Operationalizing legal rights in end-of-life decision-making: A qualitative study

Cheryl Tilse1, Lindy Willmott2, Jill Wilson1, Rachel Feeney2 and Ben White2

Abstract

Background: For a patient’s legal right to make end-of-life treatment decisions to be respected, health care practitioners, patients and their substitute decision-makers must know what rights exist and how to assert them (or support others to assert them). Yet very little is known about what enhances or obstructs the operationalization of legal rights from the perspective of patients, family members and substitute decision-makers.

Aim: To explore barriers and facilitators to the operationalization of rights in end-of-life decision-making from the perspectives of terminally-ill patients and family members and substitute decision-makers of terminally ill patients in Australia.

Design: Semi-structured interviews (face to face and telephone) with patients, family or substitute decision-makers experienced in end-of-life decision-making completed between November 2016 and October 2017. A thematic content analysis of interview transcripts.

Setting/participants: Purposive sampling across three Australian states provided 16 terminally-ill patients and 33 family and/or substitute decision-makers.

Results: Barriers and facilitators emerged across three overlapping domains: systemic factors; individual factors, influenced by personal characteristics and decision-making approach; and communication and information. Health care practitioners play a key role in either supporting or excluding patients, family and substitute decision-makers in decision-making.

Conclusion: In addition to enhancing legal literacy of community members and health practitioners about end-of-life decision-making, support such as open communication, advocacy and help with engaging with advanced care planning is needed to facilitate people operationalizing their legal rights, powers and duties. Palliative care and other support services should be more widely available to people both within and outside health systems.

Keywords
Advance care planning, end-of-life decision-making, law, legal rights, palliative care

What is already known about the topic?

- Knowledge of law and its role in end-of-life decision-making is variable among health care practitioners.
- Community knowledge is also variable with some areas of the law and decision-making better understood than others.
- Lack of awareness of the relevance of the law is a key barrier to assertion of legal rights.

What this paper adds

- A shift in focus from knowledge of the law in end-of-life decision-making to operationalization of it in practice.
- Data on communication, systemic and individual barriers to appropriate participation in end-of-life decision-making by patients, decision-makers and families.
- Identification of the supports needed to assert legal rights across a range of health contexts.

1School of Nursing, Midwifery and Social Work, The University of Queensland, Brisbane, QLD, Australia
2Australian Centre for Health Law Research, Queensland University of Technology, Brisbane, QLD, Australia

Corresponding author:
Professor Lindy Willmott, Australian Centre for Health Law Research, Queensland University of Technology, GPO Box 2434, Brisbane, QLD 4001, Australia.
Email: l.willmott@qut.edu.au
Implications for practice, theory or policy

- While knowledge of law is important, it is not sufficient and so support to assert and operationalize legal rights and responsibilities is needed.
- Wide-ranging supports for patients, substitute decision-makers and families are needed including from within the health and hospital system (where care is received) but also outside it through patient advocacy and illness support groups.

Introduction

Legal knowledge is fundamental to recognizing and asserting rights. Varied understanding of law’s role in end-of-life decision-making has been demonstrated in health care practitioners\(^1,2\) who, alongside patients and relatives, play key decision-making roles. The community’s understanding of law’s role is also variable.\(^3\) The law provides patients, families, and substitute decision-makers with the right to participate in decision-making including around medical treatment decisions. Yet knowledge alone is insufficient; supports are often needed to operationalize legal rights and responsibilities. By operationalizing legal rights and responsibilities, we are referring to parties being aware of legal rights and having the opportunity and power to exercise them to achieve their desired outcomes. Considerable work has been undertaken on difficulties the community face in accessing legal services and asserting rights in other settings,\(^4,5\) but virtually no research has examined ‘operationalizing law’ in relation to end-of-life care to improve the ability of patients and relatives to participate in treatment decisions. This paper reports on research exploring experiences of operationalizing rights in this context.

Legal frameworks grant important rights and powers and also impose significant duties and responsibilities on those involved. Australian law, consistent with the law of other Western nations, clearly recognizes the ability of patients with decision-making capacity to make decisions about their end-of-life care.\(^6\) Where a patient has capacity, their rights include the right to receive sufficient information from doctors about their prognosis and treatment options (which should include palliative care if appropriate) and the right to either consent to or refuse offered treatment.

