Role of Law in End-of-Life Decision-Making: Perspectives of Patients, Substitute Decision-Makers and Families

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The law regulating medical end-of-life decisions aims to support patients to receive high-quality health care. It does so through ensuring treatment received reflects the person’s wishes and values and protecting health professionals who provide adequate pain and symptom relief even if that treatment may coincidentally hasten death. However, good decision-making is predicated by those involved, including patients themselves and those supporting patients, being familiar with the law and the role it plays in the decision-making process. This article reports on a study exploring the role that law plays in end-of-life decision-making from the perspective of terminally-ill patients, their substitute decision-makers and family members. While participants’ decision-making practices were often underpinned by a legal framework, the role of the law was largely invisible. Community education is needed for the public to know their legal rights and responsibilities, and to understand that the law plays a role in supporting end-of-life decision-making.

Keywords: role of law in end-of-life decision-making; community perspectives; resolving conflict; advance care directives; enduring powers of attorney; end-of-life decision-making; legal literacy; substitute decision-making

I. INTRODUCTION

The law plays an important role in supporting the provision of high-quality health care, including at the end-of-life. It mandates patient participation in decisions about their health care. Consent must be given prior to treatment and patients must be properly informed before making treatment choices. Formal advance care planning processes (e.g., advance directives) enable patients to express decisions about care wanted or refused if they lose capacity to decide for themselves. Adult guardianship legislation also facilitates this participation through the appointment of substitute decision-makers where patients lack capacity. This kind of participation is integral to achieving “patient-centred care” which is at the heart of safe, high-quality health care.1 The law also supports health professionals providing medication required to alleviate pain and suffering at the end-of-life by providing legal protection if the palliative

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1 Australian Commission on Safety and Quality in Health Care, Patient-centred Care: Improving Quality and Safety through Partnerships with Patients and Consumers <https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care>.

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medication coincidentally hastens the patient’s death.² Lack of appropriate pain and symptom relief harms patients at the end-of-life and can cause long-lasting distress to the family. The law also provides dispute resolution mechanisms if there is conflict between health professionals and patients, their substitute decision-makers and families, or conflict within families themselves.

However, it is not enough for jurisdictions simply to have appropriate regulation. For regulation to be effective, its content and the role that law plays must be understood by those affected by it, namely health professionals, patients, substitute decision-makers and families. Yet prior research in Australia has established that there are significant gaps in legal knowledge among doctors in end-of-life decision-making.³ Areas of uncertainty for doctors include when an advance directive is valid, whether a doctor is legally obliged to follow an advance directive that refuses clinically indicated treatment, and how to identify a patient’s legally authorised substitute decision-maker.⁴ A lack of legal knowledge among doctors on these issues is concerning as it may result in decision-making not reflecting the patient’s views and wishes. There is also Australian research suggesting that nurses caring for patients at the end-of-life may not understand that health professionals are legally protected when providing palliative medication.⁵

Health professionals are responsible for ensuring that patients receive high-quality care. If health professionals have deficits in their legal knowledge, it becomes even more important for patients, substitute decision-makers and families themselves to be aware of their legal rights. Patients’ lack of awareness regarding their right, or the right of their substitute decision-maker, to participate in end-of-life decision-making may reduce their involvement in end-of-life discussions, which increases the risk of adverse outcomes such as receiving aggressive and unwanted medical interventions near death.⁶ If substitute decision-makers or family members are not aware that it is lawful to give sufficient medication at the end-of-life to alleviate pain and other symptoms, they will not be equipped to effectively advocate for a person to ensure he or she receives appropriate palliative medication. If they are not aware of legal avenues to challenge decisions about medical treatment, they will be unable to challenge decisions made by health professionals.

While questions have been raised about whether patients and the broader community are aware of their basic legal rights and responsibilities at the end-of-life,⁷ few studies been undertaken in this area. Research which has been conducted is either dated, has primarily focused on older people or those with specific medical conditions, or has concerned only advance care planning, including advance directives.⁸ Few studies have looked at community knowledge of other areas of law such as capacity and consent to treatment, guardianship and substitute decision-making, withholding and withdrawing life-sustaining treatment and palliative medication.

The research that is reported in this article is a component of a multi-year study which examines the extent to which community members know the law and the extent to which they are able to operationalise

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² For an examination of the relevant law in Australian States and Territories, see B White, F McDonald and L Willmott, Health Law in Australia (Lawbook Co, 3rd ed, 2018) Ch 15.
³ B White et al, “Doctors’ Knowledge of the Law on Withholding and Withdrawing Life-Sustaining Medical Treatment” (2014) 201(4) Med J Aust 229.
⁴ White et al, n 3.
⁵ L Willmott et al, “Nurses’ Knowledge of Law at the End-of-Life and Implications for Practice: A Qualitative Study” (2020) 34(4) J Palliat Med 524.
⁶ KM Detering et al, “The Impact of Advance Care Planning on End-of-Life Care in Elderly Patients: Randomised Controlled Trial” (2010) 340 BMJ 1345.
⁷ VE McLennan et al, “Relinquishing or Taking Control? Community Perspectives on Barriers and Opportunities in Advance Care Planning” (2015) 39(5) Aust Health Review 528; M Brown et al, “The Experience of Patients with Advanced Chronic Obstructive Pulmonary Disease and Advance Care-Planning: A South Australian Perspective” (2012) 20(2) JLM 400.
⁸ McLennan et al, n 7; ER Spelten et al, “Factors Influencing the Engagement of Cancer Patients with Advance Care Planning: A Scoping Review” (2019) 28(3) Eur J Cancer Care 13091; A Ugalde et al, “Does Implementation Matter If Comprehension Is Lacking? A Qualitative Investigation into Perceptions of Advance Care Planning in People with Cancer” (2018) 26(11) SCC 3765.
their legal rights to be involved in decision-making about end-of-life treatments. Data for this stage of the study were collected through in-depth interviews with 49 community members from Victoria, Queensland and New South Wales with experience of terminal illness and medical end-of-life decision-making. The primary goal of this article is to present the participants’ perspectives of the role that law plays in end-of-life decision-making.

II. METHODS

Ethics approvals were obtained from the Human Research Ethics Committees at Queensland University of Technology, The University of Queensland, Cancer Councils of New South Wales and Victoria, and UnitingCare Queensland. The larger study, including the interviews reported here, was conducted in New South Wales, Queensland and Victoria. These States were selected due to their similarities, yet also key differences between them. The methodology detailed below applies to the interview stage of the study. The results relate specifically to findings from the interviews on the role that law plays in end-of-life decision-making from the perspective of terminally ill patients, their substitute decision-makers and family members.

