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**Doctors' perspectives on law and life-sustaining treatment: survey
design and recruitment strategies for a challenging cohort**

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Abstract

Background: Palliative medicine and other specialists play significant legal roles in decisions to withhold and withdraw life-sustaining treatment at the end of life. Yet little is known about their knowledge of or attitudes to the law, and the role they think it should play in medical practice. Consideration of doctors' views is critical to optimising patient outcomes at the end of life. However, doctors are difficult to engage as participants in empirical research, presenting challenges for researchers seeking to understand doctors' experiences and perspectives.

Aims: To determine how to engage doctors involved in end-of-life care in empirical research about knowledge of the law and the role it plays in medical practice at the end of life.

Methods: Postal survey of all specialists in palliative medicine, emergency medicine, geriatric medicine, intensive care, medical oncology, renal medicine and respiratory medicine in three Australian States: New South Wales, Victoria and Queensland. The survey was sent in hard copy with two reminders and a follow up reminder letter was also sent to the directors of hospital emergency departments. Awareness was further promoted through engagement with the relevant medical colleges and publications in professional journals; various incentives to respond were also used. The key measure is the response rate of doctors to the survey.

Results: Thirty-two percent of doctors in the main study completed their survey with response rate by specialty ranging from 52% (palliative care) to 24% (medical oncology). This overall response rate was twice that of the reweighted pilot study (16%).

Conclusions: Doctors remain a difficult cohort to engage in survey research but strategic recruitment efforts can be effective in increasing response rate. Collaboration with doctors and their professional bodies in both the development of the survey instrument and recruitment of participants is essential.

Keywords: Survey Methods; Respondents; Empirical Research; End of Life Care; Law

Introduction

Decisions about withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity are made frequently in the practice of palliative medicine. Palliative medicine specialists (and other specialists who practise in the end-of-life field) play a critical clinical role in decision-making about end-of-life treatment. However, it is less frequently acknowledged that such specialists also have significant legal roles. A doctor may be required to assess a patient's capacity to make treatment decisions, to identify the legal decision-maker if the patient does not have capacity, and to determine whether previously-expressed wishes comprise a valid advance directive that must be followed. Empirical research is needed to understand properly the important legal role that doctors play in end-of-life decision-making.

Yet doctors are difficult to engage in health and socio-legal research, presenting considerable systemic challenges for researchers. Doctors' response rates to surveys are low and are declining.^{1,2} Flanigan, McFarlane and Cook attribute poor response rates to doctors' demanding workloads, too frequent requests to participate in research, and clinic staff acting as "gatekeepers" to shield time-poor practitioners from impositions on their time.³ Other contributing factors to nonresponse are the perceived value of the research, the length of the survey, confidentiality concerns and whether survey questions enable a choice of responses, or seem biased.^{1,4} Low response rates to surveys may result in nonresponse bias.¹

These challenges confronted our research team as we undertook the first empirical study in Australia which examined doctors' knowledge of the law and the role it plays in

medical practice at the end of life. Our survey was administered to palliative medicine and other specialists most likely to be involved in end-of-life decision-making in three Australian States: Victoria, New South Wales and Queensland. These jurisdictions are home to 77% of all Australian doctors⁵ and have key similarities and differences in the law relating to end-of-life decision-making.

This research revealed that doctors, including palliative care specialists, have significant knowledge gaps about the law in this field.^{16,17} The goal of this paper, however, is not to report on the overall results of the research, but rather to reflect on the relatively low participation rate in this research by doctors, notwithstanding the extensive recruitment strategies used. This paper reports on our methodology designed to maximise doctors' participation, including careful consideration of the design and mode of administration of the survey instrument, determination of the sample cohort, and tailored recruitment strategies.

Methods

Developing the survey instrument

The survey instrument was developed through a two-year process that included legal research and analysis, focus groups, and pre-testing and piloting the instrument.

