

FUTILITY AND THE LAW: KNOWLEDGE, PRACTICE AND ATTITUDES OF DOCTORS IN END OF LIFE CARE

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Despite the potential harm to patients (and others) and the financial cost of providing futile treatment at the end of life, this practice occurs. This article reports on empirical research undertaken in Queensland that explores doctors' perceptions about the law that governs futile treatment at the end of life, and the role it plays in medical practice. The findings reveal that doctors have poor knowledge of their legal obligations and powers when making decisions about withholding or withdrawing futile treatment at the end of life; their attitudes towards the law were largely negative; and the law affected their clinical practice and had or would cause them to provide futile treatment.

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I INTRODUCTION

Futile treatment, which is treatment that brings no benefit to a patient,¹ is a concerning issue in end of life care. Research from other countries suggests that dying patients receive futile treatment for a number of reasons, including fear of legal liability, and disputes between the patient or family and doctors over whether active treatment should continue.² The provision of futile treatment is problematic because it does not benefit a patient, can cause harm through unnecessary pain or discomfort and can prevent a ‘good death’.³ The provision of futile treatment can also cause distress to families and treating health professionals.⁴ Doctors play a critical role in making decisions about whether or not to persist with treatment that is futile.⁵ When doctors make decisions about whether or not to withhold or withdraw treatment at the end of life, they do so, knowingly or unknowingly, within a broader regulatory framework of laws and policies.

Despite the adverse outcomes associated with futile treatment, there has been no empirical research in Australia investigating why doctors provide such treatment, including the role the complex legal environment plays in their decisions to provide it. The extent to which doctors are aware of or are influenced by the law on futile treatment in the course of their clinical practice is not clear. A recent large-scale survey suggests that doctors lack accurate knowledge about the law on withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity.⁶ One of the aims of this research is to explore doctors’ understanding of the law that governs the provision of futile treatment at the end of life, and whether they believe it will support them in their decision-making.

The research findings reported in this article form part of a larger project, which explores how doctors understand futile treatment, why and how often they provide it (including the impact of laws and policies), and the cost of doing so. Data for this stage of the project were collected through a series of in-depth interviews with doctors at three public hospitals.

¹ National Health and Medical Research Council, *An Ethical Framework for Integrating Palliative Care Principles into the Management of Advanced Chronic or Terminal Conditions* (September 2001), 17 <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/rec31_ethical_framework_palliative_care_termina_110908.pdf>.

² See eg Robert Sibbald, James Downar and Laura Hawryluck, ‘Perceptions of “Futile Care” Amongst Caregivers in Intensive Care Units’ (2007) 177(10) *Canadian Medical Association Journal* 1201; Valerie Palda et al, ‘“Futile” Care: Do We Provide It? Why? A Semi-Structured, Canada-wide Survey of Intensive Care Unit Doctors and Nurses’ (2005) 20(3) *Journal of Critical Care* 207; Seth Rivera et al, ‘Motivating Factors in Futile Clinical Interventions’ (2001) 119 *Chest* 1944.

³ Richard Smith, ‘A Good Death’ (2000) 320 *British Medical Journal* 129.

⁴ Randall J Curtis and Robert A Burt, ‘Why Are Critical Care Clinicians So Powerfully Distressed by Family Demands for Futile Care?’ (2003) 18(1) *Journal of Critical Care* 22.

⁵ Ben White et al, ‘The Legal Role of Medical Professionals In Decisions To Withhold Or Withdraw Life-Sustaining Treatment: Part 1 (New South Wales)’ (2011) 18 *Journal of Law and Medicine* 498; Lindy Willmott et al, ‘The Legal Role Of Medical Professionals In Decisions To Withhold Or Withdraw Life-Sustaining Treatment: Part 2 (Queensland)’ (2011) 18 *Journal of Law and Medicine* 523 (‘The Legal Role Of Medical Professionals (Queensland)’); Lindy Willmott et al, ‘The Legal Role Of Medical Professionals In Decisions To Withhold Or Withdraw Life-Sustaining Treatment: Part 3 (Victoria)’ (2011) 18 *Journal of Law and Medicine* 773 (‘The Legal Role Of Medical Professionals (Victoria)’).

⁶ Ben White et al, ‘Doctors’ Knowledge of the Law on Withholding and Withdrawing Life-Sustaining Medical Treatment’ (2014) 201(4) *Medical Journal of Australia* 229.

The primary goal of this article is to present what these interviews revealed about doctors' knowledge of and attitudes to the law on futile treatment at the end of life, for patients with and without capacity. Prior research demonstrates that doctors who know the law are more likely to protect patients' rights and less likely to practise defensive medicine.⁷ It is also important that doctors know the law to protect themselves against legal sanction. Further, doctors who have positive attitudes towards the law might be more open to knowing and complying with it. To provide context for these findings, Part II of the article describes the law in Queensland. This is important because the law in Queensland is particularly complex, and presents a challenge to doctors who regularly grapple with end of life decision-making in practice. In Queensland, a doctor's authority to cease futile treatment unilaterally (that is, without obtaining consent) turns on whether or not a patient has the capacity to make a treatment decision, and therefore whether the situation is governed by the common law or guardianship legislation, respectively. Part III then details the interview method, including recruitment, sample, and qualitative analysis techniques. Part IV presents the results of doctors' knowledge of the law on futile treatment, their attitudes towards it and the extent to which they report that the law affects their clinical practice. The article concludes with recommendations for law reform and education to address issues raised by the results.

II QUEENSLAND LAW

A *General Duties To Provide Medical Treatment*

In Queensland, as in most (if not all) common law jurisdictions, duties are imposed on doctors to provide medical treatment in certain circumstances. Some of these are civil law obligations. For example, a doctor is required by the general law of negligence to use reasonable care and skill when making treatment decisions in relation to his or her patient.⁸ If withholding or withdrawing life-sustaining treatment falls short of reasonable care, then that duty may be breached. The criminal law also gives rise to duties to provide life-sustaining treatment in certain circumstances. The duty that has been identified in Queensland as the principal source of potential criminal responsibility for those involved in decisions to withhold or withdraw life-sustaining treatment is that imposed by section 285 of the *Criminal Code* (Qld) to provide the 'necessaries of life'.⁹ That duty will arise if a doctor has the care or charge of a person, and that person is unable to care for him- or herself.¹⁰

⁷ Ibid.

⁸ *Rogers v Whitaker* (1992) 175 CLR 479; see also Des Butler, Tina Cockburn and Jennifer Yule, 'Negligence' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) 255 for more detail on the content of this duty and how civil liability legislation has altered, and in some instances, replaced, the common law.