A. Ethical Considerations

There was a risk that the sensitive subject matter of the interview could distress participants, but participants were informed volunteers, and many terminally-ill patients want to participate in research about dying. Several strategies were implemented to reduce the risk of participant distress and minimise burden. These included taking time to develop rapport during the initial contact and at the beginning of the interview; advising participants that they could choose not to answer questions and take breaks during the interview or complete the interview over multiple sessions; and placing check questions within the interview to review participant well-being and willingness to continue. When participants displayed signs of distress during or after the interview, the interviewer followed an established distress protocol which was modified from the protocol by Draucker and colleagues and provided information on appropriate counselling. Interviewers were trained on implementation of the distress protocol and were aware of relevant ethical issues.

B. Interview Guide Development

The interview guide was developed and pre-tested by the researchers with input from the study steering committee. Development was informed by survey findings from the previous stages of the study (an examination of the relevant law, a review of publicly available web-based resources about end-of-life law and a community telephone survey about knowledge and experience with end-of-life law). The interview guide covered eight topic areas: demographic and background information; end-of-life decision-making context; nature and experiences of end-of-life decision-making; barriers and facilitators...
to operationalising legal duties, rights and powers; knowledge of end-of-life law using own and hypothetical scenarios; sources of knowledge on end-of-life law; suggested strategies to support patients and substitute decision-makers to operationalise their legal duties, rights and powers when engaging with health systems and professionals at end-of-life; and final comment/s. Wording of questions was adapted for each State law as needed, and for the participant’s role. Scenario questions testing legal knowledge were developed drawing on the researchers’ legal expertise and then tested with three independent legal experts, one from each jurisdiction. Demographic and background information was collected via the completion of a sheet either prior to, or at the beginning of, the interview. Further information on the nature of the participant’s role, the type of terminal illness, and treatment location, was collected in the first part of the interview.

C. Sampling

Purposive sampling of adults who had engaged with the health and/or guardianship system, in the context of end-of-life decisions was guided by the results of the study’s earlier stages, and issues raised by research collaborators from the Cancer Councils of Queensland, New South Wales and Victoria. As a result, the sample included adults with experience of end-of-life decision-making in a range of roles (ie patient, substitute decision-maker, family member) and in diverse settings (ie home, hospice, hospital, residential aged care). The sample included a continuum of experiences (conflict, negative, positive); a mix of locations (urban, regional and rural; and across the three States); men and women, and a broad age range.

Eligible participants were aged over 18 years, resident in Queensland, New South Wales or Victoria, and either: (1) had been diagnosed with a terminal illness and had engaged in some processes about end-of-life decision-making, or (2) had experience of end-of-life decision-making as a substitute decision-maker for a person with terminal illness either through a formal appointment by the adult or a tribunal or as a default decision-maker (eg a “person responsible”), or (3) was a family member (partner, adult child or other relative) who had witnessed or been involved with (but not as substitute decision-maker) end-of-life decision-making by or for a relative with terminal illness. End-of-life decision-making could include (but was not limited to) consideration of what treatment/s would or would not be used, discussing treatment preferences with family/medical professionals, making decisions about palliative care (eg, pain relief) or completing a document appointing someone else to make future medical decisions. Voluntary assisted dying (or euthanasia) was not considered a medical treatment for the purposes of the interviews (and so was not part of the interview guide).

D. Recruitment

Recruitment occurred over a 12-month period. A broad range of recruitment strategies included print and social media, flyers in hospitals, and support and advocacy group newsletters and emails. Recruitment in New South Wales proved challenging; targeted recruitment strategies were somewhat successful, but the overall number of participants there remained relatively low.

Potential participants contacted the researchers by telephone or email in response to a general invitation. At the initial point of contact participants were assessed for eligibility. People who did not meet the eligibility criteria were thanked for their interest and offered the study URL for more information on the research (and study findings at a later date). Those who had experienced bereavement more than three to four years prior were also screened for their perceived ability to recall their experiences in sufficient detail. Potential participants who were eligible and interested in receiving more information about research participation were forwarded the participant information sheet and consent form, either by email or post. The information sheet included an explanation of the study’s purpose, estimated interview length, relevant ethics information, assurance of the confidentiality and privacy of collected answers, and research team details. Follow-up via email or phone was undertaken if no response had been received within a month; if there was still no response, no further attempts were made to contact the person. Once consent was obtained from a participant, the interview was scheduled.
E. Pilot and Main Interviews

Ten pilot interviews were undertaken by two trained interviewers between November 2016 and April 2017, in a two-phase process. The interview guides were reviewed and revised after the first eight interviews. After the final two pilot interviews, minor adjustments were made to question wording and order, and the interview guide was updated and finalised.

Interviews were conducted between November 2016 and October 2017. Fifteen interviews were completed in person, at a university office or the participant’s home. The remaining 34 interviews were completed by phone, either due to preference or distant location of participants. All interviews were audio-recorded, and additional written notes were made during the interview. Interviews generally took between 45 and 90 minutes. Participants were provided with accurate legal information about end-of-life issues following interview completion.

1. Sample

Sixty-nine potential participants contacted the researchers. Fifty-nine were eligible and were forwarded the participant information sheet. Five potential participants did not respond to follow-up contact, and one decided not to proceed after reading the information sheet. A total of 53 participants consented to be interviewed, with 49 completing the interview. Four interviews were scheduled but not completed because of the participant’s ill health (1), distress (1), loss to follow-up (1) and personal circumstances (1).

2. Sample Demographics

The sample comprised 49 adults from the three States (see Table 1). Participants ranged in age from 28 to 86 years. Most were female (41) and Australian-born (40). The largest proportion of participants resided in Queensland (24). Nearly a third of participants (14) were health care professionals (who may be anticipated to have relevant knowledge and experience with end-of-life decision-making in their professional capacity as well).

