need for better communication around end of life to ensure that decisions about the type or extent of care are consistent with a person's values and preferences has long been recognised.[15] Greater collaboration between members of the interdisciplinary team can also enhance end-of-life decision-making and care.[1] What is less well recognised is that knowledge and understanding of the law that underpin these decisions are just as important as knowledge about a patient's preferences, healthcare conditions and the likely response to treatment,[16] and can contribute to more consistent decision-making.

A better understanding of the law can enhance nursing practise in three ways. First, the close relationship that nurses have with patients and their families at the end of life provides unique insights into their values and preferences, and the opportunity to advocate on their behalf.[1] Advocacy that promotes or supports shared decision-making consistent with the law is recognised as a professional obligation.[17] However, unless nurses are familiar with the content of the law, they will not be able to fulfil this obligation. Those that know the law will be better placed to identify if healthcare treatment is inconsistent with a patient's previously expressed values and preferences and raise this with members of the medical team. They may also be able to identify who should act as the legal substitute decision-maker.

Second, although nurses are not responsible for making end-of-life decisions, they are frequently responsible for implementing them. While providing professional compassionate end-of-life care to the patient, they will also be responsible for comforting grieving family and friends and responding to questions about the withdrawal of care. This can be confronting and at times conflicting, which contributes to moral distress.[18] Being confident that the end-of-life decision has been made appropriately, and is not in breach of the law, can help to mitigate this distress.

Third, where there are gaps in nurses' knowledge of the law they may assume that medical practitioners know and correctly apply the law. However, recent research demonstrates that medical practitioners' also have knowledge deficits in this area.[19] There are a range of legal

consequences that could follow if nurses implement decisions that have not been made in accordance with the law. They include complaints that result in disciplinary proceedings, civil liability or even criminal responsibility if treatment is withdrawn unlawfully.[20] Being aware of the law that regulates end-of-life decision-making will assist nurses to practice within these boundaries.

**Recommendations and conclusions**

Knowledge of the law that applies to end-of-life decision-making can improve patient outcomes by ensuring they receive care that is consistent with their previously expressed values and preferences. Nurses play an integral role in ensuring that the end of life decisions they implement meet these legal requirements. However, they cannot do this if they are not familiar with the law. Currently, the extent to which there are gaps in nurses' knowledge of this law is relatively unknown. More research on this topic is needed to understand the extent of potential knowledge gaps, and also the educational resources and other strategies that are needed to support nurses' to work within the law. Evidence to determine how nuanced resources and strategies can be embedded within current or future systems is also required. Collectively, this knowledge can promote transparent, consistent decision-making, reduce nurses' moral distress, and provide better outcomes for patients at the end of life.

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