Stage 1: Legal research and analysis

A review and critique of the law and associated literature concerning withholding and withdrawing life-sustaining treatment (WWLST) from adults who lack capacity revealed that the law in the three states is complex and uncertain, which could limit

doctors' legal knowledge. Three papers explaining state differences were published at the start of the study.⁶⁻⁸

Stage 2: Focus groups

Following ethics approval from the researchers' three university Human Research Ethics Committees, a focus group in each state explored the legal role doctors play in end-of-life decisions. A hypothetical case scenario (tailored for the different legal regimes in each state) was used to examine:

- doctors' legal knowledge;
- the effect of doctors' legal knowledge on medical practice;
- whether doctors think it is important to know the law;
- the interaction between law, ethics and clinical practice; and
- doctors' views on the adequacy of educational resources and training in this area of law, and future training needs.

Convenience sampling was used to invite focus group participants from surgery, oncology, palliative care, intensive care, emergency, neurology, anaesthesiology, and general practice: specialties commonly involved in end-of-life decision-making. A thematic analysis of focus groups revealed deficits in doctors' knowledge of the WWLST law. Participants also gave views on the law at end of life, and the most appropriate methods for educating and training doctors about law. The thematic analysis of these focus groups informed the survey design. Feedback was also sought from partner organisations (guardianship bodies) and academic colleagues.

Stage 3: Pre-testing the survey instrument

Pre-testing of the survey instrument occurred over a six-month period. Participants were asked to complete the draft survey instrument and provide written feedback on format, question and instruction clarity, wording, content, appropriateness of questions and length. They were also asked to nominate the specialties most likely to be involved in decisions to WWLST from adults who lack capacity. Specialists in intensive care (including anaesthesiology), emergency, palliative care, haematology, surgery, geriatric medicine, oncology and renal medicine, plus general practitioners, provided feedback via email, letter or interviews. Leading legal experts also tested the instrument to confirm the accuracy and wording of legal questions and the correct answers. Feedback was also sought from academics with survey expertise and partner organisations about content, format and readability.

The pre-testing feedback was used to revise the instrument and inform decisions about which specialties to include in the pilot survey.

Stage 4: Piloting the survey

The survey was piloted with doctors from the three states (see below for discussion of sample and administration mode). The response rate to the pilot survey (26%) was lower than anticipated. Reweighting by specialty to reflect the proposed sample cohort for the main survey, taking account of oversampling of some specialties in the pilot, suggested a likely response for the main survey of only 16%. These results are examined in further detail later in the article.

In order to improve the response rate for the main survey, the length of the instrument was reduced from 13 to six pages, wording and formatting were changed to improve readability, a graphic designer was engaged to improve the survey's format and aesthetics, the sample cohort was reduced, and considerable effort was made to engage the various specialty groups.

Establishing the sample cohort

Feedback from focus group and pre-pilot participants, and a review of literature revealed that doctors specialising in intensive care, medical oncology, emergency, palliative, respiratory (thoracic), renal and geriatric medicine were most often involved in end-of-life decisions.^{9,10} General practitioners were ultimately excluded because the literature suggested they have less involvement in end-of-life decision-making than doctors practising in the acute setting.^{10,11} In addition, pre-testing revealed challenges designing a survey with case studies relevant to both acute and primary care settings. Anaesthetists and surgeons were also excluded from the sample as neither the literature nor the pre-pilot feedback identified them as frequently being involved in decision-making at end of life. Specialists in intensive care, medical oncology, emergency, palliative, respiratory (thoracic), renal, geriatric and general medicine were included in the pilot survey.

Of note in the pilot was the response rate of general physicians which was only 6%, the lowest of all specialties surveyed. Due to their poor response rate, and concerns about the extent to which end-of-life decision-making is central to the diverse practice of general physicians, they were removed from the study. The remaining seven specialities

comprised the main survey sample cohort. The survey was sent to all doctors from these specialties in the three states, excluding those surveyed in the pilot phase.