Table 1. Participant demographic characteristics

|                      | Queensland | New South Wales | Victoria | Total |
|----------------------|------------|-----------------|----------|-------|
| Gender               |            |                 |          |       |
| Male                 | 2          | 1               | 5        | 8     |
| Female               | 22         | 5               | 14       | 41    |
| Age group            |            |                 |          |       |
| 25–34                | 2          | 0               | 1        | 3     |
| 35–44                | 5          | 2               | 3        | 10    |
| 45–54                | 5          | 1               | 2        | 8     |
| 55–64                | 3          | 2               | 6        | 11    |
| 65–74                | 5          | 0               | 3        | 8     |
| 75+                  | 4          | 1               | 4        | 9     |
| Education level      |            |                 |          |       |
| Year 10 or lower     | 5          | 0               | 5        | 10    |
| Year 12              | 1          | 2               | 0        | 3     |
| TAFE/Diploma         | 6          | 0               | 4        | 10    |
| Bachelor’s degree    | 3          | 2               | 4        | 9     |
Within the sample, there were two distinct participant groups. Sixteen participants described their current practices and experiences of making treatment decisions or seeing them be made (ie current patients and current witnesses). Thirty-three participants described their past experiences of decision-making for and/or with a patient (deceased prior to the interview) with terminal illness (ie formally appointed substitute decision-makers, default decision-maker, and previous witnesses). Of these, 20 were spouses/partners (11 formally appointed, 4 default decision-makers and 5 who were current or previous witnesses of end-of-life decision-making). Eleven substitute decision-makers were adult children of the patients (eight formally appointed, three default decision-makers); one was a grandchild (formally appointed). One parent of a patient was interviewed (as a witness of end-of-life decision-making).

All interviews related to a person with terminal illness: 43 patients had cancer, two Alzheimer’s Disease or other dementia, and three had other conditions, for example Motor Neurone Disease. Of these, nine were multiple or complex cases, for example where the person had cancer and another major condition such as a stroke. Regarding treatment location, 36 cases were treated in the public system. Twelve of these were in a public hospital with the remainder being some combination of care by a general practitioner, being cared for at home/palliative care at home, a residential aged care facility or in a palliative care ward or facility. Thirteen were treated in the private system, including seven in a private hospital.

F. Data Analysis

Interviews were transcribed verbatim, checked for accuracy against the original recordings and corrected where necessary. Participant documentation such as interview recordings and transcripts were given a unique identifier code. Cleaned versions, de-identified of participant and/or patient name (but not names of other family members or treating health care professionals) were uploaded into NVivo. Pilot interviews were included in the analysis.

As the interviews followed a defined structure informed by previous stages of the study, a framework approach to analysis was used. This analytic technique combines thematic and case-based analysis using a systematic approach to summary and synthesis, and is well adapted to research designed around specific a priori issues, while allowing for emerging themes and issues (ie both deductive and inductive).\footnote{NK Gale et al, “Using the Framework Method for the Analysis of Qualitative Data in Multi-Disciplinary Health Research” (2013) 13(1) BMC Med Res Methodol 117.} Initial themes and associated coding nodes were primarily created from the interview questions and the study’s research questions; as other themes emerged from the interview data, these were used to create additional nodes.
The preliminary coding framework was established based on the 10 pilot interviews, and results were reviewed by the research team to ensure the interview data were answering the research questions. This framework emerged from two meetings of the research team that centred on developing and then finalising the coding framework. Group coding by the research team of three interviews took place to ensure coding consistency. All interviews were manually coded. The framework matrix available in NVivo was then utilised to cross-tabulate selected participant characteristics with responses to questions/topics of interest. This avoided the fragmentation that can result from using thematic analysis only.

III. RESULTS

This section reports on the extent to which, and how, terminally ill patients, substitute decision-makers and family members perceive law as having a role in the end-of-life decision-making process. As explored further below, three themes emerged from the data: that law is generally not perceived as playing a role in the decision-making process; nevertheless, participants felt supported by the law in making end-of-life decisions; and that law is more likely to play a role if there is conflict at the end-of-life (though participant views varied in terms of the law’s usefulness in such cases).

A. Law Generally Does Not Play a Role in End-of-Life Decision-Making

Participants had variable views on the role of law with most perceiving it as not playing a role when it came time to make a decision about medical treatment as the patient approached the end-of-life. Treatment decisions were made and issues resolved without a need to resort to the law. One possible exception noted by participants was in cases of significant conflict (reported in the third theme below). Several participants commented that they really did not think about the law because it did not come into play; they did not experience any difficulties or conflict. Decision-making was seen as the province of the treating team and family:

[T]here was not one time where I thought what does the law say about these kinds of situations because I just assumed, or I just expected that any decisions that needed to be made about someone’s health should be up to the family. (Substitute decision-maker, 25–34, Victoria, regional, public system)

As evidenced by one participant responding to a question about law’s role, doctors rather than law were seen as responsible for guiding medical decision-making:

I can imagine it can be if there are disputes within family over treatment or if there’s issues over money or something like that, but I guess you sort of a little bit blindly place your faith in the medical facility and the doctors that you’ve got to guide you through the various stages of what happens and what’s appropriate. (Patient, 55–64, Victoria, city, private system)

Most participants reported that patients they were supporting had engaged in some formal advance care planning, whether that was appointing a substitute decision-maker or making an advance directive. In several cases, this advance care planning had been completed prior to diagnosis of terminal illness, sometimes because of previous life experience, or a proactive “planner/organiser” style of decision-making. Although such documents are legal documents that are facilitated by statutes, until prompted, participants did not conceptualise documents that appointed substitute decision-makers or contained directions about future treatment as relating to the law or being underpinned by the law:

I’ve got one, the power of attorney anyway. But besides that I don’t really – you place all your faith I guess in your doctors and your hospital. You don’t kind of see this as a legal situation as such. (Patient, 55–64, Victoria, city, private system)

Most statements about what participants wanted to happen (having a particular person as their decision-maker) or what decisions were made (under their advance directive) accorded with the law, or indeed relied upon the law, as their basis. Statements concerning the right of a patient to refuse medical treatment were an example. While some participants were clear that the law guaranteed a patient’s right to refuse treatment, or for substitute decision-makers to do so on their behalf, other participants indicated
that they saw the right to refuse in terms of general human rights (ie “soft law”), rather than being conceptualised or referred to in terms of legal rights:

I thought it was everyone’s right to actually refuse treatment if you felt you didn’t want to have it. I would assume, if you’ve got full faculty, that you have that right. (Witness, 65–74, Queensland, city, public system)

B. Feeling Supported by the Law and the Usefulness of Legal Documents

Although participants did not generally perceive the law to play a role in making decisions, many felt supported by the law. For those who did feel supported by the law, this generally related to advance care planning and the ability to plan for medical decision-making in the future when they had lost decision-making capacity. Some patients found it reassuring to record their wishes in an advance directive or appoint their substitute decision-maker through an enduring power of attorney or guardianship and, in this way, felt supported by the law. Those who completed enduring documents were secure in knowing that it empowers the people they have appointed to make decisions on their behalf. Advance directives could be referred to for decision-making, drawn upon, and used to advocate for the patient. There was some comfort that their wishes had been made clear for future decisions. Documents that talk about treatment preferences also provide reassurance and guidance to substitute decision-makers and reduce second-guessing decisions. Some participants also raised the importance of having an advance directive in place to refer to in the event of disagreement between family members about treatment:

