Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists

Ben White, Lindy Willmott, Colleen Cartwright, Malcolm H Parker, Gail Williams

ABSTRACT

Objective: Decisions about withholding or withdrawing life-sustaining treatment (WWLST) from adults who lack capacity are an integral part of intensive care (IC) practice. We compare the knowledge, attitudes and practice of intensivists in relation to the law about WWLST with six other specialties most often involved in end-of-life care.

Design, setting and participants: We used a cross-sectional postal survey of medical specialists in the three most populous Australian states, and analysed responses from 867 medical specialists from the seven specialties most likely to be involved in WWLST decisions in the acute-care setting (emergency, geriatric, palliative, renal and respiratory medicine, medical oncology and IC).

Main outcome measures: Attitudes to, and knowledge and practice of, the law relating to end-of-life care.

Results: Of 2702 surveys sent to eligible practitioners, 867 completed questionnaires were returned. There was an overall response rate of 32% and an IC response rate also of 32% (125/388). Intensivists performed better than average in legal knowledge but important knowledge gaps remain. Intensivists had a more negative attitude to the role of law in this area than other specialty groups but reported being seen as a leading source of information about legal issues by other medical specialists and nurses. Intensivists also reported being the specialists most frequently making decisions about end-of-life treatment.

Conclusions: Improved legal knowledge and open engagement with the law can help manage the risk of harm to patients and protect intensivists from liability. IC guidelines and continuing professional development are important strategies to address these issues.

Almost 40 000 adult deaths are estimated to occur each year in Australia after a medical decision in favour of withholding or withdrawing life-sustaining treatment (WWLST).1 These decisions are an important part of practice in intensive care (IC).2-5 Usually these decisions are made for patients who lack decision-making capacity; only about 5% of patients are competent when a WWLST decision is made,4,5 and one study found that 73% of all patients being cared for in the intensive care unit are not competent.3 Most countries have laws that establish frameworks for these decisions that permit, for example, the completion of advance directives (ADs) and the appointment of substitute decision makers.6-10 These laws aim to safeguard patient interests (including autonomy), protect doctors acting within the law and establish a process for resolving intractable disputes.8

This means that intensivists have a legal as well as a clinical role when providing end-of-life care. This includes assessing a patient’s decision-making capacity,9 determining the legally authorised decision maker and the scope of their power,10 and knowing whether an AD is valid.1 The legal role played by intensivists is further evidenced by the consideration of law that occurs in various IC guidelines for end-of-life decision making.11-14

Despite this, there is a growing body of evidence that medical specialists, including intensivists,15 lack legal knowledge.16-18 In their systematic review, Visser and colleagues identified a “lack of knowledge about the relevant legal framework” as one of the “barriers to the provision of good end-of-life care to patients in the ICU”.19 Studies in the United States have found that poor legal knowledge increases unnecessary fear of legal liability, resulting in the practice of defensive medicine.17,18 Although formal engagement with the legal system is rare, the “shadow of the law” can still influence decisions at the bedside.20 A lack of legal knowledge also poses risks for patients in either not receiving needed treatment (eg, refusal by a substitute decision maker who lacks legal power to do so) or receiving unwanted treatment (eg, when lawful refusal of such treatment by a substitute decision maker or in an AD is ignored).16

Our research examined the attitudes, knowledge and practice of intensivists and six other medical specialties involved in end-of-life care in relation to the law that deals with WWLST for adults who lack capacity. We focused on intensivists because of their central role in end-of-life care. This perspective is also critical not only because the ICU is
instrument, developed over 18 months, was informed by a detailed review of the law in each state,1,23,24 focus groups, pretesting and pilot testing with doctors. The accuracy of the legal questions (which varied slightly between states to take account of different laws) and responses was confirmed by independent experts. A more detailed description of the development of the survey instrument, and the wider project methodology, has been published elsewhere.25

The sample comprised all specialists who identified their main specialty as being in ICU, medical oncology, emergency, geriatric, palliative, renal or respiratory medicine; and who were listed in the AMPCo Direct database26 at the time the survey instrument was distributed (N = 2858). These specialties were determined, by literature review, interviews and an analysis of pilot results, to be most likely to be involved in decisions about WVLST. AMPCo Direct (AMPCo is a subsidiary of the Australian Medical Association) has Australia’s most comprehensive and accurate doctor database and has been used for other major studies of Australian doctors.27

AMPCo Direct administered the survey mail-out from July 2012. Strategies to improve response rates included having the survey instrument professionally designed, providing incentives (continuing professional development [CPD] points, educational material and a chance to win one of six bottles of prestige wine), engaging with the colleges and societies of target specialties, and publishing editorials in relevant professional journals to request participation in the study, where possible.28,29 Two follow-up requests were sent to non-responders and the survey closed on 31 January 2013.