Where a patient lacks decision-making capacity, adult guardianship and medical treatment legislation provides legal frameworks for decision-making about treatment that include substitute decision-making and advance care planning. In Australia, substitute decision-makers can be appointed by an adult (with capacity) or by a guardianship tribunal (for adults lacking decision-making capacity).\(^7\) If no-one is formally appointed, legislation has a default hierarchy of potential substitute decision-makers who have power to act, usually those in close family relationships.\(^7\) Advance care planning instruments provide direction for health care practitioners when the patient is unable to make decisions and aim to maximize patient control. Legal status of these instruments varies widely across countries and user rates remain low.\(^8,9\)

Empirical studies demonstrate that an understanding of rights, duties and responsibilities of substitute decision-makers and preparedness to act as such is limited.\(^10,11\) Johnson\(^12\) argues that in Australia, although advance care planning is promoted in policy, existing legal, organizational, cultural, and conceptual barriers limit its implementation. Further barriers include a lack of formal training and appropriate communication skills for practitioners, limited space and time to initiate and follow through advance care planning and discussions, limited or no reimbursement for time spent and poor information transfers across providers and settings.\(^12,13\) For practitioners, lack of time, not knowing when to initiate conversations, fear of making patients uncomfortable or dealing with family conflict are additional barriers.\(^14\)

Clinical guidelines for enhancing communication and resolving conflict often pay limited attention to advocacy and legal rights, despite evidence that lack of legal knowledge contributes to disputes.\(^13\) A recent English study exploring unmet social welfare and advance planning legal needs for terminally-ill patients and their informal careers noted a lack of awareness of legal issues as a route to resolution. While there is extensive literature on human rights and palliative care, where legal rights and needs are addressed, the focus is generally on social security, discrimination, advanced planning, and family law\(^15\) rather than participation in medical treatment decisions. An understanding of what enhances or obstructs the operationalization of legal rights from the perspective of patients, family members, and/or substitute decision-makers who have experience making medical treatment decisions at end of life is needed. A small number of empirical studies have identified key barriers and facilitators to operationalizing patient and substitute decision-maker rights in end-of-life decision-making. Barriers include poor communication with practitioners and lack of information on or understanding of treatment options and prognosis, and insufficient information and support.\(^16\) Patients report confusion over who will initiate end-of-life discussions and planning or assume that practitioners will act.\(^16\) Patients and family members lack understanding of relevant aspects of the law including who could make decisions if they lost capacity.\(^17,19\) Patients may find it difficult to reflect on and discuss deterioration at the end of life.\(^16\) Facilitators
include support and encouragement from practitioners, including sensitive initiation of future planning discussions, clear and honest communication and information provision, prior experience with end-of-life care, access to appropriate resources and support and assistance with advance care planning. Existing studies have focused broadly on older adults, or specific health populations, or particular aspects of operationalizing the law (e.g. advance care planning). Few have focused specifically on terminally-ill patients and family members. The current study aims to gain a broad understanding of the barriers and facilitators to terminally-ill patients and substitute decision-makers exercising their legal rights to be involved in making end-of-life treatment decisions. This will inform the development of strategies and resources to support these individuals to assert legal rights.

**Methods**

**Research design**

This research comprised stage three of a mixed method project exploring community knowledge and use of law in end-of-life decision-making. Given the exploratory purpose to describe and display phenomena as experienced by participants, an interpretivist perspective underpinning a qualitative approach was appropriate. This stage aimed to capture the perspective of adults with experience of terminal illness and decision-making as a patient, a family member or a substitute decision-maker in acute hospital, palliative care, residential care, or community setting.

**Research questions**

- What are the barriers and facilitators to adult patients, family members and substitute decision-makers operationalizing legal duties, rights and powers when making decisions about medical treatment at end of life?
- What strategies will support adult patients and substitute decision-makers to operationalize legal duties, rights and powers?

**Population/setting**

The study population was sampled within the three most populous Australian states: New South Wales, Victoria, and Queensland.

**Sampling approach**

Purposive sampling was guided by the results of the prior stages that identified the need for recruitment to be undertaken with regional and urban participants and reflect diversity in health care settings. The inclusion criteria were adults:

- With a diagnosis of terminal illness who have engaged in end-of-life decision-making processes and have capacity to consent to participation.
- With experience of end-of-life decision-making as a substitute decision-maker for an adult with a terminal illness through a formal appointment by the adult or a tribunal or as a designated decision-maker.
- Who were family members (partners, adult children, or other relatives) that have witnessed or been involved in end-of-life decision-making (but not as substitute decision-maker) by or for a relative with a terminal illness.