I feel secure that the law is there to protect me with that advance health directive. (Substitute decision-maker, 75+, Queensland, regional, public system)

Other participants presumed the law would support the decisions they made; their perception was that what they were doing was consistent with the law, therefore it would be supported by the law should the decision ever be challenged:

I believe that, yes, we had a clear position under the law for what we were asking for and what we expected. Yes. So the law was, I believe, quite clearly on our side. (Substitute decision-maker, 55–64, Queensland, regional, public system)

However, there was one important exception to the feeling of being supported by the law, and that relates to voluntary assisted dying. At the time of the interviews for this study, voluntary assisted dying had not been legalised in any Australian State or Territory, and was outside the scope of this study. Further, at the time of recruitment, it was clearly indicated that the study was not about voluntary assisted dying and whether this should be permitted for patients at the end-of-life. Despite these factors, the inability to receive assistance to die was a central issue for some of the participants. The fact that individuals at the end-of-life were unable to receive assistance to die meant that a minority of participants did not feel supported by the law:

I still feel that people should have a right to euthanise, so therefore the law lets you down there. You shouldn’t have to wait until you are really incapacitated and in a lot of pain to be able to actually take enough pain relief to end it. I don’t think that’s fair. (Patient, 45–54, Queensland, regional, private system)

C. Role of Law during Conflict

The one situation for which the participants reported law could play a role is in managing conflict which can arise at the end-of-life. Conflict can arise when making treatment decisions at the end-of-life in two different contexts: between the treating team and the patient/substitute decision-maker/family; and within the patient’s family, whether that was between the patient and other family members, or different members of the family had different views about treatment. While many participants identified law as having a role when conflict arose, they reported varying levels of comfort in pursuing legal action and limited degrees of satisfaction when they did so.

16 Nevertheless, the reform process had been commenced in Victoria. See B White and L Willmott, “Future of Assisted Dying Reform in Australia” (2018) 42 Aust Health Review 616.
1. **Conflict between the Treating Team and the Patient/Substitute Decision-Maker/Family**

There were 11 cases where participants reported that major conflict was experienced between the treating team and the patient/substitute decision-maker/family, and in 6 of these cases, the “law” was implicated as playing a role in its resolution (or attempted resolution).

(a) **Case One**

**Context:** The first case involved the authority of substitute decision-makers being ignored or challenged by a nurse (and on occasion, other members of the clinical team). The participant and a sibling had been formally appointed as substitute decision-makers (attorneys) by the patient. However, there was disagreement between the treating team and family as to whether the patient had decision-making capacity, with the broader family (including the attorneys) maintaining that he was unable to make complex decisions following a stroke. As a result of this, the clinical team treated the patient as the decision-maker whereas the attorneys perceived that they had authority to make decisions on the patient’s behalf. While in some regards this was not problematic (patient and family wishes were consistent), it meant that the attorneys were not informed and consulted in a way that was consistent with their perceived rights as substitute decision-makers. There was also some conflict within the family regarding decision-making processes, with the participant reporting that other family members did not respect their role as legally recognised decision-makers.

**Action taken:** The appointed attorneys were pursuing an ongoing official complaint against one of the nurses in relation to their decision-making authority being challenged. The participant also considered organising a formal capacity assessment for the patient and consulted a lawyer for general advice and information about lawyers who have relevant expertise should they wish to engage other lawyers.

**Resolution:** This case involved a complaint that was ongoing at the time of interview. The conflict situation was seen as “annoying” by the participant and “distressing” for the other attorney. Despite this, the participant felt that the hospital was taking the complaint seriously, that there was genuine concern about the grievance, and that there had been acknowledgment from the nurse involved that the claims made were accurate.

**Perceptions about the role of law:** The participant felt that the law supported their inclusion in treatment discussions and decisions. The participant felt confident that the patient no longer had capacity to make complex medical treatment decisions and felt certain of their right to make decisions for the patient having been appointed as an attorney. The participant also recognised that under the law they had special decision-making authority compared to other family members who were not appointed attorneys and described displaying the enduring power of attorney on the wall in the patient’s hospital room. The attorneys demonstrated good knowledge of the law and were of the view that improved legal knowledge within the clinical team would have helped to prevent conflict.

(b) **Case Two**

**Context:** The second case also involved the authority of a substitute decision-maker being ignored or challenged by members of the clinical team (nurses and doctors). Similarly, there was disagreement between the participant and team regarding whether the patient had capacity (and hence whether the guardian had authority to make decisions on their behalf). The participant had been formally appointed as a substitute decision-maker by the patient. The case involved a backdrop of general concerns about standards of patient care and communication.

**Action taken:** The participant made a complaint against the relevant public hospital to the Health Care Complaints Commission (NSW) at the suggestion of staff from another hospital. They also sought advice on the matter from a family solicitor.

**Resolution:** Mediation was provided by the Health Care Complaints Commission. This led to various outcomes including an apology from the hospital, some changes to hospital processes around substitute decision-making and filing of relevant documentation, and the assistant director of nursing was disciplined. There was also some improvement in the relationship with hospital staff.
Perceptions about the role of law: Again, the participant felt supported by the law in this conflict situation. Having assured the family solicitor that the patient had capacity when they appointed her as a guardian, the participant felt that the law supported her right to make decisions as an appointed guardian. The participant also referred to the patient’s advance directive to make decisions as providing them with authority to act. The participant did not find the family solicitor to be helpful, stating that they were “very reluctant to being involved any further than to document the guardianship and attorney files”. However, they were positive about how the complaint was handled by the Health Care Complaints Commission, stating that:

The mediation that they provided was very valuable, very valuable for the hospital to hear, for the administrators, the director of medical services and the director of nursing services. Mum got the apology that she deserved. We weren’t after money or trying to sue anyone. They just needed to apologise to her for how she had been treated. It wasn’t good enough. Mum was really, really proud because she made change. (Substitute decision-maker, 35–44, New South Wales, regional, public system)

(c) Case Three

Context: The third case again involved the authority of substitute decision-makers being ignored or challenged by a nurse (and on occasion, other members of the clinical team). The participant had been formally appointed as a substitute decision-maker by the patient, and there was an advance directive in place. The case also involved a backdrop of general concerns about standards of patient care and communication.