⁹ See eg, *Re RWG* [2000] QGAAT 2, [55]-[63]; *Re HG* [2006] QGAAT 26, [101]-[107]; *Re SAJ* [2007] QGAAT 62, [54].

¹⁰ For further discussion of this provision and its possible application in the end of life setting, see Ben White, Lindy Willmott and John Allen, 'Withholding and Withdrawing Life-Sustaining Treatment: Criminal Responsibility for Established Medical Practice?' (2010) 17 *Journal of Law and Medicine* 849.

B Treatment Being 'Futile' Relieves These Duties

Under the common law, a determination by a doctor that treatment is 'futile' relieves him or her of these duties to provide it. This is so even if the adult patient or his or her family wants treatment to be provided. The courts have relied on two alternative approaches in reaching this conclusion. The first is that there is no duty to provide futile treatment because doing so would not be in the patient's best interests.¹¹ Where a patient is an adult who lacks capacity, and the family wants to challenge this decision, the matter could be decided by the Supreme Court exercising its *parens patriae* jurisdiction. If the Court, in assessing a patient's best interests, agrees with the doctor's assessment of futility, it will not interfere with the proposed non-treatment plan. A similar position arises where the patient is an adult with capacity, as the courts have concluded that a person cannot demand treatment that is not clinically indicated.¹²

The second approach is that not providing treatment that is futile would not breach the doctor's obligation under the criminal law to provide the necessities of life. If treatment is futile, it could not be regarded as a 'necessary of life'.¹³ Further, even if the medical treatment were regarded as a necessary of life, it might be argued that there is a 'lawful excuse' for not providing the treatment if such a course would be consistent with good medical practice.¹⁴

C Guardianship Legislation Changes This Position In Queensland

In Queensland, the legal landscape described above was altered for adults lacking capacity, as a result of the enactment of guardianship legislation which is comprised of the *Powers of Attorney Act 1998* (Qld) ('PAA') and the *Guardianship and Administration Act 2000* (Qld) ('GAA').¹⁵ This is because, under the GAA and PAA, 'health care' is defined to include withholding and withdrawal of a life-sustaining measure if the commencement or continuation of the measure would be inconsistent with good medical practice.¹⁶ As not providing treatment is 'health care', consent must be obtained from a substitute decision-maker (or other authority) for treatment to be withheld or withdrawn.¹⁷ This is the case even if the life-sustaining measure is regarded as futile.

¹¹ *Application of Justice Health; Re a Patient* [2011] NSWSC 432, [2]; *Melo v Superintendent of Royal Darwin Hospital* (2007) 21 NTLR 197, [27]; *In the matter of Herrington; Re King* [2007] VSC 151, [24]; *Messiha v South East Health* [2004] NSWSC 1061, [26] and [28]. For a consideration of 'best interests' in the context of decisions to withhold and withdraw treatment from individuals who lack decision-making capacity, see Lindy Willmott, Ben White and Malcolm K Smith, "Best Interests" and Withholding and Withdrawing Life-Sustaining Treatment from an Adult Who Lacks Capacity in the Parens Patriae Jurisdiction' (2014) 21(4) *Journal of Law and Medicine* 920.

¹² *R (on the application of Burke) v The General Medical Council* [2006] QB 273, 301-302.

¹³ While there is no direct Queensland authority for this proposition, it is likely that the same approach would be taken to this issue as the New Zealand High Court in *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235.

¹⁴ Again, there is no direct Queensland authority, but it is possible to advance the reasoning regarding 'lawful excuse' which was applied by the New Zealand High Court in *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235. For a more detailed discussion of Queensland's criminal law framework in the context of decisions about life-sustaining treatment, see White, Willmott and Allen, above n 10.

¹⁵ Cf the law in the other Australian jurisdictions, which reflects the common law. See Lindy Willmott, Ben White and Jocelyn Downie, 'Withholding and Withdrawal of 'Futile' Life-Sustaining Treatment: Unilateral Medical Decision-Making in Australia and New Zealand' (2013) 20(4) *Journal of Law and Medicine* 907.

¹⁶ GAA, Sch 2, s 5(2). See also the definition of 'life-sustaining measures': GAA, Sch 2, s 5A.

¹⁷ Section 79 of the GAA makes it an offence for a health provider to carry out 'health care' for an adult with impaired capacity unless the appropriate consent (or some other authorisation) is obtained.

Where the treating team and the family disagree about treatment (and the family refuses consent to withhold or withdraw the life-sustaining measure), various mechanisms are available under the legislation to resolve this dispute. In an appropriate case, a decision about whether to withhold or withdraw treatment may be made by the Public Guardian (formerly the Adult Guardian),¹⁸ the Queensland Civil and Administrative Tribunal¹⁹ or the Supreme Court.²⁰

Although there is considerable commentary on the operation of the legislation,²¹ there is relatively little judicial or quasi-judicial authority on the operation of the legislation in the context of potentially futile treatment. Nevertheless, some observations were made about the Queensland framework in the 2009 Coronial decision, *Inquest into the case of June Woo*.²² In that case, the Queensland State Coroner considered the above interpretation of the GAA, and concluded that ‘the patient or a person authorised under the GAA must consent to the withholding of life-sustaining measures.’²³ Mrs Woo was 82 years of age and had a significant history of pulmonary fibrosis and chronic respiratory failure. She had lost capacity shortly after being admitted to hospital. A ‘not for resuscitation’ (NFR) order was made and so resuscitation was not attempted when she died a day later. While the Coroner concluded that Mrs Woo received appropriate medical care, he expressed concern about the decision-making process in relation to the NFR order. The treating doctor believed that resuscitation was futile and so ‘did not consider the decision was one the relatives could consent or object to’.²⁴ However, given the legal position outlined above, this was not the case and the Coroner found that the order was not made with the family’s consent as was required by the guardianship legislation. Although the Coroner concluded that by the time of Mrs Woo’s death the family had given tacit consent to the NFR order, he noted that had she died at an earlier time and without that consent that ‘significant legal consequences may have followed’.²⁵

¹⁸ Pursuant to s 43 of the GAA, the Public Guardian is empowered to make a decision about a health matter if a substitute decision-maker refuses to make a decision or makes a decision that the Public Guardian believes is contrary to the health care principle. The ‘health care principle’ is set out in Schedule 1 of the legislation and requires the person making the decision to exercise power in a particular way including in a way that is least restrictive of the adult’s rights and in the adult’s best interests.