Our project was approved by the human research ethics committees at the Queensland University of Technology, the University of Queensland and Southern Cross University. All participants provided informed consent to the study by completing the survey.

Measures
The survey instrument (available on request from the authors) included sections on perspectives about the law, legal knowledge, practice and experience in end-of-life decisions, and participant characteristics.

Perspectives on the law were examined through two questions that asked respondents to rate their level of agreement with a series of statements on a five-point scale from “strongly disagree” to “strongly agree”, with “unsure” as the middle option (Figure 1). One question contained 11 statements about the role of law in this area of medicine, and the second question contained 11 statements about specific aspects of knowing and following the law. For each question, items were scored from 1 to 5, with 5 representing a positive attitude, and the 11 item scores were added to produce a score from 1 to 55 for attitude to the role of law. Item scores were added to produce a score from 1 to 50 for attitude to knowing and following the law (one item was omitted as it was considered neutral in attitude).

The knowledge section contained two questions, with a total of seven items. The first question comprised six statements in relation to relevant state law: three items concerned the validity of an AD, two concerned consent...
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Table 1. Mean score (SD) for positive attitudes to role of law in medicine (out of 55) and to knowing and following the law (out of 50), by specialty

<table>
<thead>
<tr>
<th>Specialty (n)</th>
<th>Role of law in medicine (n = 810)*</th>
<th>Knowing and following the law (n = 809)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intensive care (124)</td>
<td>31.5 (7.1)*</td>
<td>34.4 (3.8)</td>
</tr>
<tr>
<td>Emergency medicine (269)</td>
<td>32.0 (5.9)*</td>
<td>33.9 (3.7)</td>
</tr>
<tr>
<td>Renal medicine (80)</td>
<td>32.3 (5.7)</td>
<td>34.1 (3.5)</td>
</tr>
<tr>
<td>Respiratory medicine (98)</td>
<td>33.0 (6.8)</td>
<td>33.7 (3.8)</td>
</tr>
<tr>
<td>Medical oncology (80)</td>
<td>33.5 (5.8)</td>
<td>33.6 (3.4)</td>
</tr>
<tr>
<td>Geriatric medicine (107)</td>
<td>34.6 (5.7)*</td>
<td>35.3 (3.8)**</td>
</tr>
<tr>
<td>Palliative care (52)</td>
<td>36.2 (5.7)*</td>
<td>36.4 (3.6)**</td>
</tr>
<tr>
<td>Overall (810)</td>
<td>32.9 (6.3)</td>
<td>34.3 (3.8)</td>
</tr>
</tbody>
</table>

* Two respondents (one intensive care and one emergency medicine specialist) had missing attitude scores. † Three respondents (one intensive care and two emergency medicine specialists) had missing attitude scores. ‡ Although intensive care had the lowest actual mean score, the smaller number in that sample meant that the result only approached significance (P = 0.08). § Mean score for emergency medicine (given the higher number of respondents) was significantly lower than the overall score (P = 0.05). ¶ Mean scores for geriatric medicine and palliative care were significantly higher than the overall score (P = 0.008 and 0.0003, respectively). ** Mean scores for geriatric medicine and palliative care were significantly higher than the overall score (P = 0.008 and 0.0001, respectively).

Table 2. Mean correct responses out of 7 (SD) to knowledge of law questions, and number of respondents scoring ≥ 4, by specialty

<table>
<thead>
<tr>
<th>Specialty* (n)</th>
<th>Mean correct score (SD)</th>
<th>No. of respondents scoring ≥ 4 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intensive care (125)†</td>
<td>3.48 (1.35)</td>
<td>63 (50.4%)</td>
</tr>
<tr>
<td>Emergency medicine (270)†</td>
<td>3.09 (1.27)</td>
<td>103 (38.1%)</td>
</tr>
<tr>
<td>Renal medicine (80)</td>
<td>3.37 (1.13)</td>
<td>37 (46.3%)</td>
</tr>
<tr>
<td>Respiratory medicine (98)‡</td>
<td>2.72 (1.34)</td>
<td>25 (25.5%)</td>
</tr>
<tr>
<td>Medical oncology (80)</td>
<td>3.07 (1.23)</td>
<td>29 (36.3%)</td>
</tr>
<tr>
<td>Geriatric medicine (107)‡</td>
<td>3.89 (1.28)</td>
<td>61 (57.0%)</td>
</tr>
<tr>
<td>Palliative care (52)</td>
<td>3.71 (1.49)</td>
<td>27 (51.9%)</td>
</tr>
<tr>
<td>Overall (812)</td>
<td>3.26 (1.32)</td>
<td>365 (42.1%)</td>
</tr>
</tbody>
</table>