Action taken: The participant met with the nurse in question to discuss their concerns, filed a complaint with the director of the hospital unit, and sought advice from both a lawyer and an academic expert (friend) about their decision-making authority. They also filed a formal complaint with the hospital, lodged just before the interview.

Resolution: At the time of interview, the hospital had issued an apology, however the formal complaint against the hospital was still being investigated.

Perceptions about the role of law: The participant felt supported by the law, particularly once their rights were confirmed by others. For example, the director of the hospital unit highlighted the importance of stating that they were an appointed guardian and that they had power to withdraw treatment consistent with the patient’s advance directive. The participant’s legal authority to make decisions for the patient was also confirmed by both the lawyer and academic expert. Again, this participant noted that there were gaps in health professionals’ knowledge about the rights of substitute decision-makers to make decisions on behalf of patients.

(d) Case Four

Context: The fourth case involved decision-making on behalf of a patient lacking decision-making capacity. The participant reported that decisions were being made by the clinical team to the exclusion of the family, and in some instances, decisions were made that went against the family’s expressed wishes. The participant had not been appointed as a substitute decision-maker by her husband but had assumed that she could make decisions on his behalf if he were unable to make his own decisions.

Action taken: The participant made an application to a tribunal to be appointed a guardian of the patient, in the knowledge that tribunals may appoint legally recognised guardians to make medical treatment decisions for others.

Resolution: The application was successful, and the participant was appointed as guardian for the patient. This allowed the participant to arrange for her husband to be transferred from the hospital to an aged care facility to receive palliative care.

Perceptions of the law: While not commenting specifically on the process of being appointed as a guardian, the participant reported that the whole experience was “shocking” and could not understand why she had not been permitted to make decisions for her husband without going through a formal process.
(e) Case Five

**Context:** Conflict arose in this case because a doctor failed to discuss and obtain consent for referral of the patient to a palliative care service. The case involved a backdrop of general concerns about standards of patient care and communication.

**Action taken:** Several actions were taken by the participant including speaking with various members of the clinical team, hospital Registrar, and hospital liaison office; writing letters to the hospital; filing a complaint with the Health Ombudsman; communicating with the hospital board (and having further discussions with the palliative care doctors); requesting a case review from the Health Ombudsman; and writing to the Health Minister. They also sought legal advice from a solicitor.

**Resolution:** While there were some responses and outcomes arising from these actions (eg, written responses, a conciliation meeting), the participant felt that ultimately there was no satisfactory resolution to these actions. The solicitor’s advice was also that nothing further could be done.

**Perceptions of the law:** The participant was aware of their right to make decisions as an attorney and felt supported by the law through having been appointed by the patient. However, in relation to action taken to resolve the conflict, the participant reported that this had not accomplished much and had added to the distressing nature of the whole experience.

(f) Case Six

**Context:** This case differed from the others in that it was not the participant who identified the “law” as potentially playing a role in the resolution of major conflict. This case involved conflict between the patient/substitute decision-maker and the clinical team regarding the withdrawal of active treatment and provision of community-based palliative care. It also involved a backdrop of general concerns about standards of patient care and a lack of consideration of the wishes of the patient and substitute decision-makers. The participant and others had been formally appointed as substitute decision-makers by the patient.

**Threatened action by treating team:** During a family meeting with team, hospital staff highlighted that they had the option of taking the matter to the Victorian Civil and Administrative Tribunal to attempt to prevent the patient from going home. While hospital staff also indicated that they did not intend to take such action, the participant and their family members were astonished and appalled by the comment.

**Perceptions of the law:** They did not see the law as being relevant to decision-making (or conflict), considering instead that all that was relevant was the wishes of the patient and family. When the participant’s decision-making authority was challenged, they did not think to draw on having been formally appointed by the patient or bring the treating team’s attention to relevant documentation:

> No. I don’t think we ever even knew that that was an option. I think if they had completely stonewalled us and said “No, we’re going to VCAT [Victorian Civil and Administrative Tribunal]. You’re not taking him home”, we would have just accepted that. I don’t think we realised that there was any other remedy other than that … Probably if we had further knowledge of the law, we could have sought – after the insults and the trying to sort of deter us from what we thought was best for him, I would have called their bluff and said “Enough of this. This is actually the law, that he can ask to go home and have this treatment modality ceased and he can live at home for as long as his life allows”, then I probably would have been more defiant at that point, but it’s quite hard when you’re in that situation. It’s hard to argue with the experts.

(Substitute decision-maker, 45–54, Victoria, city, private system)

**Resolution:** Ultimately, after the patient had been allowed to return home for palliative care, the participant wrote a letter of complaint to the hospital. They were disappointed with the apology received and viewed the response as generic and lacking any indication that processes or decisions would be reviewed.

In contrast to those detailed above, other cases involving conflict did not result in action being taken to resolve the conflict. Patients or substitute decision-makers who experienced conflict were sometimes unaware they could draw on the law or felt too overwhelmed to do so:

> Seeking a legal opinion just didn’t occur to me. (Patient, 65–74, Queensland, city, private system)
My sister had enough on her plate. She said “I don’t want to take this on legally … I’ve got enough to deal with. I could go through all this and nothing might happen”. (Patient and substitute decision-maker, 55–64, Victoria, city, private system)

Participants who had not encountered conflict with members of the treating team when making medical decisions were also asked how they thought they would respond to such conflict. These participants identified a range of possible options that they might pursue before exploring legal options. These other strategies included communicating with the health care professional directly, seeking a second opinion, changing doctors, moving from the current hospital, or contacting patient complaints services or social workers. Of those participants who reported being prepared to pursue legal options, 10 advised that they would draw the attention of the health care professional to the relevant document, namely the enduring power of attorney or advance directive. Participants in eight cases said that, if necessary, they might consider legal options/processes. Another eight cases would seek advice from a family solicitor:

   After I’d referred them to all of this documentation and said those were her wishes and just pointed out that they had been her wishes – these doctors would have been the doctors in hospital I presume, not her GP … I would think that I would just keep saying to the doctors who might be differing with me that that was what the person wanted. I’d probably call on my solicitor and get some legal advice as well. (Substitute decision-maker, 75+, Victoria, regional, public system)

Those participants who reported they would not use legal options gave a variety of reasons for taking that position. Some of those reasons related to the legal process itself: resolving conflict through legal means would not be feasible given the timeframes involved; poor previous experiences with legal processes; belief that the legal profession and processes are biased towards medical professionals; the perceived expense; and difficulties knowing how to find a lawyer with appropriate expertise:

   I guess it all depends on what the dispute is. Legal processes take time and if she needs the pain relief now, legal process is not going to help. So yes, aware of a legal process, but I think in that environment it’s really not going to be of any benefit. (Substitute decision-maker, 45–54, Queensland, city, private system)

But other reasons related to the characteristic and nature of the participants, reporting that this is not how their family resolves issues (though believing that legal processes should be available), that the law is not a constructive route, or that the law should not be needed as the patient’s wishes were clear (having completed an advance directive). There also appeared to be a generational difference, with older participants more likely to place their trust in health care professionals and not wishing to question their judgment.

