Should law have a role in end of life care?

What do physicians think of law? Do they know the law? What role does it have in the provision of end of life care? Physicians in New South Wales, Victoria and Queensland are being asked about these issues in a study by the Queensland University of Technology entitled “Withholding and withdrawing life-sustaining treatment from adults who lack capacity: The role of law in medical practice”. This research aims to examine the role that law plays in decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity.

This interdisciplin ary research project, funded by the Australian Research Council, will explore the legal knowledge of specialists who make end-of-life decisions, the extent to which legal issues are relevant to their clinical decision-making, and what legal education or training (if any) these specialists want. The final field work stage of the project is a survey which is now being administered to seven specialties (including physicians who specialise in geriatric medicine, medical oncology, palliative medicine, renal medicine and respiratory medicine) that are likely to be involved in decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity.

Doctors have significant medico-legal roles at the end of life

We estimate that almost 40,000 adult deaths occur nationally each year following a medical decision to withhold or withdraw treatment. [1] As such, decisions to not provide or continue life-sustaining treatment are a common part of medical practice for many specialties. When these decisions are made, doctors are not only performing their clinical role, they are also acting in significant medico-legal roles. For example, they may decide whether an adult lacks capacity, or guardianship legislation may grant them power to be a decision-maker or to supervise decisions made by others. Undertaking these roles can be challenging because of insufficient training, and because of complexity and ambiguity in the law. [1]

This means that the above questions about the role of law in medical practice are important ones. However, despite the significance of these issues, they have been the subject of very little research. For example, there is only limited work in the United States, Denmark and the United Kingdom that purports to examine in a systematic way what doctors know of this area of law. [2, 3, 4, 5] In Australia, no comprehensive empirical research has been conducted, although there have been studies into parts of the law that can be relevant to these decisions. [6, 7, 8, 9, 10] A further gap in understanding in this area is that the few Australian studies that exist have tended to focus only on particular subsets of doctors such as general practitioners [6, 7], emergency physicians [8] or intensivists [9]. We know very little about the medico-legal understanding and perspectives of the wider group of physicians being surveyed in this study – those who specialise in geriatric medicine, medical oncology, palliative medicine, renal medicine and respiratory medicine – despite them playing a significant role in the provision of end of life care. The limited body of research undertaken to date reveals gaps in legal knowledge and training for doctors [8, 9, 10], and calls for further research to be undertaken across specialties. [8]
Better law and enhanced legal training

The current study will identify the legal education or training needs (if any) of the specialists surveyed. It will also make recommendations to improve the law, informed by clinical perspectives as to how the law is actually operating in practice. Improved law and legal understanding in this area will help doctors manage legal risk and reduce possible exposure to criminal, civil or disciplinary action. Adverse engagement with the law can have significant implications for doctors personally, financially and professionally, so supporting them to better understand and navigate the relevant legal framework is important. We also believe that this research can help lead to better outcomes for patients and their families, as well as a more appropriate allocation of scarce health resources. Research suggests limited legal knowledge is linked to the practice of defensive medicine, and that fear of legal liability can lead to the provision of treatment that patients do not want [2, 4].

The perspectives of different specialties are critical

From late 2011 to early 2012, we conducted a pilot study to test our survey instrument. The results of that pilot were generally positive and those who responded provided a great deal feedback which enhanced the survey instrument and our understanding of the issues. In July 2012, the questionnaire for the main study was posted to seven specialties who are commonly involved in decisions at the end-of-life: physicians who specialise in geriatric medicine, medical oncology, palliative medicine, renal medicine and respiratory medicine as well as emergency physicians and intensivists. About the time this editorial is published, a final reminder, along with another copy of the questionnaire, will have been sent to those who have not yet responded.

One issue that emerged from the pilot data was some variation in medico-legal knowledge and perspectives across specialties. We are keen to explore this further as we understand that decisions in particular specialties about whether to withhold or withdraw life-sustaining treatment are made in a range of different settings. Sometimes decisions need to be made quickly; sometimes not. A doctor may know his or her patient very well (and perhaps too their family); or he or she may be meeting them for the first time as they lie unconscious in hospital. The nature of the treatment not being provided – for example, cardio-pulmonary resuscitation, chemotherapy, dialysis, artificial ventilation, or antibiotics – can also affect decision-making in this area. An understanding of the appropriate role of law in end of life care, and how law itself can be improved, needs to take account of this complexity and variation in medical practice.

So it is critical that our findings – which include recommendations to improve the law and support doctors through training and education – are informed by a clear understanding of the perspectives of the different specialties participating in this project. We appreciate those physicians who have already responded to our survey and invite those who have not yet done so to consider supporting this research and share their perspectives and those of their specialty.
Competing Interests:
The questionnaire ‘Withholding and withdrawing life-sustaining treatment from adults who lack capacity: The role of law in medical practice’ was sent out to seven specialties (physicians who specialise in geriatric medicine, medical oncology, palliative medicine, renal medicine and respiratory medicine as well as emergency physicians and intensivists) in mid July 2012.

Reminders have been sent to those who have not yet responded to seek their assistance in completing the questionnaire. The survey will close soon in September 2012 so we encourage you to share your views.

Current and future research findings about the project are available here: http://www.gut.edu.au/research/research-projects/withholding-and-withdrawing-life-sustaining-medical-treatment

References