**Recruitment**

The sample is a hard-to-reach group. Recruitment took place from September 2016 to September 2017. A general invitation using print media (e.g. letters to the editor and articles in regional print media), social media (e.g. Facebook call outs and tweets from Cancer Councils across three states, tweets from the administering research Centre), flyers in hospitals, support/advocacy group newsletters (e.g. Cancer Councils in three states) and emails (to non-government organizations including diagnosis-specific organizations) resulted in 53 respondents who met the criteria.

**Data collection**

Semi-structured interviews, developed from the research questions, collected demographic and decision-making context information and then explored participants’ knowledge of their legal duties, rights and powers through scenarios and describing their own experience; barriers and facilitators to operationalizing rights, duties and powers; their experience of decision-making; what conflict, if any, arose, and how it was managed (see Supplemental Material for interview topics). The guide was piloted on ten people. As the pilot suggested only minor adjustments to wording and question order, the results were included in the analysis. Two trained interviewers conducted telephone or face-to-face interviews between November 2016 and October 2017. The interview mode was determined by participant preference and/or distance and feasibility of face-to-face contact. Interviews lasted between 32 and 104 min (mean of 66 min), were audio recorded, professionally transcribed verbatim and imported into NVivo11 for analysis.

**Analysis**

As the interviews followed a defined structure, the thematic content analysis (Table 1) combined deductive and inductive approaches.
Ethics

All participants were given prior written information about the study and signed consent forms. A distress protocol was developed and implemented as required, with further follow up provided to one participant to offer access to support and counselling. Ongoing support, training and debriefing was provided for interviewers. Approval was obtained from relevant human ethics committees (detailed at the end of the paper).

Results

Forty-nine participants aged 28–86 were interviewed (Table 2). Four withdrew for health or other reasons after information/consent materials were sent. The sample included adult patients with a diagnosis of terminal illness (n = 16); formally appointed substitute decision-makers (n = 20) and adult family members (partners, adult children and others) who had witnessed or been involved with end-of-life decision-making by or for a relative with terminal illness (n = 13). The patients and decision-makers were not dyads. The results describe 49 separate experiences.

Although just over half the participants (27) reported being generally satisfied with decision-making processes and outcomes, only five did not indicate any barriers. Fourteen reported primarily negative experiences; seven reported mixed experiences and one was unclear. Barriers and facilitators were broadly mapped into two (overlapping) domains: systemic; and individual, influenced by personal characteristics and decision-making approaches.

Communication and information, the most common theme, cut across the two domains. As the three participant categories all reported experiences across the three domains the results are organized around the domains rather than rather the participant category.

Systemic issues

Positive systemic facilitators included continuity of care, the opportunity to establish a relationship, and good communication and trust in practitioners. For substitute decision-makers, the sense of decision-making/care being an inclusive team effort, was an important facilitator. For formally appointed substitute decision-makers, having their authority respected was a key facilitator. A good general practitioner was important to both patients and substitute decision-makers, particularly when providing continuity of care, and as a source of information about advance care planning. For some, palliative care teams provided expert guidance, information, and support.

"Making the decisions was really easy because we’d had the conversations. If we’d not had those conversations and had the guidance from the palliative care nurses and had them there with us to make sure that we were covering all the bases, we were asking the right questions, I couldn’t have done it."

Substitute decision maker, 35-44, NSW, regional, public system

Inconsistent care across different health providers was related to difficulties in establishing relationships, rapport and subsequently trust in, practitioners. In these cases, participants were more likely to experience problems with communication and therefore with decision-making. Participants noted these difficulties were exacerbated by a lack of information about available support for those experiencing difficulties or conflict within health settings, and confusion over who to even ask.

Other systemic issues concerned power imbalances between practitioners and patients and/or substitute decision-makers. A common example was the authority of the substitute decision-maker being challenged or ignored by practitioners. Several participants described cases of practitioners’ “ownership” of the patient and marginalizing the family as decision-makers. Another barrier was the fear of repercussions for the patient if substitute decision-makers assert their rights. Substitute decision-makers were afraid of “rocking the boat” or “making waves” themselves, but also described the patient expressing fears of being seen as demanding.

“Well, do I give them a bit of grief, are they going to give grief back at us and what they could do about us—you know, it’s literally life or death."