2. Conflict within Families

Conflict in decision-making at the end-of-life can also be experienced between family members, and the extent to which participants recognised the role of law in resolving disputes or preventing conflict from arising in the first place varied.

When the patient retains decision-making capacity, there is less opportunity for conflict to arise as the patient has undisputed authority to determine treatment that is refused and given. Conflict is more likely to arise when the patient loses capacity, has not made an advance directive that applies to the context, and the decision has to be made on their behalf. The law has an important role in minimising conflict and uncertainty by establishing decision-making structures within relevant legislation, whether formally through the appointment of an enduring attorney or guardian, or informally through hierarchies for determining default decision-makers. This can prevent conflict within families, particularly if all family members have discussed and understood the reasons for such appointments.

However, as revealed by the data, conflict arose even though the legally appointed decision-maker was known. One substitute decision-maker (an adult child of the patient) described conflict within the family when the patient’s spouse (the substitute decision-maker’s father) assumed he would automatically be the decision-maker as “next of kin” (a term not recognised under laws relevant to substitute decision-making). In another case, a family member described his unhappiness at not being the decision-maker for his son, because his son’s wife was the default decision-maker under the relevant legislation (as the
patient had not completed an enduring power of attorney). The father had assumed he would have a say in decision-making as head of the family. Although conflict arose in these cases, as described, the law provided the framework to determine the decision-maker in each case. In some cases, participants recognised that the law had a role to play in resolving conflict around the appointment of substitute or default decision-makers. One participant spoke about feeling supported by the law in their decision-making role even though other family members disputed this, because of the existence of an advance directive and their appointment as an enduring attorney. Another participant was appointed secondary enduring attorney and sought advice from a solicitor to clarify their legal rights and responsibilities as a decision-maker.

For patients interviewed, potential conflict between family members was largely hypothetical, but they did recognise the role that law could play in providing certainty and in avoiding conflict or hardship. Many felt that family members or their appointed attorney or guardian would invoke their legal decision-making status or could refer back to the advance directive if one was in place. Two patients had completed advance directives but not appointed an enduring attorney or guardian. This was done specifically to relieve family members from being placed in a decision-making position, and thereby to avoid family conflict. Several substitute decision-makers also felt they would be supported by the law in their role, even if, hypothetically, other family members disputed the substitute decision-maker’s authority as decision-maker.

Few participants appeared to be aware of the legal options available to them if there was disagreement between family members. Those who were aware made suggestions such as seeking a third party to mediate:

> When people don’t agree, then, yes, depending on the extent of the - I would suggest that they sit down with somebody like a social worker for a start to help mediate towards a shared agreement and if you can’t agree, it’s QCAT [Queensland Civil and Administrative Tribunal]. (Substitute decision-maker, 45–54, Queensland, regional, public system)

### IV. DISCUSSION

End-of-life decision-making is not merely a process that takes place between a doctor and a patient. As well as individual decision-making styles, personal characteristics, and approaches to death and dying, other factors influence and inform decision-making, including the medical profession, health systems, and relevant cultural and social beliefs. The law itself also has an important role to play in end-of-life decision-making. Compliance with relevant legal principles such as respecting autonomy and supporting informed decision-making will improve end-of-life decision-making with associated benefits to patients and their families. However, for these principles to truly infuse the decision-making process, those involved must both understand that law plays a role in that process and know the content of relevant laws.

The authors have elsewhere reported on significant knowledge gaps about key legal issues by patients and substitute decision-makers involved in end-of-life decision-making, including participants who were health care professionals. These findings build on that research and report on community perceptions of the role of law. Interview participants had variable views on the role of law. Most did not see it as having a role generally with participants reporting that treatment decisions were made and issues resolved without a need for law.

One exception that emerged was in cases of significant conflict, either between health professionals and the patient/substitute decision-maker/family, or within the patient and family unit. When conflict resulted in action being taken by the participant (and/or other parties), various approaches were taken to resolve the conflict. These ranged from informal processes (eg drawing health professionals’ attention to relevant documentation) to more serious action (eg formal lodging of a complaint, seeking advice from lawyer, or making an application to a tribunal). Cases were resolved through a range of avenues including assessment and investigation of complaints, local resolution at the hospital level, conciliation

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17 Tilse et al, n 9.
processes and health professional complaint process. At the time of interviews, the complaints process was ongoing for two participants. Some participants reflected that taking formal action had not accomplished much and had been a distressing process. Participants often expressed the wish to instigate changes in health professionals’ decision-making practices. Consistently, the case involving a complaint against the relevant public hospital to the Health Care Complaints Commission was viewed positively as it led to procedural changes within the hospital. In four of the six cases where action was taken (or contemplated) to resolve conflict, the participants were current or former health professionals. Some commented that they drew on their clinical experience (and sometimes legal knowledge) to help navigate conflict situations, albeit it not without difficulty. They could generally identify concerning decision-making practices (usually being excluded from decision-making processes), assert their rights as decision-makers, and challenge the authority of health professionals and/or their decisions. In this way it appeared that having a health professional background facilitated participants taking formal action in conflict situations.

Some participants expressed the view that the law is not relevant to end-of-life decisions or is less important than medical opinion and family views. However, most statements about what participants wanted to happen or what decisions were made accorded with the law or relied upon it to operate. Two obvious examples are the appointment of substitute decision-makers and the making of advance directives. These processes, which are facilitated by law and indeed created by law, were frequently (and unsurprisingly) used by this cohort as decision-making mechanisms. Nevertheless, until prompted, appointing substitute decision-makers and making advance directives were not conceptualised as legal decisions or those in which law was a relevant component. To this extent, the role of law was largely invisible. Given that law mandates patient and substitute decision-making participation in health decisions, invisibility of the law is a barrier to patients, substitute decision-makers and family members being able to operationalise their legal rights in the end-of-life decision-making context. Therefore, there is need to increase community legal literacy around end-of-life decision-making including about the role of law and knowledge of how to access appropriate legal information when it is needed.