¹⁹ Pursuant to ss 81(1)(f) and 115 of the GAA, the Tribunal can consent to the withholding or withdrawal of a life-sustaining measure if an application is brought before it.

²⁰ The *parens patriae* jurisdiction of the Supreme Court of Queensland is retained by s 240 of the GAA under which the Court could authorise the withholding or withdrawal of treatment. It is not an offence for a health provider to withhold or withdraw treatment on the basis of such authority: GAA, s 79(1)(c).

²¹ There has now been a decade of academic and other commentary on this aspect of the law: see, eg, Ben White and Lindy Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (QUT Printing Services, Brisbane, 2005) 69-72 <<http://eprints.qut.edu.au/7093/>>; Willmott et al, ‘The Legal Role of Medical Professionals (Queensland)’, above n 5; Sean Lawrence et al, ‘Autonomy Versus Futility? Barriers to Good Clinical Practice in End-Of-Life Care: A Queensland Case’ (2012) 196(6) *Medical Journal of Australia* 404; Cameron Stewart, ‘A Defence of the Requirement to Seek Consent to Withhold and Withdraw Futile Treatments’ (2012) 196(6) *Medical Journal of Australia* 406; Willmott, White and Downie, above n 15; Lindy Willmott, Ben White and Shih-Ning Then, ‘Withholding and Withdrawing Life-Sustaining Medical Treatment’ in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) 543, [14.240]; Malcolm Parker, ‘Futile Choices: Wooing Doctors to Acknowledge the Law in Queensland’ (2010) 18 *Journal of Law and Medicine* 32.

²² *Inquest into the death of June Woo* (unreported, Queensland Coroner’s Court, 1 June 2009).

²³ *Inquest into the death of June Woo* (unreported, Queensland Coroner’s Court, 1 June 2009) 23.

²⁴ *Inquest into the death of June Woo* (unreported, Queensland Coroner’s Court, 1 June 2009) 6.

²⁵ *Inquest into the death of June Woo* (unreported, Queensland Coroner’s Court, 1 June 2009) 21.

Doctors' understanding of this legal complexity in Queensland and their attitudes about it have not been explored, nor has the extent to which they believe this law (or the law in general) affects their own practice with patients at the end of life. This study aims to address these knowledge gaps, and the next part of the article describes the way in which the data about legal knowledge, attitudes towards the law and the effect of law on medical practice was obtained and analysed.

III METHOD

A *Ethics*

Human research ethics committees at the Royal Brisbane & Women's Hospital (multi-centre approval), the Queensland University of Technology and the University of Queensland approved the research.²⁶ Protecting the confidentiality of the research participants was of utmost importance to the research team. A database that included names of research participants was kept during the recruitment period to ensure that invitations were not sent to people more than once. At the time of interview, participants were assigned a participant ID number. Interviews were digitally recorded and participants were encouraged not to mention names while the recorder was on. Once the interviews were transcribed, participants were given the opportunity to review their transcript and request amendments. When the final transcript was approved, the participant's name was removed from the database, leaving only the participant ID and demographic details.

B *Recruitment*

Doctors were recruited from three public hospitals in Brisbane, Queensland from specialties who routinely encounter patients at or near end of life. The recruitment strategy was developed in consultation with the Futility Research Group ('FRG'), a locally-based group of clinicians with research interests in futility. Purposive maximum variation sampling was used to recruit a wide variety of participants to obtain a diverse range of views.²⁷ This technique allowed the research team to build up a picture of futility by considering the perspectives of different specialists, and is particularly suitable for gaining an understanding of complex problems such as futile treatment at the end of life.

C *Sample Description*

Interviews were conducted with 96 doctors at the three participating hospitals. Table 1 shows the number of doctors from each specialty interviewed (listed in descending order).

Interviews were conducted with 68 men and 28 women. The sample was made up of experienced doctors; the vast majority of participants were consultants (87), and only 9 were registrars. This is because participants who had direct responsibility for making decisions about end of life care were actively sought. The sample spanned a wide range of ages from 30 to over 70, with a mean age of 49 years. The amount of time the doctors had spent working as a doctor in Australia ranged from

²⁶ Royal Brisbane and Women's Hospital Human Research Ethics Committee, Approval number: HREC/12/QRBW/429; University of Queensland Medical Research Ethics Committee, Approval number: 2013000214; Queensland University of Technology UHREC Research Ethics Unit, Approval number: 1300000107.

²⁷ Michael Quinn Patton, *Qualitative Evaluation and Research Methods* (Sage, 2nd ed, 1990).

1 year to 49 years; the average amount of time was 19 years. Most interviews were conducted in the emergency, intensive care unit ('ICU'), palliative care and oncology departments (10-15 interviews in each), followed by renal, respiratory, internal medicine, surgery, cardiology, geriatrics and medical administration (4-9 interviews in each).

Table 1: Number of Doctors Interviewed By Specialty

DEPARTMENT	TOTAL
Emergency	15
ICU	12
Palliative care	10
Oncology	10
Renal	9
Respiratory	9
Internal medicine	9
Surgery	8
Cardiology	5
Geriatrics	5
Medical administration	4
TOTAL	96

D Interviews

The chief investigators prepared an interview guide (Appendix A), designed to address the key research questions and to allow the interviewer to follow up on ideas raised by the participant. The convergent interviewing technique was used.²⁸ This is a method of in-depth interviewing that is particularly useful when exploring issues that are difficult to define. The questioning strategy involves asking a general question at the beginning of the interview, in order to allow the participants to raise issues without prompting, before (where necessary) prompting for the topics specified in the interview guide. The convergent interviewing process also encourages analysis to occur throughout the data collection phase. The researchers' developing understanding is tested with each subsequent interview, by looking for convergence or divergence with previous interviewees on specific topics. Interviews are conducted until a stable pattern of agreements and disagreements is evident, and no new issues are revealed – a point known as saturation of ideas.²⁹

In this study, a broad question about doctors' experience with futile treatment started the interview. Doctors were asked to recall one or more experiences of care or treatment provided, which in their view did not benefit the patient. In addition, they were asked to recall cases where futile treatment had been avoided, or cases where treatment was given that might be considered futile but, in their opinion, was beneficial. As they described and reflected on these experiences, the interviewer prompted them when appropriate about their understanding of the concept of futile treatment, their

²⁸ Robert Dick, *Convergent Interviewing* (Chapel Hill, 1990); Michelle Driedger et al, 'Finding Common Ground in Team-Based Qualitative Research Using the Convergent Interviewing Method' (2006) 16(8) *Qualitative Health Research* 1145.