Substitute decision maker, 25–34, VIC, regional, public system

Further systemic challenges related to timing of end-of-life planning and confusion over who initiates the planning process and when. Some patients were proactive and sought information, but others waited, assuming that practitioners would lead the process. Even some participants who had completed advance care planning documents had not read them fully or understood their significance as legal documents.

Individual characteristics

Individual knowledge, and decision-making approaches also played a role in shaping experiences. The participant’s own medical and/or legal literacy, decision-making style, professional knowledge (especially if health care practitioners), and/or previous life experience facilitated the operationalization of rights. Family members and friends were sources of support for patients, emotionally, as advocates or shared decision-makers.
A key barrier to exercising legal duties, rights and powers was a lack of legal literacy, and participants simply not knowing that they have rights and responsibilities, or that documents and processes exist to support them.

*It’s kind of one of those things you don’t know what you’re not asking, I think.*

Patient, 35-44, NSW, city, private system

Patients’ decision-making capacity can be affected to varying degrees as they approach end-of-life. Patients reported information overload and/or the inability to absorb information, particularly verbal information. This meant patients and substitute decision-makers did not have the energy, skills, or willingness to pursue information or exercise their rights.

*You haven’t got the energy to try and fight some of these things or just think clearly to make these kinds of decisions.*

Substitute decision maker, 25-34, VIC, regional, public system

Confusion or conflict over authority and preferences presented difficulties. Not having an advance directive or an appointed substitute decision-maker presented difficulties, especially if patient preferences and wishes had not been discussed.

**Communication and information**

The dominant themes were communication and information which cut across systemic and individual domains. Clear, open, and honest communication with the treating team but also between patients and their families and substitute decision-makers was a key facilitator. All groups highlighted the importance of accurate information and the opportunity to discuss confronting issues about the patient’s prognosis and treatment options. This generally occurred when there was a good relationship with practitioners. A consultative decision-making approach enabled them to make informed choices and to feel some control in a situation where they often had very little. Some participants were happy for health care practitioners to lead the decision-making process; for others it meant they felt supported by the practitioners to lead the decision-making.

*As I said, my decisions have been respected by all the doctors involved, and it makes me feel like I’ve got a bit of control over my life.*

Patient, 35-44, QLD, regional, public system

Difficulties with practitioners’ communication emerged as the most common barrier. Patients and substitute decision-makers reported problems with limited information, not being included in decision-making, not being listened to, and being shut down if they did speak up.

*I was made to feel like an outcast for questioning anything at any point.*

Substitute decision maker, QLD, 35-44, city, public system

A lack of medical information and/or thorough explanations made it difficult for substitute decision-makers to make timely informed decisions. In some cases, limited options were given, or presented in such a way that there was only one “right” option, and patients and substitute decision-makers feared repercussions if they made decisions practitioners disagreed with.

*If they had explained to me what they were doing, I’d have been 100% comfortable in making decisions. But because I felt there was no communication, by the time I even had the opportunity to ask questions, it had already been done.*

Substitute decision maker, VIC, 55-64, city, public system

**Discussion**

**Main findings**

The interaction between systemic and individual factors shapes decision-making experiences with communication and information being an overarching theme. Knowledge of legal rights and responsibilities, continuity of care, timely open discussions, supportive relationships, and opportunities to meaningfully participate in decision-making all enhanced the appropriate implementation of legal rights and duties. Limited awareness of how the law can support participation, uncertainty about who initiates discussion about advance care planning and end-of-life decisions and when, and how to assert rights within the health setting were key barriers.

Poor information sharing was identified by some as resulting from a lack of centralized records clearly showing legal decision-makers, poor communication skills and power imbalances. Problems in sharing advance care planning directives, particularly when patients moved across health systems, presented barriers to implementing patient choices. Centralized records (e.g. e-Health) would facilitate access to a patient’s care plans and decisions but are insufficient to ensure respectful relationships and continuity of care.24

Continuity of care was not possible for those who moved across public and private systems, acute/palliative or community care and specialist and general practice. General practitioners were thus identified as playing a central role in
supporting patients and substitute-decision makers. General practitioners may need to be up-skilled in communication and advance care planning. Health care systems also need to place a much higher value on creating time for patient care and to invest in shared decision-making.25

