MEDICAL EDUCATION AND LAW: WITHHOLDING/WITHDRAWING TREATMENT FROM ADULTS WITHOUT CAPACITY

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ABSTRACT

BACKGROUND Law is increasingly involved in clinical practice, particularly at the end of life, but undergraduate and postgraduate education in this area remains unsystematic. We hypothesised that attitudes to and knowledge of the law governing withholding/withdrawing life-sustaining treatment from adults without capacity (the WWLST law) would vary and demonstrate deficiencies among medical specialists.

AIMS We investigated perspectives, knowledge and training of medical specialists in the three largest (populations and medical workforces) Australian states, concerning the WWLST law.

METHODS Following expert legal review, specialist focus groups, pre-testing and piloting in each state, seven specialties involved with end-of-life care were surveyed, with a variety of statistical analyses applied to the responses.

RESULTS Respondents supported the need to know and follow the law. There were mixed views about its helpfulness in medical decision-making. Over half the respondents conceded poor knowledge of the law; this was mirrored by critical gaps in knowledge that varied by specialty.

There were relatively low but increasing rates of education from the undergraduate to continuing professional development (CPD) stages. Mean knowledge score did not vary significantly according to undergraduate or immediate postgraduate training, but CPD training, particularly if recent, resulted in greater knowledge. Case-based workshops were the preferred CPD instruction method.

CONCLUSIONS Teaching of current and evolving law should be strengthened across all stages of medical education. This should improve understanding of the role of law, ameliorate ambivalence towards the law, and contribute to more informed deliberation about end-of-life issues with patients and families.

KEY WORDS

education, medical; terminal care; medical law; withholding treatment; decision-making

INTRODUCTION

Doctors play crucial clinical roles in the context of withholding or withdrawing life sustaining treatment from adults without capacity (WWLST), including as legal agents within complex networks of statutory and common law.[1] Knowing the relevant law is necessary for identifying and collaborating with authorised substitute decision-makers when patients' capacity is lost, and determining the existence, validity and applicability of advance care planning documents. Lack of knowledge of the law can have negative consequences, both for patients and doctors.

The legal education of doctors remains uneven and unsystematised, despite significant developments over recent decades.[3] Medical and health law is variously included in, added to, or integrated with streams in medical ethics, professionalism, communication skills and other more recent additions to undergraduate and postgraduate curricula.[4 5 6 7]

When Miles et al described medical ethics education in 1989 as "coming of age", they defined biomedical ethics as "the moral and legal foundations of medicine", and asserted that "Increasing expectations that physicians will be ethically and legally informed have renewed attention to premedical preparation in the liberal arts, communication skills, and possibly, community service".[8] Law was included in the armoury of biomedical ethics, but the latter was christened as the emerging field, and law teaching in medical schools often continues in a subsidiary position.[9] Nevertheless, the 1998 UK *Consensus Statement by teachers of medical ethics and law* [10] placed law on an equal footing with biomedical ethics, and the updated statement of 2010 clearly regards medical law as a crucial component of undergraduate medical education.[11]

Meanwhile, an equivalent Australian consensus statement of 2001[12] (not since updated) focused on ethics with no explicit reference to law. This was despite its authors being

prompted to develop the statement by the Australian Medical Council's goals and objectives of medical education which referred to "knowledge and understanding of the principles of ethics related to health care and the legal responsibilities of the medical profession".[13] The current Australian Medical Council Standards for Assessment and Accreditation of Primary Medical Programs 2012 specify that medical graduates should be able to describe and apply the fundamental legal responsibilities of health professionals, although the list is somewhat restricted.[14]

A 2008 survey showed that health law courses in US medical schools constituted only 0.5% of medical education hours, and that the majority of instructors do not publish research relevant to health law.[4] However, in the UK the recommendations of the 1998 Consensus Statement, though not fully implemented, could be described in 2006 as having had "significant impact".[15]

The extent to which improving medical students' and doctors' legal knowledge improves clinical practice standards is unclear. However, participants in a 2012 Australian study demonstrated strong positive regard for legal instruction, and considered that it helped prepare them for compliance with their legal obligations in practice.[5] There is general agreement concerning the likely benefits of teaching medical law, including a reduction in defensive medical practice,[16] the avoidance of negative legal consequences by practitioners,[17] comprehensive clinical decision-making, and awareness of professional obligations.[11] While it is difficult to establish direct effects, it would also seem likely that better acquaintance with the law would result in better patient and family outcomes, through respect for autonomy and facilitating legally appropriate substitute decision-making.