Recruitment Strategies

The challenges of engaging doctors in survey research are well documented and underline the need for targeted strategies to maximise response rates.¹ The disappointing response rate to the pilot raised concerns that a similarly poor response rate in the main survey would affect the validity of the study and introduce bias.¹ Accordingly, the researchers employed a range of recruitment strategies relating to survey administration, incentives, and engagement with the medical profession, implemented prior to the initial mail out, to maximise participation. Further strategies were timed to coincide with the first and second reminder mail outs.

Mechanics of survey administration and design

Mode of administration

Prior to disseminating the pilot survey, literature reviews were conducted to explore the effect of three modes of survey administration – web (online), mail (hardcopy) and a mixed-mode approach (combining web and hardcopy) – on doctor response rates, data integrity and quality. Findings indicated that doctors prefer surveys in hardcopy rather than online, but there is also some suggestion that mixed-mode may further increase response rates.^{1,12,13} The researchers opted for a postal survey but decided against additionally making the survey available online. In the absence of clear support from the literature that mixed-mode significantly improves response rates with doctors, we considered the additional cost and time involved in that strategy was not warranted.

Commercial database

AMPCo Direct (AMPCo), a subsidiary of the Australian Medical Association, was engaged to administer the survey mail-out across the three jurisdictions. AMPCo had more than 60,000 Australian doctors in its commercial database which could be accessed according to jurisdiction and speciality and this database has been used in other major studies of Australian doctors.¹³ Engaging AMPCo also established a “firewall” between the researchers and potential participants, thereby strengthening identity protection.

Tailored design of the survey package

The contents of the survey package were designed to enhance participation. To distinguish the survey from commercial mail outs and “junk mail”, the invitation letters to participants were printed on Queensland University of Technology (QUT) letterhead, and the survey package posted in QUT envelopes.

Following the pilot survey, a graphic designer professionally designed and formatted the survey, using vivid colours for each state to render them more professional and aesthetically pleasing and likely to motivate responses. Positive feedback about the survey design was received from some participants in their verbatim comments.

Incentives

Material incentives

Previous studies indicate that offering incentives, particularly monetary incentives, results in higher doctor response rates.¹ Feedback was received from a pre-pilot participant that offering a chance to win a high quality bottle of aged wine as a prize for participation would be attractive to some doctors. Accordingly, participants were offered the opportunity to enter into a prize draw to win one of six bottles of 1996 Penfolds Grange Shiraz.

Continuing medical education points

The three relevant Colleges for participating specialties – the Royal Australasian College of Physicians (RACP), the Australasian College of Emergency Medicine (ACEM) and the College of Intensive Care Medicine of Australia and New Zealand (CICM) – approved allocation of Continuing Medical Education (CME) or Continuing Professional Development (CPD) points to Fellows who completed the survey.

Education materials

Participants were advised if they completed the survey and returned their reply paid card they would receive educational materials containing answers to the survey's case studies and true/false questions, relevant to each participant's jurisdiction following closure of the main survey. Additional resources about the law were also made available via the study's webpage.

Engagement with the medical profession

Support of professional colleges and societies

To enhance doctors' awareness of the study we sought the assistance of the RACP, ACEM, CICM, and the specialty societies for each specialty (except emergency medicine given the ACEM's agreement to assist). The colleges and societies were asked to advise their Fellows and members about the survey by way of email or by placing a short article about the study in their newsletter or ebulletin. We also offered to support their Fellows and members in knowing more about the law by sharing the findings of our research, and providing education on the relevant legal frameworks.

All colleges and societies agreed to these requests. Short articles about the study were published in the RACP's Adult Medicine Division e-news bulletin and the CICM ebulletin, while the ACEM circulated emails (tailored to each state) to emergency physicians. Each specialty society also advised their members about the survey by email and the Australian and New Zealand Intensive Care Society's Clinical Trials Group also electronically notified members of the study. All of these communications coincided with the initial survey mail out.