²⁹ Dick, above n 28.

reasons for providing it, ways to avoid and reduce it, as well as how the legal and policy framework operated and whether or not it was helpful in these cases. At the end of the interview, doctors responded briefly to a hypothetical case in which there was family pressure to provide treatment that doctors believed did not benefit the patient. Following the format of convergent interviews, the doctors were encouraged to describe their experiences in as much detail as they could, and prompt questions were used only when interviewees did not address them spontaneously.

Doctors were very willing to give their views, and most described experiences of particular cases in great detail. The interviews took between 30 minutes and 2 hours, with the duration of most interviews being about an hour.

E Analysis

All interviews were transcribed verbatim, and the transcripts were imported into QSR International's NVivo qualitative data analysis software (Version 10). Initial analysis employed the framework approach. This is an analytic technique which combines thematic and case based analysis, using a systematic approach to summary and synthesis.³⁰ In addition to a more standard thematic analysis, a matrix was created by writing short summaries of what each participant said about themes of key interest to the investigators. This avoided the fragmentation that can result from using thematic analysis only. A matrix of summaries condensing the key themes raised by participants was brought along to team meetings for discussion. This process allowed the whole research team to be familiar with the main ideas emerging from the data, improving the analytical depth that could be achieved. Furthermore, new themes in addition to those explored in the interview guide emerged from the analysis.

To investigate doctors' knowledge of the law, most were asked whether or not they needed to obtain a patient or substitute decision-maker's consent before withholding or withdrawing life-sustaining treatment. Due to the nature of the interviews and time constraints, this question was explored in a variable amount of detail by different participants. Questions about legal issues and attitudes were asked in all interviews except two (the two initial interviews, before the investigators had refined the interview guide). These two interviews were excluded from the analysis in Part IV below.

Slightly different approaches were used to code the different data described in the results; the choice of approach was grounded in the nature of participants' responses. As discussed below,³¹ each participant's responses were analysed as a whole to determine whether the participant understood the law or not. Each participant was assigned a single score for their knowledge of each of the common law and guardianship law accordingly. The precise scoring method used is outlined in more detail in Part III(F) below. As discussed below in Part IV(B), the participants' responses were analysed as a whole to come up with an overall score, and each mention of a particular kind of attitude was also coded, in order to capture the diversity of doctors' attitudes. A single participant may have expressed a number of different attitudes (positive and negative); in this case, each attitude was coded separately. In these instances, to come up with the participant's

³⁰ Jane Ritchie and Liz Spencer, 'Qualitative Data Analysis for Applied Policy Research' in Alan Bryman and Robert G Burgess (eds), *Analyzing Qualitative Data* (Routledge, 1994) 173, 173.

³¹ See Part IV(A) below.

overall attitude the transcript was examined to determine that doctor's dominant attitude towards the law (positive or negative). The same method was used in Part IV(C), to code doctors' responses about their approaches towards law in practice.

F *Assessing Knowledge of the Law*

To capture doctors' knowledge of the law on futile treatment (Part IV(A) below), participants' explicit references to their legal obligations were coded with NVivo by the authors who possess legal expertise (LW, BW, and EC). These three authors initially discussed what the law governing futile treatment in Queensland is and what types of statements represented adequate knowledge of the various aspects of it. One of us (EC) then did the initial coding, and flagged cases in which participants' knowledge was not immediately obvious or was unclear (13 cases). These cases were coded in discussion with the other authors with legal expertise (all with LW and difficult cases also with BW) to ensure consensus about the way the transcripts were coded. When the NVivo extracts did not provide enough detail to assess the participant's knowledge of the law, the entire transcript was reviewed to uncover implicit references to the participant's understanding of relevant legal principles.

Doctors were scored as having correct (score of 1) or incorrect (score of 0) knowledge of the law in two domains: (a) the common law, and (b) the guardianship legislation. These scores were added, and resulted in an overall score ranging from 0 to 2 for each participant. Participants who simply cited the common law principle 'doctors do not have to provide treatment when it is futile' were given a correct score on the common law (1 point), even though they did not know or did not specify that this only applied to patients with capacity to make decisions. Similarly, doctors who said they must have the consent of the *patient* or substitute decision-maker to withhold or withdraw life-sustaining treatment were given a point for knowing the guardianship legislation, even though they were applying it incorrectly to patients with capacity. Only participants who scored 2 out of 2 could be said to be correct about the law as a whole.

Given the lack of specificity in some responses to interview questions, combined with the complexity of the law in this field, the researchers scored the responses generously and participants were given the benefit of the doubt when it was unclear whether they understood the law or when they were *substantially* correct about the substance and framework of the law. For example, as explained in the previous paragraph, respondents were awarded a point if they correctly described the common law (or guardianship law) even if they did not expressly say that the law applied to patients who had (or lacked) capacity. However, when participants made contradictory statements about the law, their knowledge was scored as incorrect. Participants were also scored as incorrect if they acted in a way that was consistent with the law, but did so under a misunderstanding of the legal rule that applied to the situation. For example, when asked what the law required when there was a futility dispute between the treating team and a family for a patient without capacity, one doctor responded:

Interviewee: Look, I think if there's difficulties like that, then we go to the legal guardian and we use them as our substitute decision-maker. So we then involve the law, if you like.

Facilitator: Okay, and that's because you want to involve them as a mediator or you can't do it without the family's consent? Or...

Interviewee: We actually can do it without the family's consent but it's unwise to. So I come back and say the law says that you can't force medical and nursing staff to do things that they generally believe are futile and you don't want to traumatise families by doing things that they believe are terribly wrong, either. So yes the legal guardian does become both the person that takes on that role of looking at the legal aspects but also can deal with the mediation and is also just an independent person to try and deal with conflict. (Participant 413074 – Emergency Medicine Consultant)

Although this doctor knew that futility disputes could be escalated to the Public Guardian (incorrectly referred to by the doctor as the 'legal guardian'), this participant was deemed to have incorrect knowledge of the guardianship legislation because she or he was under the impression that treatment could be lawfully withdrawn without family consent and that involvement of the Public Guardian was a matter of good practice or helpful in conflict resolution as opposed to being required.

IV RESULTS

This Part comprises an analysis of doctors' knowledge of the law on futile treatment, their attitudes towards it, and the extent to which they reported that this law affects their clinical practice.