As mentioned, participants suggested that the law was less important in the end-of-life context because they relied on medical and other health professionals undertaking their professional roles and family members collectively discussing and making medical decisions with or on behalf of the patient. In the ordinary course, such an approach is likely to lead to satisfactory outcomes for the patient. However, there are also potential risks of medical decisions being made in an environment where decision-makers are unaware of the governing legal framework.

First, in some situations, decision-making outside legal parameters (or without an understanding of those parameters) can result in sub-optimal patient outcomes. Four examples illustrate how this might be the case:

- If treatment decisions for a patient lacking capacity are made by consensus between the treating team and family members, it is possible that the wishes of the patient, as expressed in their advance directive, may be overlooked or ignored. The treating team and family may prioritise extending the patient’s life despite the patient’s previously expressed focus being on quality of their life and not wishing their life to be extended if it lacked what the patient considered to be meaningful.
- Conversely, the treating team may suggest that treatment for a patient, for example a patient who has dementia, is “futile” despite the family wanting the treatment to be provided as it will lengthen the patient’s life. Failure to understand how the law regulates decision-making in this context may result in treatment not being provided despite it potentially providing the patient with some benefit.
- The treating team may look to the incorrect substitute decision-maker to make a treatment decision for a patient who has lost capacity. This is particularly a risk when the patient with adult children has re-partnered and family members hold different views on treatment. Seeking input from the incorrect substitute decision-maker may result in a treatment decision that is inconsistent with patient preferences.
• Finally, in the absence of an understanding that it is lawful to provide sufficient palliative medication to relieve pain despite potentially hastening the patient’s death, a patient may endure unnecessary suffering at the end-of-life.

Second, and following on from the above, a lack of understanding of the role of law in the medical decision-making process may mean that patients, families and substitute decision-makers are unable to confidently identify concerning decision-making practices for example the decision-making authority of substitute decision-makers not being respected. It may also put at risk their ability to assert their rights. It may also mean that a patient/substitute decision-maker/family member will not be equipped to challenge a decision, or may be uncertain about the steps to take if conflict arises in the decision-making process. A lack of legal literacy is particularly problematic given that systemic issues such as power imbalances between health professionals and patients/substitute decision-makers can make it difficult for patients and substitute decision-makers to challenge the authority of health professionals and confidently navigate conflict situations. A greater understanding of the legal framework will better empower a patient and others to challenge the decision, whether informally through processes established within a hospital or more formally through a tribunal or, more rarely, a court. Part of the challenge then is for individuals to recognise there are legal duties, rights, and powers relevant to end-of-life decision-making. This points to the need to overcome the invisibility of law and to ensure people become aware of and recognise their rights. There is a need to enhance understanding of the role that law can and does play at the end-of-life.

To this end, we make the following recommendations intended to improve community knowledge of the role of law and its content in the context of end-of-life decision-making.

A. Community Education

First, community education should be provided so that people know that law is relevant to decision-making at the end-of-life, understand and recognise when there is a legal issue, and know how to access appropriate information on the law. Community education from a young age is supported by the literature, with recent surveys supporting education for high school and university students on substitute decision-making and advance care planning. Some studies have also reported the benefits of community education on advance care planning and advance directives for older community-dwelling adults and the period following retirement may be an optimal time to implement community education initiatives. Of particular importance is generating awareness of legal instruments that can be completed to make treatment decisions in advance of losing capacity or appointing a substitute decision-maker to make treatment decisions when they are no longer able to. Advance care planning is being more embedded into medical practice. However, awareness of advance care planning among the general population is still limited. Further, the completion of advance directives to record actual treatment decisions is less

18 K Curnow, “End-of-Life Decision-Making in a Health Services Setting: An Access to Justice Lens” (2016) 23(4) JLM 864.
19 Curnow, n 18.
20 MK Wong et al, “Does the Public Feel Prepared to be Substitute Decision-Makers? Gaps in Preparedness and Support for a High School Curriculum: A National Survey” (2020) 50(1) Age Ageing 242; P Barrison and LG Davidson, “Promotion of Advance Care Planning among Young Adults: A Pilot Study of Health Engagement Workshop Feasibility, Implementation, and Efficacy” (2020) 38(5) Am J Hosp Palliat Med 441.
21 JL Murphy, “Advance Care Planning: Community Education to Improve End-of-Life Knowledge and Communication” (2018) 48(11) Nurs 63; M Matsui, “Effectiveness of End-of-Life Education among Community-Dwelling Older Adults” (2010) 17(3) Nurs Ethics 363.
22 Wong et al, n 20.
23 M Sellars et al, “Public Knowledge, Preferences and Experiences About Medical Substitute Decision-Making: A National Cross-sectional Survey” (2021) BMJ Support Palliat Care 1 <https://spcare.bmj.com/content/bmjspcare/early/2021/03/15/bmjspcare-2020-002619.full.pdf>.
common, and initiatives to complete such documents have had fairly limited traction. There should also be continued efforts for individuals to appoint substitute decision-makers to be their decision-makers if capacity is lost given current low rates. A national cross-sectional online survey of the Australian adult public found that only 33% were aware of the existence of substitute decision-making laws, and that most people had low to moderate levels of knowledge about the substitute decision-making role. Prior conversations between patients and substitute decision-makers about treatment preferences have been found to increase the confidence of substitute decision-makers in their decision-making role, and availability of advance directives to guide decision-making may reduce substitute decision-makers’ burden and distress by creating emotional distance from decisions.

In addition to promoting an understanding of the role of enduring documents and encouraging their completion, community education should be provided so that people know, in addition to the fact that law does play a role at the end-of-life, what that law states in terms of their rights, powers and duties. Relevant areas of law include: consent including the need to have sufficient information to make a treatment decision; the law governing instruments that facilitate making advance directives about medical treatment or the appointment of a substitute decision-maker; what factors a substitute decision-maker must consider when making a decision for a person without capacity; who is the decision-maker in a particular situation; what dispute resolution avenues are available if conflict arises either between the patient, family and/or treatment team; permissible levels of pain medication; and whether a patient can demand treatment that health care professionals consider to be futile or not in the patient’s best interests.