Articles in professional journals

To further enhance doctors' awareness of the study, we wrote and published two articles in the professional journals of emergency specialists and internal medicine specialists about the study, and why legal knowledge in this field matters for doctors.^{14,15} These articles were published to coincide with the first and second reminder mail outs and were enclosed in the second reminder mail out package.

Emergency physicians

Only 17% of emergency physicians responded to the pilot survey. This raised concerns about how to encourage their participation in the main survey, given that emergency medicine is the largest of the study's seven specialties, constituting half of the main survey sample. Continued low response rates from this specialty would significantly affect the overall response rate.

We therefore devised additional recruitment strategies for emergency physicians. A modified invitation letter was included in their survey package emphasising the importance of their views to the study. Further, as noted above, an article about the research and the significant role emergency physicians' play in end-of-life decisions was published in *Emergency Medicine Australasia*.¹⁵ Other recruitment strategies for emergency physicians were undertaken prior to the second reminder mail out, and are discussed below.

Conferences

To further raise awareness about the survey, we presented the pilot results and information about the study at two international conferences and a seminar.

Additional strategies following initial mail out

An assessment of response rates by state and specialty after the initial mail-out found that emergency physicians' response rate was the lowest, by almost 10%, demonstrating little improvement on the pilot response rate. Responses for intensive care specialists

were also very low. Accordingly, we employed the following additional recruitment strategies for these doctors.

Emails through the Colleges

The ACEM and CICM were again requested to email Fellows, advising them of the closing date of the survey, and encouraging their participation. The ACEM agreed and sent further emails (tailored to each state).

Letters to Emergency Department Directors

Prior to the second reminder mail out, a personally signed, individually addressed letter was sent to Directors of emergency departments in public and private hospitals in each jurisdiction requesting their assistance in advising colleagues about the survey. Enclosed in the letters were a copy of the survey and the editorial published in *Emergency Medicine Australasia*, as well as an A3 size poster about the survey which could be placed in the Emergency Unit's staff room or other appropriate place.

We targeted 129 major public hospitals with emergency departments in Victoria, New South Wales and Queensland that were listed on the Australian Government's MyHospitals website (www.myhospitals.gov.au). Hospitals outside the scope of the survey (for example children's and psychiatric hospitals) were not included. In addition, we wrote to 15 private hospitals in the three states whose performance data on the MyHospitals website indicated that they would likely have larger concentrations of emergency specialists. In order to personally address the letters, we contacted each Hospital's emergency department by telephone to obtain the name of their Director.

Administration of the pilot and main surveys

The pilot survey was sent to 267 doctors from eight specialties across the three jurisdictions. Thirty-six doctors from each specialty (12 from each state) were invited to participate. Due to the underrepresentation of palliative medicine physicians by comparison to the other specialties, only 15 such physicians (five from each state) were selected for the pilot. Two reminder mail outs were sent to doctors who did not respond.

For the main survey, 2858 doctors across the seven specialties were invited to participate. This cohort comprised all doctors (apart from those in the pilot sample) practising in the three states who self-identified to AMPCo that their primary discipline was one of the seven selected specialties. As for the pilot, two reminder mail outs were sent to non-responding doctors.

In both the pilot and main surveys, participants were provided with a survey package containing:

- a letter inviting them to complete the survey (in the main survey, emergency physicians received a tailored letter);
- a survey;
- a Participant Information Sheet, detailing information about the project and ethics approval;
- a reply paid envelope for return of the completed survey (addressed to AMPCo); and

- a reply paid response card with the doctor's unique identifier (addressed to AMPCo) to enable participants to (a) be sent an education package at the conclusion of the survey, (b) be entered into the draw to win the wine, and (c) to prevent receipt of reminder mail outs.

The invitation letter was slightly altered for both of the reminder mail outs to include an "important note" box at the start of the letter advising the recipient that they had previously been sent a survey, and requesting that they complete it.