A Knowledge of the Law

Overall, doctors had a poor knowledge of both the common law and guardianship law, but more were familiar with the former than the latter. Doctors' varying levels of knowledge of the common law and the guardianship law is summarised in the following table:

Table 2: Doctors' Knowledge of the Law Regarding Futile Treatment in Queensland³²

Knowledge of the law	Common law (proportion)	Guardianship law (proportion)
Correct	47 (50.0%)	34 (36.2%)
Incorrect	33 (35.1%)	60 (63.8%)
Did not answer/not raised	14 (14.9%)	0 (0.0%)
Total number of doctors	94 (100%)	94 (100%)

Half of the doctors cited the common law position that they did not have to provide treatment if they thought it was futile. However, more than a third of doctors held incorrect beliefs about the common law. For example, many conflated their obligations under the guardianship law with the common law, and believed that they needed a patient's consent to withhold or withdraw life-sustaining measures, whether or not the patient had capacity:

... doctors live constantly under the fear of litigation... I believe it's a particular problem in Queensland, where the patient, or interested parties, have the direct right to demand therapy, even

³² Note that two participants were excluded from this part of the analysis as they had not discussed the law at all: see Part III(E) above.

if futile. So we're very conscious of patient or interested parties' views. (Participant 413008 – Renal Consultant)

Fourteen doctors (14.9 per cent) did not comment or were not specifically asked about the common law position, typically because of time constraints in the interview and because the discussion had focused on examples of patients without capacity to whom the guardianship law applied.

Approximately one-third of doctors understood their obligations to seek a substitute decision-maker's consent under the guardianship law. Of the two-thirds who did not have correct knowledge of these duties, some believed that the common law principle applied whether or not a patient had capacity, while others simply said they did not know whether consent was required. The following excerpts are illustrative of participants' responses where the doctors had an incorrect understanding of their obligations under the guardianship law, or were uncertain about them:

I'm quite comfortable that when something's medically inappropriate then it – you've got legal grounds not to provide it. So doctors cannot always define or - this is why it's a bit of a grey zone, doctors define what's medically appropriate. If it's not medically appropriate, it doesn't get offered. So you should only be offering medically appropriate treatment. (Participant 413012 – Internal Medicine Registrar)

...it's also absolutely clear in the law that doctors are not obligated to provide treatment they believe is completely futile. (Participant 413074 – Emergency Consultant)

The letter of the law does say that if it's futile you don't have to do it. It also wants you to talk to people about it and I interpret that. Is that a fair way to put it? I would not, whether the letter of the law said so or not, if I knew someone should not be resuscitated I wouldn't give them a choice in that. (Participant 413004 – Palliative Care Consultant)

Significantly, of the doctors who discussed both areas of law, the majority (56 doctors, 70 per cent) were familiar with *either* the common law position *or* their obligations under the guardianship law, but not both (see Table 3). Only 11 per cent of those who answered were aware of the whole legal regime. The mean overall score was 0.9 out of 2 (44.9 per cent).

Table 3: Doctors' Overall Scores (For Those Participants Who Discussed *both* the Common Law and the Guardianship Scheme)³³

Overall level of knowledge	Number of doctors (proportion)
No knowledge of the law	15 (18.8%)
Knowledge of only the common law	38 (47.5%)
Knowledge of only the guardianship legislation	18 (22.5%)
Knowledge of both the common law and the guardianship legislation	9 (11.3%)
Total	80 (100%)

³³ Those participants who did not give a specific answer (either because they did not answer or were not explicitly asked) were excluded from this table.

B *Attitudes Towards the Law*

The vast majority of doctors had an overall negative, rather than positive, attitude towards the law. The types of negative and positive attitudes that doctors had towards the law are shown in Table 4.

Table 4: Doctors' Overall Attitudes Towards Law³⁴

Attitudes towards law	Number of doctors
Overall negative attitude	59
The law does not support doctors' decisions/puts too much power in the hands of substitute decision-makers	41
The Public Guardian is unhelpful in dealing with withholding or withdrawing life-sustaining treatment	20
Afraid of legal consequences	15
The law is confusing/have not received consistent advice on what the law is	15
Causes defensive medicine	14
The law does not recognise practical considerations	10
The law is illogical	9
Lengthy time for decision-making when law is engaged	8
The law does not let us consider the need to conserve scarce resources	6
Law is irrelevant to medical practice	5
Taking legal action has a negative impact on relationship with patients/families	2
Overall positive attitude	29
The law or legal processes support appropriate outcomes	22
The law strikes the right balance between substitute decision-makers and doctors	13
The Public Guardian is helpful/supportive of doctors' decisions to withhold or withdraw life-sustaining treatment	7
I am not afraid of the law	3
The law helps resolve disputes	2

³⁴ Eight participants of the total sample of 96 either were not asked or did not express any attitudes about the law. Some participants expressed both positive and negative attitudes towards the law; each of these attitudes was coded individually and participants were also given a score of 'overall positive' or 'overall negative' based on their dominant attitude (see Part III(E)).

The most common negative attitude doctors expressed was that the law does not provide them with enough support to make appropriate decisions to withhold or withdraw futile treatment. These doctors questioned the ability of a judge or a substitute decision-maker to make a better decision than they could, as illustrated by these quotes:

I was angry with the — I thought that the law — obviously, I was wrong, but we all thought that it was actually a given that if there were multiple people agreeing that care was futile, none of us with any vested interest in thinking differently, that we should not and could not be forced to provide treatment against our wishes. No, that sounds awful. What we think is right. ... We were all in agreement, so we were all a bit stunned and shocked at the adult guardian's decision [that life-sustaining measures could not be withdrawn without the substitute decision-maker's consent] and angry, because obviously, I think intensive care beds are precious and should be used for people who've got a chance at improving. So after five or six days, she died. It might have been four or five days, I can't remember now, but it was an extraordinary waste, and not a dignified death. Dying in intensive care is not pretty. (Participant 413041 – Internal Medicine)

I would never intentionally break the law, but I think it's a little bit foolish that the people who have trained for many years and are maybe experts in their chosen field can be overruled by family with the medical treatment and often a large emotional component. ... My biggest problem with it is giving the family too much say in how someone is treated. Most of the time it's not going to be an issue. Most people are sensible. Most futile treatment, I mean, if the patient's going to die, they're going to die whether they have treatment or not, so you could argue it doesn't change the outcome very much. But I think the manner of someone's death is quite important, so that bothers me. (Participant 413068 – Internal Medicine)

I think the law should give some right for doctors to make decisions based on what they think about the best possible outcome the patient should have. If required, maybe having a medical board or a combined decision from a medical board or other to resolve the conflict, rather than totally on the patient's and the family's right. (Participant 413035 – Internal Medicine)

Doctors also often expressed frustration with the perceived lack of clarity in the law, as the following quotes demonstrate:

Look from my perspective it gets back to the fact where we have a number of people where medically we believe treatment is futile but patients and families demand therapies and there's been a shift in the culture from when I started work. Previously once you'd say look I don't think that is appropriate therapy and on my medical advice we're not going to be offering that to now - except for those extreme sorts of examples we mentioned before — now even if you advise against the therapy and the patients say I want antibiotics, I want this, you're more inclined now to give it than what you were years ago. That's partly because of perhaps the lack of clarity in terms of the law. (Participant 413053 – Respiratory Medicine)

I think this is the difficult area and I think it's not made easier by the acute resuscitation plan because previously there was a strong feeling that we could make someone not for resuscitation without consultation but we would consult the family out of courtesy of what our decision was. I think the good thing about the advanced health directive is it has made that discussion more formal and it has made us document the discussion but there's mixed messages around well we're not obliged to provide futile treatment but we have to get now consent from the family. I don't think that's ever been satisfactorily explained whether despite a family member or the surrogate

decision-maker firmly expressing the opinion about what management should be made following discussion about it. It's not — to me it's still uncertain whether you can then go against what they've said. So I'm not actually sure. I feel quite uncertain and particularly in our department there are consultants who disagree quite fervently. (Participant 413081 – Geriatric Medicine)

Other negative attitudes reflected the general theme that the law is a blunt instrument with barriers to access, and is poorly suited to medical decision-making at the end of life. Some doctors said legal mechanisms were too slow and cumbersome to resolve futility disputes, which are by their nature, time sensitive. Some also commented that the legal position does not take into account a practical understanding of medical realities. This attitude is captured in these quotes:

Clearly laws were drafted by people who have very little understanding of what goes on in the clinical environment. ... I think people have no idea what they're signing up for when they — I mean look, doctors cop a lot of flak for the historically perceived paternalistic attitude right. Because we come from this perspective of being experts in what we do. But I have to say in intensive care it's very difficult for lay people and even people who work in other areas of health care, to really understand the burdensome nature of the treatment that we provide. I think it's really difficult for people to comprehend just how tough it is. ... It's okay to put you through a short period of intensive suffering if at the end of it there's a positive benefit. But it's really not okay to do that to people if there's not a positive benefit to be achieved. I think that concept is really difficult for the community to grasp just how invasive what we do to people is. People have no concept of that and there's no real way of grasping that concept. I would say the only people who are really able to make an informed choice in that situation are health care professionals. That's what I would say. (Participant 413084 – Intensive Care)

... when they are writing the law, [they] are thinking about the person in Intensive Care who's in there for a week. Or the person who's got some underlying cognitive impairment, who's being protected by the Guardianship Act. That people aren't making unilateral [decisions] — and so that's what they're thinking about. They're not thinking about that this law actually applies to every person who's elderly who dies, which is what it does. It means that what this law means is that every person presenting to ED [the Emergency Department] in Queensland, needs to have the family's consent to not have CPR. The other thing is that in theory, you need consent to stop CPR. So if the family said no, no, keep going, then to follow the law you'd have to do it for one week, two weeks, three weeks ... the intent of the law is one thing. But the practicality of it — and I don't think — the law, I don't think, was ever written to apply to that situation. ... Which is why a legal position is one point of view, but the medical position is another. (Participant 413096 – Emergency Medicine)

Doctors also expressed concern that legal mechanisms eroded relationships with patients and families. For example:

I often say to people I believe if you have to involve a lawyer that's an abject failure of the doctor/patient relationship and you have irretrievably destroyed that relationship, that you will no longer be able to look after the patient and their family again. (Participant 413057 – Intensive Care)

Doctors' attitudes about the level of autonomy granted to doctors under the guardianship legislation were overwhelmingly more negative than positive. While 41 doctors thought that the

law put too much power in the hands of substitute decision-makers, only 13 doctors thought the law struck the right balance between patient autonomy and medical paternalism (see Table 4).

The most frequently expressed positive attitude was that the law or legal processes support appropriate outcomes. A range of sentiments are captured within this heading. Some doctors who had this attitude were simply mistaken about the law, and made positive comments about their belief that the law allowed them to refuse to provide futile treatment. Others, who were aware of the legal requirement to obtain consent to withhold or withdraw futile treatment for patients without capacity, believed that if a dispute over futile treatment escalated, the courts would support the doctors' assessment of futility. For example:

... if such a matter did progress to court, if a reasonable body of medical opinion, that's the expert opinion felt that this was in keeping with reasonable medical practice, under those circumstances the law would be on your side. That is my understanding in reading of the law, if it went to that extreme. (Participant 413051 – Renal Medicine)

The comments from doctors who felt the law supported their actions appeared to be underpinned by a common underlying belief that the law supports what is appropriate, well-intentioned and medically reasonable. One participant engaged with this concept from a slightly different point of view, commenting that the court plays an important societal role in adjudicating disputes about futile treatment, assessments of which are inherently subjective:

Well, look, I think doctors are the agents of society and, look, if a family really want to go to court, I'm happy to have society judge what we do. I don't feel as though I'm doing anything malevolent. I can't remember a case where I've been conflicted in the care of a patient. But if society wants to tell me to do something else, then, as long as they understand the facts, then, sure, we'll do that. (Participant 413019 – Intensive Care)

A comparative matrix of doctors' knowledge versus attitudes (Table 5) reveals two interesting trends. Firstly, doctors' attitudes towards the law were negatively associated with their level of knowledge of the guardianship legislation. Those who knew the guardianship legislation tended to have more negative attitudes towards the law in this area, compared to those who knew only the common law or had no knowledge of the law. This is unsurprising, given that 41 doctors (46.6 per cent of those who expressed a view on the law) voiced the opinion that the law detracts from their autonomy and does not adequately support their decisions to withhold or withdraw futile treatment at the end of life (see Table 4). Second, of those doctors who had a positive attitude towards the law, the vast majority (23 doctors, 79.3 per cent) were unaware of their obligations to seek consent to withhold or withdraw life-sustaining treatment under the guardianship regime. These doctors had either no knowledge of the law or thought that the common law principle that they did not have to provide treatment when it was futile.

Table 5: Doctors Overall Attitudes Towards the Law Compared To Their Knowledge Of The Law On Futile Treatment

Level of knowledge of the law	Number of doctors with an overall positive attitude	Number of doctors with an overall negative attitude
No knowledge of the law	9	11
Knowledge of only the common law	14	20

Knowledge of only the guardianship legislation	5	20
Knowledge of both areas of law	1	8
Total	29	59

C *The Impact of Law on Clinical Practice*

The way in which the law governing futile treatment has, or has not, affected doctors' practices was also examined. Some doctors spoke of how the law influenced their practices (ie ways that the law has compelled them to act, or actions or behaviours they take to avoid engagement with the legal system), while others said the law did not affect them. Although the vast majority of doctors held negative attitudes towards the law, about half indicated that the law influenced how they practised medicine (see Table 6).