B. Accessible Education to Be Available from Diverse Publicly Available Sources

Community education should be provided in a range of ways but most importantly, there should be publicly available resources that are readily accessible and easily understood to diverse community groups. More needs to be done to make existing online and print resources easy to locate (particularly for online resources) and easy to understand by containing appropriately pitched content and being in an accessible format. A variety of targeted resources are needed to reach different parts of the community and to cater for individual needs and decision-making styles. These include online resources such as community websites and dedicated end-of-life law websites, as well as materials in print format for example posters in health care settings and brochures available in GP practices, hospitals, specialist practices and through palliative care services.

24 J Bryant et al, “Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities” (2021) BMJ Support Palliat Care https://spcare.bmj.com/content/early/2021/01/03/bmjspcare-2020-002767; KM Detering et al, “Prevalence of Advance Care Planning Documentation and Self-reported Uptake in Older Australians with a Cancer Diagnosis” (2020) 12(2) J Geriatr On 274; KM Detering et al, “Prevalence and Correlates of Advance Care Directives among Older Australians Accessing Health and Residential Aged Care Services: Multicentre Audit Study” (2019) 9(1) BMJ Open e025255; K Buck et al, Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services Report (Advance Care Planning Australia, 2020) <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/report-national-acd-prevalence-study-2019.pdf?sfvrsn=4>.

25 Buck et al, n 24.

26 M Sellars et al, “Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making: A National Cross-sectional Survey” (2021) BMJ Support Palliat Care 1 https://spcare.bmj.com/content/bmjspcare/early/2021/03/15/bmjspcare-2020-002619.full.pdf+.

27 A Majesko et al, “Identifying Family Members Who May Struggle in the Role of Surrogate Decision Maker” (2012) 40(8) Crit Care Med 2281.

28 TV Cunningham et al, “How Do Clinicians Prepare Family Members for the Role of Surrogate Decision-Maker?” (2018) 44(1) J Med Ethics 21.

29 J Tran et al, “Systematic Review and Content Analysis of Australian Health Care Substitute Decision Making Online Resources” (2021) 45(3) Aust Health Review 317; SS Yap et al, “Exploring the Knowledge, Attitudes and Needs of Advance Care Planning in Older Chinese Australians” (2018) 27(17–18) J Clin Nurs 3298.

30 Tran et al, n 29; White et al, n 13.
Participants in this study relied on advocacy and support groups (eg Cancer Councils, Breast Cancer Network Australia) as a trusted source of information about end-of-life law, and those who accessed information on these websites, or who received information from these organisations found the content useful and easy to understand. This highlights the potential role of these groups in providing community education on end-of-life law.

C. Education of Health Care Professionals

Educating health care professions is critical, and we make this recommendation for two reasons. First, health professionals are seen as a trusted source of legal information, so need to be aware of the law in this area. A finding from an earlier component of this study, a telephone survey of members of the public,\(^31\) is that patients see health care professionals as a source of legal knowledge for end-of-life decision-making, and this is consistent with research undertaken with substitute decision-makers.\(^32\) However, the quality of the information provided by these professionals will depend on their level of legal knowledge. It is therefore important for health care professionals to understand the relevant duties, rights, and powers that patients and their families possess when making end-of-life treatment decisions, and guide patients and families at this time.

But second, as we have seen earlier, failure of health care professionals to know the law can lead to conflict with the patient and/or family members. This is powerfully illustrated by reports of participants that members of a patient’s treating team did not realise that the legally appointed substitute decision-maker was authorised and indeed required to make health care decisions on behalf of a patient who lacked decision-making capacity.

D. Support to Operationalise Legal Rights, Powers and Duties

Finally, assuming members of the community are aware of the relevant legal framework, support is needed to facilitate people operationalising their legal rights, powers and duties and this support should be available to people both within and outside of health systems. Put another way, knowing that law has a role to play and even knowing the content of the law by community members are not sufficient on their own; they must also be able to raise those legal rights in practice including being able to initiate dispute resolution processes. While many substitute decision-makers lack confidence in decision-making,\(^33\) there is currently insufficient support for substitute decision-makers in making medical decisions,\(^34\) and guidance from treating clinicians is variable.\(^35\) People with dementia and their carers have reported a lack of confidence in the information and support available to them in health care settings when undertaking advance care planning.\(^36\) There is a need for explicit instruction on how to perform the substitute decision-making role\(^37\) as well as resources addressing the types of challenges they are likely to encounter.\(^38\) Strategies could include providing advocates in hospital settings who can talk through end-of-life legal information with patients, substitute decision-makers and family members; dedicated support services that patients can access for assistance to complete advance care planning or to appoint enduring attorneys or guardians such as free seminars, assistance from someone in person (eg social worker) or by telephone. Different strategies would need to be employed outside the hospital

\(^{31}\) White et al, n 9.

\(^{32}\) Sellars et al, n 26.

\(^{33}\) Majesko et al, n 27.

\(^{34}\) Sellars et al, n 26.

\(^{35}\) Cunningham et al, n 28.

\(^{36}\) M Sellars et al, “Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care: A Systematic Review and Thematic Synthesis of Qualitative Studies” (2019) 33(3) Palliat Med 274.

\(^{37}\) Cunningham et al, n 28.

\(^{38}\) Sellars et al, n 26.
setting including in the primary health care setting, where general practitioners and advocacy and support groups may have a role.

E. Limitations
Challenges with recruitment of participants (common for studies involving terminally ill patients and their families) meant that the sample has a higher proportion of females, health care professionals and participants from Queensland and Victoria. Furthermore, participants self-selected into the study, and demographics tended towards people who were well educated, in stable partnerships, and who by and large had supportive spouses and/or family members around them. A further limitation is the potential for recall bias.

V. CONCLUSION
End-of-life decision-making is complex and influenced by a range of factors. Although potentially not seen by those involved in these decisions, we contend that law is an important consideration in decision-making at the end-of-life. The law promotes decision-making autonomy by ensuring decisions are informed and by establishing legal processes so that decisions are made consistent with the patient’s values and wishes, even after the patient loses decision-making capacity. For the law to be effective, its role and its content need to be understood by those it purports to regulate.

A better understanding of relevant legal duties, rights and powers of patients, substitute decision-makers and families will ensure their genuine participation in treatment decisions at the end-of-life. This should improve the quality of decision-making and experiences end-of-life, meeting the significant and growing social imperative to improve how end-of-life treatment decisions are made. The recommendations arising from this study are aimed at improving end-of-life decision-making by enhancing understanding of the law by members of the community as well as the role that law can play at the end-of-life.