* There were no missing data for this question, as missing responses were interpreted as incorrect. † Scores for intensive care did not differ significantly from the overall mean. † Scores for geriatric medicine and palliative care were significantly higher than the overall mean (P = 0.03 and P < 0.001, respectively). § Scores for geriatric medicine and palliative care were significantly above the overall mean (P < 0.001 and P = 0.03 respectively).

from and the authority of substitute decision makers, and one dealt with both issues. The response options were “true”, “false” or “don’t know”. The second question in the knowledge section involved a scenario asking which of four plausible decision makers had legal authority to make medical decisions for an adult patient without capacity. Participants could score 0–7 correct responses (“don’t know” was counted with incorrect responses).

Practice and experience in end-of-life decision making was measured by asking participants how many WWLST decisions they had been directly involved with as a member of the treating team in the previous 12-month period, including instances when such decisions were considered but treatment was ultimately provided or continued. Participants were also asked how often people (eg, other specialists or nurses) asked them about issues relevant to this area of law, and respondents were presented with the options “never”, “seldom”, “sometimes”, “often” and “very often”.

Statistical analysis

We coded the questionnaires, double-entered the data into an Access database (Microsoft) and transferred the data to SPSS, version 20 (IBM) and SAS, version 9.3 (SAS Institute) for analysis. Preliminary analyses examined descriptive statistics and bivariate associations between categorical variables by χ² tests. Scores were analysed as means with SDs, because only limited distinct scores could be attained but the overall distributions were approximately normal. Formal comparison of mean scores and proportions of responses with particular attitudes were performed using a generalised linear model, incorporating state as a covariable, and assuming a normal distribution for scores or using a logistic model for proportions. Mean scores and proportions for subgroups were compared with the sample average, using the Nelson–Hsu method, within the procedure GENMOD in SAS, which also adjusts for multiple comparisons. We used χ² tests to compare specialties and the frequency of being asked about issues relating to WWLST. A two-sided alpha level of 0.05 was used to define statistical significance.

Results

Response rates

The final sample, after deleting specialists who were not at the contact address or not currently or previously in the relevant discipline, was 2702, and 867 completed questionnaires were returned (response rate, 32%). Fifty-five questionnaires were excluded from this analysis because the respondents did not indicate their main specialty, or indicated a specialty outside the designated groups, which resulted in a net sample of 812.

The response rate of intensivists was 32% (125 from 388) and specialty response rates ranged from 52% (palliative care) to 24% (medical oncologists). A comparison
of respondents with the original AMPCo Direct sample by age, sex, specialty and state found that respondents were similar in most comparison variables, except that there were fewer younger doctors among respondents than in the sample population (Appendix Table S1, online at cicm.org.au/Resources/Publications/Journal).

**Perspectives on law**

Intensivists had the lowest (and therefore most negative) attitude score of all specialties towards the role of law in this area of medicine (Table 1), although the difference from the overall score only approached significance \( P = 0.08 \). In terms of the individual statements comprising this attitude score, the two statements distinguishing intensivists were “the law is out of touch with medical practice” and “the law provides a useful framework for decision-making”, with intensivists much more likely than the overall group to agree or strongly agree with the first statement \( P < 0.001 \) and less likely than the overall group to agree or strongly agree with the second statement \( P = 0.06 \). Intensivists were the only specialty, through these two statements, to have “negative attitudes” towards the role of law that were of, or approached, significance in this item.

By contrast, compared with their attitude to the role of law, intensivists had a more positive attitude to knowing and following the law. They were not significantly different from colleagues in other specialties on this measure (Table 1).

**Knowledge of the law**

IC was the third-best performing of the seven specialties by both mean correct responses to the legal knowledge questions and the proportion of specialists who got four or more of the seven questions correct (this latter score reflecting the traditional pass mark of > 50% correct). Although they performed significantly better than the other six specialties combined, their mean score was still below 3.5 correct (50%), and about 50% of intensivists answered only three or fewer knowledge questions correctly (Table 2).