Failure of practitioners to communicate appropriately was the most commonly reported barrier. Improving communication needs to be embedded in practice through formal practitioner training, recognition in funding of the time required for advance care planning discussions and the provision of various information and support services at appropriate points in the treatment journey. Power imbalances may prevent the assertion of rights and can be compounded when patients and substitute decision-makers do not understand their legal rights or are unaware that they can draw on law when faced with challenges. This can be addressed by improved legal literacy, and the availability of advocates and support staff (e.g. social workers, patient liaison staff, counsellors) and family conferences. Advocates may be needed to promote communication between all parties, ensure people have all their rights protected, and to advocate for patients. Palliative care services were noted as offering good support, but not everyone accessed or needed palliative care when completing or acting on advance care planning documents. In addition to accessing support staff in health settings, patient advocacy groups or support organizations can also play an important role in ensuring patients, families, and substitute decision-makers reach accessible, accurate information about rights and responsibilities.

Not all patients or families want to engage with or are willing to assert rights.26 Substitute decision-makers and patients do not always agree.26 Individual barriers included preferred decision-making styles; the ability to deal with the emotional aspects of decision-making; willingness to engage with advance care planning processes and documentation; family conflict; and a lack of legal literacy. Some of these problems can be addressed by community education, highlighting the need for reliable and accessible information about end-of-life law.17,27 Others such as family conflict may need mediation or counselling.

Conflict can stem from knowledge gaps, power imbalances and/or communication breakdowns at a systemic or individual/family level. Effective strategies for managing conflict include allowing time to make decisions, facilitating open discussions, well managed family conferences, and family support staff.13,28,29

**Strengths and limitations**

The focus on operationalizing legal rights in end-of-life decision-making for a range of actors, across various settings is innovative. Given the cohort of interest, there were difficulties in recruiting participants. The sample has an overrepresentation of females and participants with health care practitioner experience. The self-selected participants tended to be well-educated, in stable partnerships, described having stable life trajectories, and who by and large had supportive family members around them. Such a cohort may be better able to navigate health systems than others, suggesting the support needed to operationalize rights and duties may be underestimated.

**What this study adds**

The findings concur with empirical studies of what patients and families seek when dying in hospital: effective communication, shared decision-making, expert and compassionate care, trust in practitioners, and knowledge of the patient and family.30,31 This research goes beyond knowledge of legal rights to provide insight into what is needed to support the operationalization of rights at a systemic and individual level. It also adds recommendations to improve processes and thus outcomes. Palliative care models offer insights into how consistency of care, open communication and support can facilitate people operationalizing their legal rights, powers, and duties. This study highlights the importance of developing and evaluating programs to support the operationalization of rights outside of palliative care settings.

**Conclusion**

End-of-life decision-making sits at the intersection of health, law, ethical practice, and personal, family, and socio-cultural values. Decision-making is a fluid process with multiple influences, and changes over time as a person’s situation and illness trajectory changes. No single mechanism will address the barriers identified in this study. But regardless of the context, the law is relevant to the experience of decision-making.
Although a better understanding of relevant legal duties, rights and powers by patients, families and health professionals will improve experiences through facilitating the opportunity to participate in decision-making supported by law, support for recognizing and exercising rights and duties is variable and urgently needed. As Lombard32 has argued in the palliative care context, there is an opportunity to use law as a tool for change.

Acknowledgements
The authors wish to thank Ms Michele Ferguson for her contributions to the project and Professor Joanne Aitken for her comments on the manuscript.

Author contributions
All principal researchers (CT, LW, JW, BW) were involved in conceptualization of the larger research project. CT, LW, JW, BW were involved in design of this stage of the research with input from RF. RF and another interviewer carried out the data collection under the supervision of all other authors. CT, LW, JW, BW were involved in analysis and interpretation. CT drafted the paper with input from LW, JW and BW. All authors contributed to critical revision of the paper and approved the final version of the paper for submission.

Declaration of conflicting interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article:

The project was funded by the Australian Research Council Linkage Grant scheme (LP140100883) and the Cancer Councils of Victoria, Queensland, and New South Wales, Australia, as collaborative partners.

Ethics and consent
Approval was obtained from the Human Research Ethics Committees at the Queensland University of Technology (#1600000569 18/07/2016), The University of Queensland (#2016000068 16/08/2016), Cancer Council Victoria (#1610 14/10/2016), Cancer Council NSW (#308 02/12/2016), and UnitingCare Queensland (White20316 16/01/2017).