Law and ethics in the west have increasingly tracked and reflected each other in the medical arena, with significant sharing of conceptual categories, reasonable rather than ideal standards, and a shared theoretical basis and applications of liberal principles.[18 19] This is

certainly the case in the end-of-life field in western jurisdictions. [20 21 22 23] However, clinicians may act in a way that they see to be ethically and professionally appropriate but which conflicts with law.

Little is known about doctors' knowledge of the law in this area. This paper reports on a survey in Queensland, NSW and Victoria (the Australian states with the largest populations and medical workforces) of all specialists from the fields involved decision-making for adults without capacity at the end of life. The research was funded by the Australian Research Council as a Linkage Grant (Project number LP0990329),[2] with seven guardianship offices and tribunals from the three states as research partners. In this paper we provide selected results from the survey, and make recommendations for undergraduate and postgraduate education.

MATERIALS AND METHODS

Ethics

The project was approved by the human research ethics committees at Queensland University of Technology (1100001137), University of Queensland (2011001102) and Southern Cross University (ECN-11-222).

Survey and statistical analysis

Development of the survey instrument was informed by a detailed legal review and checking by legal experts in each state; and focus groups, pre-testing and piloting with specialists in each state. The sample cohort comprised all specialists in emergency, geriatric, palliative, renal and respiratory medicine, intensive care and medical oncology on the Australian Medical Publishing Company Proprietrary Limited Direct database (AMPCo Direct) [24] in the three states at the time of distribution. These specialties were determined to be most likely to

be involved in making the decisions that the survey investigated, on the basis of the relevant literature, interviews carried out in the pre-pilot stage and an analysis of pilot results. Specialists who were sent a survey instrument during the pilot phase were excluded from the main survey. AMPCo Direct administered the distribution of the hard copy survey through the mail.

The survey had 6 sections: doctors' perspectives about the law; education and training received; knowledge of the law; practice of and compliance with the law; experience in making end-of-life decisions; and demographics. Perspective was assessed by two questions, each of 11 statements which participants rated from Strongly Disagree to Strongly Agree, on (i) the role of law in medical practice; and (ii) knowing and following the law. The knowledge section comprised: a question with 6 legal statements, to be rated as True, False or Don't Know about substitute consent requirements under different conditions and some of the legal rules governing validity and implementation of advance directives: possible correct score from 0-6. A second question related to a clinical scenario with respondents asked to identify who would be legally entitled to consent to medical treatment, from four plausible substitute decision-makers. A correct answer to this question scored 1, giving a total knowledge score from 0-7. All questions were worded to reflect the specific legal framework of each State.

Questionnaires were coded and double-entered into an Access database, then transferred to SPSS 20 and SAS 9.3 for analyses.[25] Preliminary analyses included computation of descriptive statistics and chi-squared tests for associations between variables. Comparison of mean scores was performed using a general linear model, assuming a normal distribution for scores. Variables examined as predictors of knowledge were doctors' perception of their knowledge, specialty and continuing professional development training, with adjustments for state, gender, and country of birth. Adjusted mean scores for specialty were compared to the

overall sample average using the Nelson-Hsu method within the procedure GLM in SAS, which also adjusts for multiplicity of comparisons. A Kruskal-Wallis nonparametric test was conducted, comparing the knowledge scores with the responses to the statement that the law is too complex. An exact P-value was calculated using simulations.

RESULTS

The overall response rate was 32% (867) of those contacted (2702 after deletions of uncontactable/ineligible participants); within this overall response, there was a range of specialty/state rates from a high of 75% of palliative care specialists in Victoria to a low of 22% of medical oncologists in NSW. Respondents' gender, specialty, and state closely matched the proportions of these variables in the AMPCo database, but there were proportionately fewer younger respondents than in the database.

Perspectives on the law

Main findings from the first set of statements included: (1) 88% of respondents agreed or strongly agreed (A/SA) that the law has a place in the practice of medicine; and (2) 77% disagreed or strongly disagreed (D/SD) that the law is not relevant to making the kinds of decisions in question. However, other statements were less strongly supported: (3) only 40% A/SA that the law is helpful when making these decisions; 32% D/SD, with 28% not sure (NS) (4) 50% A/SA that following the law can lead to inappropriate treatment decisions; and (5) 60% A/SA that medical and family consensus matters more than the law.