**Practice and experience of end-of-life decisions and law**

Intensivists recorded the highest mean for decisions about WWLST they were directly involved with in the previous 12 months (Table 3). Twenty-five per cent of intensivists had made more than 50 such decisions during this period.

Intensivists also reported being seen by others as a source of advice for issues relevant to this area of law. Intensivists were more likely than other specialties to report being consulted on this “often” or “very often” by other medical specialties and by nurses (Table 4).

**Discussion**

Intensivists reported that they were a key repository of legal knowledge for medical specialist colleagues and nurses, yet their knowledge of law in this area is limited. Although they performed better than some other specialties, intensivists achieved only a mean result of 50% on the legal knowledge questions. This is of particular concern given our findings that intensivists report that they make decisions about WWLST more frequently than other specialists. Also of concern is their negative attitude towards the role of law in this area, with intensivists more likely than other respondents to regard the law as irrelevant and out of touch with medicine. Interestingly, though, this attitude (relative to other specialties) did not carry through to attitudes about knowing and following the law. This may reflect a pragmatic approach by intensivists who do not like the intrusion that the law makes on clinical practice but nevertheless recognise that the law increasingly affects clinical decisions at the end of life and feel able to navigate that legal landscape and manage its impact on clinical decision making.
These results pose challenges for intensivists, their colleges and societies, and their patients. The law is one part of the environment in which ICU practice occurs, and a failure to engage with it gives rise to risks for doctors and patients. A lack of legal awareness also means the role of the law in providing a framework for resolving intractable disputes may not be used effectively. These risks cannot be managed and potential benefits realised if the law is not known or, even if it is, the attitudes to it mean it is bypassed or not considered.

One response to this is for IC colleges, societies and other professional medical groups to produce IC guidelines about end-of-life care that adopt an educative and legitimising approach to law. A recent example of an educative and legitimising approach is the revised Australian and New Zealand Intensive Care Society Statement on care and decision-making at the end of life for the critically ill.\(^\text{11}\) The Statement contains detailed engagement with law (eg, Chapter 2 is devoted entirely to legal issues) and urges intensivists to be familiar with the relevant law in their jurisdiction. Our survey was undertaken before release of the Statement, and it would be interesting to repeat it to see what impact the Statement may have had on the legal knowledge of intensivists. There are also other national and international IC guidelines that provide instruction on the law and/or make clear the importance of knowing, and being educated about, the relevant legal framework.\(^\text{12-14}\)

For the educative purpose, guidelines should include a statement of relevant law, and that statement needs to be legally accurate and expressed in terms that are accessible and relevant to the decisions that intensivists need to make. Such guidelines should also adopt a position that accepts, and even endorses, that the law has a legitimate role in this area. The law can be seen as a reflection, through parliament, of community values, and it is appropriate that the community has an interest in how these life-and-death decisions are made, and that this is seen to be the case.

This is not to say that the law and its operation cannot be criticised. The medical profession has a vital role to play in advocating for law reform where it believes the law is not working.\(^\text{31}\) But we argue that it is important to recognise the institutional role of law granted by parliaments in this area. We also suggest that the law should be seen by doctors as having some utility as a source of dispute resolution for situations in which conflict has become intractable.

However, even high-quality guidelines can have limited impact on clinical practice.\(^\text{32}\) This points to the need for IC colleges, societies and other professional medical groups to reflect these educative and legitimising approaches to law in their wider engagement with the specialty, including in the implementation and promulgation of such guidelines. One possible action is to attempt to fill gaps in legal knowledge with relevant and ongoing CPD. Recent CPD training in this area of law has been shown to increase knowledge.\(^\text{16}\)

A limitation of our research is the low response rate (32%), which is common to survey research involving doctors, for whom response rates are low and declining.\(^\text{33}\) Non-response bias cannot be ruled out, although comparisons of respondents with the wider sample support their representativeness (Appendix Table S1). Any potential bias in our study may overestimate legal knowledge and underestimate more neutral attitudes to the law, because non-responders are less likely to be legally knowledgeable and less likely to hold strong opinions about the law (whether negative or positive). However, we note that our sample, which included all doctors from the seven specialties most likely to be involved in end-of-life decision making in the three most populous Australian states, is more representative than previous related studies examining