Table 6: Doctors' Views on the Impact of Law on Their Practice³⁵

Impact of law on practice	Number of doctors
Law has an impact on practice (overall)	48
Caused futile treatment	27
Consulted colleagues for a second opinion on futile treatment for legal protection	17
Consulted other hospital authorities or defence organisation for legal advice	16
Consulted Public Guardian to act as a substitute decision-maker	15
Consulted Public Guardian to resolve futility dispute	14
Provided futile treatment as a result of interaction with the Public Guardian	12
Needed to interpret the content and legal weight of advance care planning documents	8
Escalated to the Queensland Civil and Administrative Tribunal to resolve a futility dispute	4
Advance Health Directives address my worries about future legal risk	2
Law does not have an impact on practice (overall)	44
Good medical practice is enough	36
If you communicate well with the family you do not need to worry about law	26
I do not think about the law	16

³⁵ Four participants of the total sample of 96 did not comment on the impact of the law on their practice. Some participants expressed more than one way that the law had (or did not have) an impact on their practice; each of these impacts was coded individually and participants were also given an overall score based on their main response (see Part III(E)).

The ways in which the law affected doctors' practices varied. The most frequent impact on practice doctors discussed was that the law (or fear of the law) caused futile treatment to be provided. For example:

We can either go against our best wishes and keep the family happy and do whatever we feel. Or we can go to the Guardian and try and get an overrule around that. Now to go to the Guardian and get an overrule from a legal point of view to refuse to abide by next of kin's wishes is time consuming. So invariably we'll probably be forced to go ahead and do some treatment we don't agree with until we can go through the process of getting a ruling of support. (Participant 413034 – Emergency Medicine)

I think if someone gave me the opportunity to die of a heart attack suddenly at the age of 85 that would be fantastic. But — so when I get that phone call at three o'clock in the morning that's what I really think should be done and I honestly think that's in the best interests of the patient. The thing that prevents me from saying no I don't want to do anything is that there's no medico-legal construct, as far as I can tell. ... There's nothing that protects me. There's not a medico-legal construct that protects me from sanction as a result of that decision. (Participant 413082 – Cardiology)

Several doctors also reported providing futile treatment as a result of interactions with the Public Guardian, either because they were directed to do so, or because the Public Guardian did not make a decision about withholding or withdrawing treatment.

Doctors also reported that the law led them to take steps to protect themselves against legal sanction. Some doctors described ways that they would seek institutional assistance when unsure about the law, by escalating a matter to hospital authorities or lawyers, or to the Public Guardian. A number of doctors said that when they thought treatment was futile, they sought second opinions from colleagues to help discuss their position with the patient or family and such action would provide legal protection.

About half of the participants said that the law did not affect their practice. Most thought that following 'good medical practice' (broadly understood by the participants as doing the right thing for the patient) was the appropriate course of action whether supported by law or not, as described in the following quotes:

I would not, whether the letter of the law said so or not, if I knew someone should not be resuscitated I wouldn't give them a choice in that. (Participant 413004 – Palliative Medicine)

Whether or not I had contravened the G & A [Guardianship and Administration] Act by not following through with what had been expressed in the past as the wishes of the family — to me it's only secondary to whether or not I practice outside of the scope of practice which morally, ethically and probably from a societal point of view would have been perceived to be the right thing to do. (Participant 413022 – Intensive Care)

A number of doctors said that as long as the medical teams took enough time to communicate with substitute decision-makers, legal mechanisms do not need to be engaged or even considered. For example:

With compassion, empathetic communication skills and with talking through what is appropriate practice or not and having doctors uniting in their voice towards these families. Most times, we will get through it without thinking about the law. (Participant 413024 – Palliative Medicine)

Doctors usually characterised these discussions with family as being part of good medical practice, rather than something that the consent requirement in Queensland guardianship law has compelled. However, it may be that the law is playing some part in driving these extensive discussions. For example, an intensivist made the following comment when discussing withdrawing futile treatment from a patient without capacity:

Participant: I would usually attempt to achieve consensus [with the family], and you get there eventually but it takes time.

Facilitator: But if the law supported you more would you still try and reach a consensus?

Participant: That's a good question. Probably not. I think it would be beneficial to have the support of the law in making the decisions that we make all the time anyway, rather than to be at odds with it. But would it change clinical practice. ... It would be helpful in those situations where there is an impasse with the family, you know what I mean. It would be helpful to say, look we have no further requirement to provide this and I can tell you that we should stop and that's all we're going to do. It would be nice to have that as a fall-back position. (Participant 413084 – ICU Consultant)

V DISCUSSION AND CONCLUSIONS

This article presents findings from our analysis of the transcripts of 96 in-depth interviews. The limitations of the research method should be noted. The study is based on the views held by doctors who volunteered to be interviewed and who may have had strong views about the subject matter. The findings therefore may not be generalisable to a broader cohort. Nevertheless, some strong trends emerged from the research, which may provide important information to hospital executives, medical colleges and societies, the medical profession generally, and medical educators, about the need for clinical practice and medical education to take account of the law and the legal context in which treatment decisions are made.

When reporting on doctors' knowledge of the law in this field, it is important to acknowledge that the law is complex, and perhaps more so in Queensland where the law differs depending on whether a person has capacity (common law) or not (guardianship regime). Further, some may regard the law as counter-intuitive, as a doctor is not required to obtain patient consent to withhold or withdraw life-sustaining treatment when he or she has decision-making capacity, yet must obtain consent (generally from a member of the patient's family) when the patient lacks capacity and may well be in a more dire medical condition than a patient who still retains capacity. Indeed, some may suggest the Queensland law should be reviewed.³⁶ Nevertheless, the findings of this research point to some concerns, in that 89 per cent of the doctors who were specifically asked

³⁶ Two of the authors have elsewhere considered the appropriate nature of the legal regime in this field. See Jocelyn Downie, Lindy Willmott and Ben White, 'Cutting the Gordian Knot of Futility: a Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2014) 26(1) *New Zealand Universities Law Review* 24.

about their obligation to seek consent to withhold or withdraw futile treatment did not fully understand the legal position for a patient with and without capacity.³⁷

This article also reports on the negative attitudes that doctors have toward the law on this issue. Overall, doctors did not perceive the law in a positive light, with 59 doctors having a negative attitude towards the law and only 29 doctors observing that it could be helpful in end of life decision-making. Of those doctors who had positive attitudes about the law, most were unaware of their obligations under the guardianship legislation. Negative attitudes about the law were associated with increased knowledge of the guardianship legislation; this may reflect the frequently cited view expressed by participants that the law overly fetters their autonomy in this area. Half the participants said that the law affected their practice; the primary perceived impact was that the law causes futile treatment to be provided.