(Table 1 about here)

Palliative care specialists were significantly more likely than others to A/SA with (3) - the law is helpful when making these decisions - (70% compared with 40% overall; χ^2_{12} = 40.329; p <0.001) and to D/SD with (4) (36% compared with 23% overall; χ^2_{12} = 32.01; p

<0.001) and (5) (44% compared with 23% overall; $\chi^2_{12} = 42.458$; p <0.001). Medical oncologists were significantly more likely than other specialists to state that they were NS about statements (3) and (4) (42% and 43% respectively, compared with 28% overall for (3) and 27% overall for (4)).

Main findings from the second set of statements included: A strong majority acknowledged that they should know (97% A/SA) and follow (84% A/SA) the law and that this would help manage legal risk (88% A/SA); 63% A/SA that they worry about legal risk; and 54% A/SA that the law is too complex (33% were NS about this, leaving only 13% who D/SD). Even with the high overall agreement, palliative care specialists were still significantly more likely than others to A/SA that it is important to follow the law (96% compared with 84% overall; $\chi^2_{12} = 21.995$; p = 0.038), and medical oncologists were significantly more likely than others to A/SA (74% compared with 62% overall; $\chi^2_{12} = 28.791$; p = 0.004) that they worry about legal risk.

Knowledge of the law

Doctors' knowledge of the law relating to WWLST shows critical gaps. The mean overall correct knowledge score for the set of six questions was 3.26/6. The Kruskal-Wallis nonparametric test comparing the knowledge scores with the responses across the 3 collapsed categories (A/SA, Neither Agree nor Disagree, D/SD) for the statement that the law is too complex, showed significant variation in scores (P = 0.027) with those who A/SA having higher knowledge scores than the other two groups which did not differ between themselves. Sixty-one percent of respondents acknowledged having very little or only some knowledge of the relevant law. Palliative care specialists (66%) and geriatricians (57%) claimed to have moderate or considerable knowledge. While perceptions about knowledge are not evidence

for it, there was a highly significant and linear association between doctors' perceptions and their actual knowledge of the law in this study, when correct scores/7 (for the six True/False/Don't know questions and the scenario) were compared with self-perceived knowledge (Table 2, $r^2 = 0.047$, $P < 0.0001$), which remained after adjusting for state, specialty, gender and country of birth ($P < 0.0001$).

(Table 2 about here)

Knowledge scores/7 also varied significantly by specialty (Table 3). After adjustment for state, gender and country of birth, specialists in geriatric medicine had significantly higher scores than the overall average (3.71 compared with 3.28 overall – unadjusted; $p < 0.001$), and specialists in emergency medicine (2.95), medical oncology (2.94) and respiratory medicine (2.60) had significantly lower scores than average. Specialists in palliative care also had higher than average knowledge and specialists in intensive care lower than average knowledge but these groups were relatively small and differences were of borderline significance.

(Table 3 about here)

Education and training

Only 32% of respondents stated that they had received instruction in the law relating to withdrawing and withholding treatment from adults lacking capacity at undergraduate level. The figures were higher for postgraduate training (50%) – defined in the survey as that "received during intern and early postgraduate years as well as vocational training in a chosen specialty" - and for Continuing Professional Development (CPD) (60%). A majority of those who had received training at any time found it helpful (H) or very helpful (VH), and more found CPD training H/VH (86%), with palliative care specialists significantly more likely to fall into this category than the other groups (98% compared with 86% overall; $\chi^2_6 = 16.10$; $p = 0.01$).

Mean knowledge score did not vary significantly according to whether participants received training or not in their undergraduate degree or in the immediate postgraduate period, but doctors who had received CPD training had greater knowledge than those who had not, and the association between knowledge and recency of training was significant and linear (Table 4, r^2= 0.019, P =0.007 for linear trend in mean scores, after adjusting for state, specialty, gender and country of birth).

(Table 4 about here)

Respondents indicated their preferences for CPD training in the relevant law from 1-3, from a list of possible methods. The majority (72%) selected workshops based on case studies as one of their top three preferred methods for CPD. Support for other methods of training included: online resources (56%); a manual containing the law on key issues (41%); conferences and seminars (41%); lectures/grand-rounds (37%); articles in medical journals (35%); and clinical training (34%) (percentages do not add to 100% as each option was independently rated). Respondents reported being asked about the law in this area often or very often by hospital medical staff (40%), nursing staff (30%) and medical students (20%), as well as by patients and families (31%).