For the main survey, the back page was marked with a small letter 'A' (for the first reminder mail out) or a small letter 'B' (for the second reminder mail out) to enable identification of the mail out from which each completed survey originated, to allow assessment of response rates per mail out. The survey package for the final reminder also contained a "with compliments slip" attaching a copy of either the *Emergency Medicine Australasia* article (forwarded to emergency physicians), or the *Internal Medicine Journal* article (for the other six specialties).

The survey packages were compiled and sent by AMPCo. The invitation letters were also printed by AMPCo to enable insertion of participant's names and addresses from the AMPCo database, and to protect the identity of participants from the research team. Completed surveys were returned anonymously to AMPCo where they were date stamped but not opened, and then couriered to the researchers at QUT. "Return to Sender" surveys were received directly by researchers at QUT.

Results

Response rates

Pilot survey

Of the 267 surveys sent, nine “Return to Sender” surveys were received, leaving a total of 258 valid surveys. From these 258, 67 responses were received. This was a “raw” response rate of 26%; reweighting by specialty suggested a likely response rate of 16% for our main survey cohort. Sixty-six percent of responses were from the initial mail out, 25% from the first reminder mail out and the remaining 9% from the second reminder.

Main survey

The final denominator for the sample was 2702 doctors (excluding ineligible responses and surveys returned to sender). A total of 867 valid surveys were received, an overall response rate of 32%. Of those responses, 65.5% were from the initial mail out, 21.7% from the first reminder and the remaining 12.7% from the second reminder. The response rate for the initial mail out is consistent with the pilot survey, with a lower response rate for the first reminder but a slight improvement on the second reminder.

Table 1 provides a comparison of the response rates from the pilot survey and main survey based on self-reported specialty. As seen in Table 1, there was an increased response rate for all specialties except palliative medicine, which had an increased response rate in Queensland and Victoria but a significant decrease in New South Wales. The most notable increase overall was for oncologists, which increased from 8% in the pilot to 24% for the main survey. Other notable changes included an increase

among geriatricians in Queensland (from 33% to 62%) and an increase among renal physicians in New South Wales (from 17% to 31%) but a corresponding decrease for this group in Queensland (from 42% to 28%).

Looking at the main survey sample and comparing respondents to the AMPCo sample as a whole, respondents were similar on most comparison variables except that there were fewer younger doctors among respondents, particularly in relation to emergency medicine, intensive care and renal physicians.

Discussion

Despite the challenges in attracting participation in surveys, the total response rate to the main survey was double that predicted by the pilot (32% compared to 16% in the pilot when reweighted by specialty). These results were particularly encouraging given the diversity of the population surveyed, across both urban and rural regions, in Australia's three largest medical jurisdictions. Overall the survey was positively received by participants, many of whom acknowledged the importance of research in this area, and welcomed the opportunity to participate. We believe that the methods employed to design the survey instrument and recruit participants were integral in maximising response rate.

Developing the survey was not without its challenges, the greatest of which was enlisting doctors to participate in the focus groups and pre-testing. The primary reason cited by invitees for non-participation was lack of availability, while last minute cancellations also occurred due to some participants being "on call". Doctor

participation in the pilot survey was also lower than anticipated. Our experience suggests that lack of time to participate in research continues to be a critical issue for doctors.³

We believe the recruitment strategies employed for the main survey significantly contributed to the improved response rate. In particular, collaborating with the colleges and specialty societies to raise awareness about the survey and improve doctors' perceptions of credibility and relevance of the research seemed to be well received by the target cohort. Use of professional avenues to communicate with specialists was particularly beneficial in capturing a large cohort of doctors who may otherwise have chosen not to complete the survey.

The timing of the colleges' and societies' communications about the survey was also critical. By sending emails and news bulletins about the research immediately prior to survey dissemination, doctors were alerted to the survey's existence and could anticipate its arrival. Further promotion occurred through publishing articles in targeted journals, timed to coincide with the second reminder mail out. Offering incentives, particularly the opportunity to win a bottle of Penfolds Grange Shiraz and CME/CPD incentives, may also have motivated doctors to participate.