In light of these empirical findings and the current legal framework in Queensland, we make the following recommendations. Firstly, the legal framework needs to be certain and clear (and, ideally, consistent across all Australian jurisdictions). Three of the authors have elsewhere made suggestions in this regard.³⁸ Further, health departments and hospitals should develop policies that translate legal obligations into accessible language that will guide clinical practice. In addition, position statements and professional guidelines developed by professional bodies and societies should be consistent with those legal obligations and indeed encourage legal compliance. It is not sufficient to suggest that acting according to professional ethics or principles of ‘good medical practice’ will be sufficient to ensure legal compliance.

Secondly, this research points to the need to educate medical professionals. Doctors need to know when they are required to seek consent from substitute decision-makers to stop treatment that has already commenced, or to withhold other treatment. However, our findings about doctors’ attitudes towards the law also point to the need to persuade doctors about the importance of knowing and complying with the law. Unless doctors form the view that it is important to carry out their practice in a legally compliant manner, we are unlikely to see any improvement in doctors’ knowledge of the law governing decision-making at the end of life. Greater collaborative educational efforts should occur, involving medical schools, hospitals, specialist colleges and societies, and the Office of the Public Guardian, to clarify Queensland’s unique legislative requirements to obtain consent to withhold or withdraw futile treatment from patients without capacity.

³⁷ For further research into the knowledge of specialists on the law that governs withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity, see White et al, above n 6.

³⁸ Willmott et al, ‘The Legal Role Of Medical Professionals (Victoria)’, above n 5.

APPENDIX A - INTERVIEW GUIDE

Note: these questions are to be used as a flexible guide. The interviewer will begin with a general question like those described, and use the other questions as prompts depending on what the participant says. The interview will be conversational, and participants will answer questions in their own words and address issues in the order they wish.

General questions

Initial question: Can you please describe a situation from your experience (one you were responsible for or one from a colleague) when a person got treatment at the end of life you didn't think they should have had?

- Why was this treatment provided?
- How did you feel about this experience?
- What do you think could have been done differently (if anything)?

What about a situation where a patient *didn't* get treatment that you thought they should have had?

Can you describe a situation where treatment at the end of life was appropriately withdrawn?

Describe a situation where a decision was made to withhold or withdraw treatment that resulted in a poor outcome?

Have *you* ever given treatment you knew was futile (ie likely to be ineffective)? Why?

- What factors led to the decision?
- Why was treatment withheld/withdrawn?
- Why did you/others think that treatment was futile/inappropriate?
- Why do you/others think that treatment was appropriate?
- How did you feel?
- What was your colleague's reaction?
- What do you think could have been done differently (if anything)?

Prompts

- Family
 - a. What role, if any, do you think family members play in the provision of futile treatment?
 - b. What role, if any, do you think patients play in the provision of futile treatment?
 - c. How often is futile treatment given just because family requests it?
- Interpersonal dynamics/communication
 - a. Some believe that communication plays a role in futile treatment. What do you think about this? (i.e. communication with other staff, family, patient)
 - b. Some believe that expectations play a role in futile treatment. What do you think about this? (i.e. expectations of other staff, family, patient, self)

- Institutional culture
 - a. Why do doctors make varying decisions about when to withhold or withdraw treatment at the end of life?
 - b. Is your practice similar to others in your specialty? Why or why not?
 - c. What is the impact (if any) of interaction/opinions of nurses, registrars, other staff ?
 - d. Some say that this treatment is provided because doctors don't have enough time to have adequate conversations because of workload. What do you think about this?

- Training
 - a. What training (if any) did you receive in relation to how to deal with end of life care? Deciding when to cease active treatment?
 - b. Nature, duration, place of training
 - c. What, if anything, should be done to change this training?

- Resources
 - a. Some say resources are a factor in assessing whether or not to offer treatment that may be futile. What do you think about this?
 - b. Some say that by providing treatment that is futile (even when there is some justification) others miss out on beneficial treatment. What do you think about this?

- Law
 - a. Some believe that if they do not provide treatment when a patient/substitute decision-maker requests it, there may be legal consequences. What do you think about this?
 - b. What does the law say on this?
 - c. What do you think of the law? Is treatment provided because of it?
 - d. Have you ever had a situation escalate to a legal proceeding?
 - e. Thoughts on the legal proceeding?
 - f. Does the law support your decisions in this area?
 - g. Would an increased understanding of the law assist?

- Policy
 - a. Are there any policies/practices/guidelines in your department/hospital/Queensland Health that deal with futile treatment at the end of life?
 - b. What do they say?
 - c. What do you think of these?
 - d. Do you use them in practice?
 - e. What about professional/ethics guidelines? Do they address this? What do you think of them?

- Nature of futile treatment
 - a. Can you think of instances in other specialties when this occurs? Which ones?
 - b. What is the nature of futile treatment provided (resuscitation/medication/procedures, etc)?
 - c. What about your own specialty (discipline, department) – any examples?
 - d. How frequently do you perceive futile treatment occurs in your department?
 - e. Main reason that futile treatment is provided?

- Definition
 - a. What do you mean by futile treatment?
 - b. Can you define futile treatment?

- Improvement
 - a. Is it a problem? What troubles you the most about it? (Harm to patient, resource use, doctor's autonomy, etc.)
 - b. What do you think needs to happen (if anything) to address the issue of futile treatment?

Case example

The interviewer will use the case study in a flexible way, encouraging the participant to guide the discussion.

Case study

- John is an 84 year old male with advanced dementia and end stage bowel cancer which has metastasised
- He is admitted from the high care unit of an residential aged care facility to hospital with abdominal pain
- It is possible to undertake surgery, but this is expected to have limited, if any, benefit
- John's daughter demands the operation despite the poor prognosis

What to do – listen for cues from participant:

1. Administer treatment? When? Why this point?
2. What information would you want?
3. How would you make this decision? Who would you speak to?
4. Any laws/policies/processes affecting your decision?
5. Cost considerations?
6. What if John did not have dementia and was requesting futile treatment?

Categorise

- Continue even if know is futile?
- Or stop because know is futile?