DISCUSSION

While less than ideal, the overall response rate of 32%. This is consistent with findings that doctors' response rates to surveys are low and are declining.[26 27] There was strong congruity between proportions of demographic and specialty variables in the respondent sample and the originating database, limiting the risk that low representativeness in the sample has confounded the results. The likelihood that a proportion of respondents were motivated to participate by an interest in the topic and associated knowledge could mean that if the results are skewed, it may be in the direction of underestimating the gaps in knowledge across the broader populations of doctors. Our results demonstrate that while doctors generally

recognise that they should know and follow the law governing end-of-life care, they do not see it as an overriding factor in decision-making, with half the participants considering that the law can lead to inappropriate treatment decisions, and almost two thirds seeing medical and family consensus as more important than law. They consider that knowledge would help manage legal risk, but their knowledge shows critical gaps and differences in knowledge across specialties. Even those with high knowledge levels are twice as likely to agree as to disagree that the law is too complex. Undergraduate and immediate postgraduate training did not affect knowledge, but CPD training, particularly if recent, was associated with greater knowledge. Any training was perceived as helpful, but CPD training is seen as the most helpful.

Not surprisingly, as a largely autonomous profession medicine has, to some extent, resisted the increasing influence on practice of statutes and common law decisions, cleaving to what it perceives as its own ethical/professional standards. It has been suggested that it has also sometimes encouraged negative attitudes towards law in students,[9] via the hidden educational curriculum,[28] and sometimes more overtly. Our results, including perceptions on the helpfulness of the law, the inappropriateness of decisions resulting from following the law, and the preference for medical and family consensus over the law, reflect this continuing trend.

Some of the authors have observed elsewhere the complexities of the law in this field including unhelpful cross-jurisdictional inconsistencies, and the need for the law to be reformed.[29] The current state of the law is no doubt a barrier for doctors seeking to know it. However, ignorance of relevant law can result in the denial of patients' rights which reflect community values as expressed through Parliament and the courts. Better knowledge of the law should increase respect for patient autonomy, through complying with advance directives and seeking consent from authorised substitute decision-makers. Ignorance of the law can

also push doctors towards more defensive and unnecessary practices.[16] While the law may be challenged on ethical grounds, and doctors may not always agree with the law that governs their practice, doctors should know the relevant law and its rationale, including the legal consequences of acting contrary to the law. The best way of achieving both better recognition of patient rights and a mature but critical respect for the law is by teaching that integrates ethical, professional and legal perspectives at all stages.

Given that significant minorities of doctors report being asked about the law by medical and nursing staff, students, patients and families, improved knowledge of the law would also contribute to more efficient deliberation and education about the difficult issues and conflicts that arise. Although health care is increasingly delivered by teams, doctors continue to carry greater legal responsibility for the decisions considered here, and responsibility to their student colleagues and others to provide accurate information and advice.

Our results do not unequivocally demonstrate deficiencies specific to particular specialties amongst those surveyed in relation to attitudes towards the law. Nevertheless, results such as the significant differences in some response rates, the higher commitment to following the law on the part of palliative specialists, the significant association between doctors' perceptions and their actual knowledge of the law, and the significant knowledge differences between geriatric and palliative specialists (higher) and medical oncology, emergency and respiratory specialists (lower), raise tantalising questions that merit further research.

Knowledge of the role of law in areas of clinical practice such as the end of life should be a routine, comprehensive aspect of all stages of medical education.[30] Each stage of instruction would support the next, and subsequent stages would reinforce the conceptual and practical attainments of earlier ones.

Undergraduate training in ethical and legal principles at the end of life, within a wider framework of integrated coursework in medical ethics and law, should be provided by

medical schools, required by their accrediting bodies, and supported by medical deans' groups and professional teaching associations. On-the-job and/or quarantined training for junior hospital doctors should include review of the ethical and legal fundamentals, with application in the practical setting, under the leadership of specialist consultants with suitably qualified legal contribution.

Specialist colleges whose members are involved with end-of-life decision-making should require the inclusion of legal components in CPD programs on a regular, cycling basis. Against the background of formal undergraduate training as suggested above, CPD would be more soundly based and effective, but it should also be more systematised, consistent with the learning preferences that emerged in this study.