It is difficult to assess whether, and to what extent, the techniques used were individually successful (e.g., administering hard copy surveys as opposed to a mixed-mode approach). However, queries were received from some doctors about whether the

survey was available online, indicating a preference, at least for these doctors, for alternative options of survey completion.

A further challenge for a postal survey was reaching potential participants, as approximately 5% of the overall sample was “Return to Sender”. The most common reason specified on the envelope for being returned was “not at this address”, followed by “no longer at this hospital”, or other comments indicating the doctor had left the hospital or department/unit. This factor suggests the transient nature of a proportion of medical specialists, and the high level of doctor movement between hospitals and health settings.

Personally contacting the Directors of emergency departments also appears not to have been as successful as the other strategies as the response rate of emergency physicians to the second reminder remained comparable to the rest of the sample, and there was only a 8% increase in total response rate for the main survey over the pilot survey.

Our final results showed that palliative care specialists had the highest overall response rate of the seven specialties in both the pilot and main surveys (67% and 52% respectively), while medical oncologists had the lowest overall response rate (8% and 24%), followed by emergency physicians (17% and 25%). The reasons for the difficulties in engaging these groups in particular are unknown. However, their results were disappointing, given our understanding of the frequency with which these specialties are involved in WWLST from adults who lack capacity, and the tailored recruitment strategies employed to promote the response rate for emergency physicians.

Conclusion

The final results of the study, though a considerable improvement on the pilot revealed that, consistent with the findings of previous studies, doctors, including palliative care specialists, remain a challenging cohort to engage in health and socio-legal research. However, understanding their perspectives on complex and sensitive areas of medical practice, including WWLST from adults who lack capacity, is vital to optimising patient outcomes by improving the law, health policy and clinical practice. Best practice for doctor engagement in survey research therefore warrants further exploration in future methodological studies.

Over the course of this project we dedicated significant time and resources to designing our survey instrument, and to devising targeted recruitment strategies. From this experience, we conclude that engagement and collaboration with doctors and their professional bodies in the design of survey research, the subject matter of the research, and in recruiting participants, is critical to improving participation. We recommend that those seeking to engage palliative care specialists and other doctors in socio-legal survey research consider adopting the following strategies to achieve maximum participation:

- (1) Engage and collaborate with doctors' professional bodies to raise awareness of the research among their membership;
- (2) Offer a range of material and non-material incentives tailored to participants;

- (3) Promote the research through publication of articles in widely circulated professional journals; and
- (4) Collaborate with doctors in the design of the survey instrument, and undertake pre-testing and pilot testing to refine it.

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Table

Table 1: Response rates by state based on self-reported specialty: pilot survey and main survey

	New South Wales		Queensland		Victoria		Total	
	Pilot	Main	Pilot	Main	Pilot	Main	Pilot	Main
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Emergency medicine	17	26	8	25	25	24	17	25
General medicine	0	n/a	17	n/a	0	n/a	6	n/a
Geriatric medicine	33	42	33	62	42	37	36	43
Intensive care	8	26	33	37	25	37	22	32
Medical oncology	8	22	8	28	8	24	8	24
Palliative care	80	33	60	67	60	75	67	52
Renal medicine	17	31	42	28	33	35	31	32
Respiratory medicine	17	24	33	35	25	35	25	30
Other or unspecified	n/a	5 [†]	n/a	9 [†]	n/a	6 [†]	n/a	6 [†]

[†]Note: The percentage given for 'other or unspecified' is not a response rate (as this cannot be calculated) but the percentage this group represented in the overall responses from those states.

Acronyms and abbreviations used

- ACEM – The Australasian College of Emergency Medicine
- AMPCo – Australian Medical Publishing Company Direct (AMPCo Direct)
- CICM – The College of Intensive Care Medicine of Australia and New Zealand
- CME – Continuing Medical Education
- CPD – Continuing Professional Development
- QUT – Queensland University of Technology
- RACP – Royal Australasian College of Physicians
- WWLSMT – withholding and withdrawing life-sustaining treatment