<table>
<thead>
<tr>
<th>Specialty (n)*</th>
<th>Other medical specialists (n = 799)</th>
<th>Interns/residents/registrars (n = 801)</th>
<th>Medical students (n = 797)</th>
<th>Nurses (n = 800)</th>
<th>Patients/families (n = 803)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intensive care (124)</td>
<td>42 (34%)</td>
<td>57 (46%)</td>
<td>32 (26%)</td>
<td>59 (48%)</td>
<td>44 (35%)</td>
</tr>
<tr>
<td>Emergency medicine (267)</td>
<td>36 (14%)</td>
<td>121 (45%)</td>
<td>52 (20%)</td>
<td>87 (33%)</td>
<td>81 (30%)</td>
</tr>
<tr>
<td>Renal medicine (78)</td>
<td>13 (17%)</td>
<td>23 (29%)</td>
<td>7 (9%)</td>
<td>21 (27%)</td>
<td>18 (23%)</td>
</tr>
<tr>
<td>Respiratory medicine (97)</td>
<td>12 (12%)</td>
<td>29 (30%)</td>
<td>11 (11%)</td>
<td>14 (14%)</td>
<td>28 (29%)</td>
</tr>
<tr>
<td>Medical oncology (79)</td>
<td>3 (4%)</td>
<td>15 (19%)</td>
<td>6 (8%)</td>
<td>9 (11%)</td>
<td>18 (23%)</td>
</tr>
<tr>
<td>Geriatric medicine (107)</td>
<td>18 (17%)</td>
<td>53 (50%)</td>
<td>30 (28%)</td>
<td>34 (32%)</td>
<td>44 (41%)</td>
</tr>
<tr>
<td>Palliative care (51)</td>
<td>10 (20%)</td>
<td>32 (63%)</td>
<td>25 (49%)</td>
<td>21 (41%)</td>
<td>22 (43%)</td>
</tr>
<tr>
<td>Overall (803)</td>
<td>134 (17%)</td>
<td>330 (41%)</td>
<td>163 (20%)</td>
<td>245 (31%)</td>
<td>255 (32%)</td>
</tr>
<tr>
<td>(P (\chi^2\ test))</td>
<td>&lt; 0.001</td>
<td>&lt; 0.001</td>
<td>&lt; 0.001</td>
<td>&lt; 0.001</td>
<td>0.025</td>
</tr>
</tbody>
</table>

* Maximum \(n\) for any specialty (varies across columns due to missing responses).
ORIGINAL ARTICLES

Critical Care and Resuscitation • Volume 18 Number 2 • June 2016

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References


Author’s contributions
All authors were responsible for the study concept and design, acquired the data and interpreted it. Ben White and Lindy Willmott drafted the manuscript. Colleen Cartwright, Malcolm Parker and Gail Williams critically revised the manuscript for important intellectual content. Gail Williams and Colleen Cartwright were responsible for the statistical analysis. Ben White and Lindy Willmott supervised the study. All authors read and approved the final manuscript.

Competing interests
Our study was funded by the Australian Research Council Linkage Projects scheme (project no. LP0990329) and the seven guardianship bodies who were partner organisations: New South Wales Civil and Administrative Tribunal, New South Wales Public Guardian, Office of the Public Advocate (Victoria), Victorian Civil and Administrative Tribunal, Queensland Civil and Administrative Tribunal, Office of the Public Guardian (Queensland) and Office of the Public Advocate (Queensland). The Australian Research Council had no further role in the study. The partner organisations also provided in-kind support (as required by the relevant funding scheme) that included assisting in the study design and drafting of the survey instrument. They did not have access to the data, nor were they involved in the interpretation of the data, but they did have an opportunity to comment on an earlier version of this manuscript. All authors are independent of the funders. We have no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years, and no other relationships or activities that could appear to have influenced the submitted work.

Acknowledgements
We thank Mark Eade for his outstanding research and other support.

Conclusions
Intensivists play an integral role in delivering end-of-life care, and self-report as being a leading source of advice for other specialists and health professionals on the law in this area. However, there are significant gaps in their legal knowledge and they are negatively disposed towards the role of the law in their practice. Leadership from within the specialty, particularly through IC guidelines and their active implementation, together with CPD, is needed to ensure that the legal aspects of WWLST are known and considered in decision making to avoid harms to patients and doctors.

law in medical practice. Those studies have generally been drawn from participants in specified training courses or cohorts, specific health facilities or a single specialty and/or society. A final limitation is that our results may not be generalisable to other jurisdictions without comparable law, as the nature of the regulatory framework affects knowledge of and attitudes to it.
Original Articles