CONCLUSIONS

We surveyed a range of selected specialists' knowledge and perspectives concerning the law governing WWLST, in three Australian states. Respondents demonstrated somewhat ambivalent attitudes towards the role of law in this area, as well as critical gaps in knowledge of the law.

Law is an integral component of clinical practice concerning WWLST, but this can be generalised to other aspects of end-of-life care, and beyond that to almost every aspect of clinical practice. In the context of continuing inadequacies and variations in undergraduate and postgraduate instruction in medical law, our results point to the need for increased efforts to strengthen and formalise teaching and learning formats that provide comprehensive coverage of existing law and changes over time. Accurate knowledge of the law is one of the requirements to ensure good medical practice and the protection of human rights at the end of life.

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- The Public Guardian (NSW)
- Queensland Civil and Administrative Tribunal
- Office of the Adult Guardian (Qld) (now the Office of the Public Guardian (Qld))
- Office of the Public Advocate (Qld)

TABLES

Table 1

Extent of Agreement with Q1 Statements re Perspectives on the Law: % (n)

Q1	Statement	N	SD/D	NS	A/SA	MEAN/3 & SD
1	The law has a place in the practice of medicine	857	4 (37)	8 (65)	88 (755)	2.84 (0.47)
2	The law is not relevant to making these decisions	857	77 (659)	8 (72)	15 (126)	1.38 (0.73)
3	The law is helpful when making these decisions	854	32 (272)	28 (238)	40 (344)	2.08 (0.85)
4	Following the law can lead to inappropriate treatment decisions	859	23 (194)	27 (231)	50 (434)	2.28 (0.81)
5	Medical and family consensus matters more than the law	860	23 (198)	17 (144)	60 (518)	2.37 (0.83)

SD/D: strongly disagree/disagree; NS: not sure; A/SA: agree/strongly agree; SD – standard deviation

Table 2

Association between doctors' perceptions and actual knowledge of law (scores 4/7 or above)

Perception of Knowledge of Law	N	Mean correct score/7	SD of correct score	Percent correct score ≥ 4	Mean score adjusted for state, specialty, gender and country of birth (95% CI)
Very Little	136	2.83	1.24	28.7	2.88 (2.64-3.11)
Some	330	3.15	1.21	39.1	3.09 (2.92-3.27)
Moderate	258	3.42	1.39	45.3	3.35 (3.14-3.55)
Considerable	42	4.14	1.34	71.4	4.06 (3.67-4.46)
TOTAL	766	3.24	1.32	41.1	

SD – standard deviation; CI: confidence interval

Table 3
Knowledge scores by specialty (scores of 4/7 or above)

Specialty	N	Mean correct score/7	SD of correct score	Percent correct score ≥ 4	Mean score adjusted for state, gender and country of birth (95% CI)
Geriatric Medicine	107	3.89	1.28	57.0	3.71 (3.45-3.96)
Palliative Medicine	52	3.71	1.49	51.9	3.57 (3.22-3.93)
Intensive Care	125	3.48	1.35	50.4	3.43 (3.18-3.67)
Renal Medicine	80	3.37	1.13	46.3	3.24 (2.95-3.53)
Emergency Medicine	270	3.09	1.27	38.1	2.95 (2.77-3.14)
Medical Oncology	80	3.07	1.23	36.2	2.94 (2.65-3.27)
Respiratory Medicine	98	2.72	1.34	25.5	2.60 (2.32-2.88)
TOTAL	812	3.28	1.33	42.5	

SD – standard deviation; CI: confidence interval

Table 4

Knowledge scores by receipt and recency of training (scores of 4/7 or above)

CPD Training	N	Mean correct score/7	SD of correct score	Percent correct score ≥ 4	Mean score adjusted for state, specialty, gender and country of birth (95% CI)
None	343	3.07	1.37	36.7	3.10 (2.92-3.28)
5 or more years ago	107	3.30	1.26	43.0	3.22 (2.95-3.49)
3-4 years ago	132	3.33	1.32	44.7	3.17 (2.93-3.42)
1-2 years ago	143	3.36	1.25	44.1	3.33 (3.09-3.56)
Within last year	126	3.60	1.30	53.2	3.46 (3.21-3.72)
TOTAL	851	3.27	1.33	42.4	

SD – standard deviation; CI: confidence interval