ORCID iDs
Rachel Feeney https://orcid.org/0000-0002-8306-1030
Ben White https://orcid.org/0000-0003-3365-939X

Data sharing
To protect participants’ privacy, the audio-recorded interviews and transcripts are not available. However, additional information regarding the findings presented can be requested from the corresponding author.

Supplemental material
Supplemental material for this article is available online.

References
1. Cartwright CM, White BP, Willmott L, et al. Palliative care and other Physician’s knowledge, attitudes and practice relating to the law on withholding/withdrawing life-sustaining treatment: survey results. Palliat Med 2016; 30(2): 171–179.
2. Willmott L, White B, Yates P, et al. Nurses’ knowledge of law at the end of life and implications for practice: a qualitative study. Palliat Med 2020; 34(4): 524–532.
3. Tilse C, Wilson J, White B, et al. Community knowledge of law on end-of-life decision making: an Australian telephone survey. J Law Med 2019; 27(2): 399414.
4. Law and Justice Foundation of NSW. Legal Australia-wide survey: legal need in Australia, http://www.law-foundation.net.au/ljf/site/templates/LAW_AUS/Sfile/LAW_Survey_Summary_FINAL.pdf (2012, accessed 29 September 2020).
5. Balmer N, Buck A, Patel A, et al. Knowledge, capability and the experience of rights problems. London: Plenet, 2010.
6. Willmott L, White B and Then S-N. Withholding and withdrawal of life-sustaining medical treatment. In: White B, McDonald F and Willmott L (eds) Health law in Australia. 3rd ed. Sydney: Thomson Reuters Lawbooks, 2018, pp.571–623.
7. White B, Willmott L and Then S-N. Adults who lack capacity: substitute decision-making. In: White B, McDonald F and Willmott L (eds) Health law in Australia. 3rd ed. Sydney: Thomson Reuters Lawbooks, 2018, pp.207–249.
8. Blank RH. End-of-life decision making across cultures. J Law Med Ethics 2011; 39(2): 201–214.

Table 2. Participant demographic characteristics.

| Decision-making role* | Total | N  |
|------------------------|-------|----|
| Patient                | 16    | 16 |
| Substitute decision maker formally appointed by adult (19) or tribunal (1) | 20 | 20 |
| Substitute decision maker/witness not formally appointed | 13 | 13 |
| Gender                 |       |    |
| Male                   | 8     | 8  |
| Female                 | 41    | 41 |
| Age                    |       |    |
| 25–44                  | 13    | 13 |
| 45–64                  | 19    | 19 |
| 65+                    | 17    | 17 |
| Education              |       |    |
| School only            | 13    | 13 |
| Post school certificate/diploma | 10 | 10 |
| Bachelor degree/Postgraduate degree | 26 | 26 |
| Location               |       |    |
| Capital city           | 23    | 23 |
| Regional               | 26    | 26 |

*Participants comprised three groups. No dyads were involved.

Participant demographic characteristics.
9. White BP, Willmott L, Tilse C, et al. Prevalence of advance care directives in the community: a telephone survey of three Australian states. *Intern Med J* 2019; 49(10): 1261–1267.

10. Sellars M, Tran J, Nolte L, et al. Public knowledge, preferences and experiences about medical substitute decision-making: a national cross-sectional survey. BMJ Supportive and Palliative Care, 2021, https://spcare.bmj.com/content/early/2021/03/15/bmjspcare-2020-002619.

11. Wong MKY, Jiang M, Medor MC, 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. *Age Ageing* 2021; 50: 242–247.

12. Johnson S, Kerridge I, Butow PN, et al. Advance care planning: is quality end of life care really that simple? *Intern Med J* 2017; 47(4): 390–394.

13. Curnow K. End-of-life decision-making in a health services setting: an access to justice lens. *J Law Med* 2016; 23(4): 864–886.

14. Fulmer T, Escobedo M, Berman A, et al. Physicians’ views on advance care planning and end-of-life care conversations. *J Am Geriatr Soc* 2018; 66(6): 1201–1205.

15. Ezer T, Burke-Shyne N and Hepford K. Legal support for palliative care patients. *J Pain Symptom Manag* 2018; 55(2S): S157–S162.

16. Close H, Sidhu K, Genn H, et al. Qualitative investigation of patient and carer experiences of everyday legal needs towards end of life. *BMC Palliat Care* 2021; 20(1): 47.

17. Lind R, Lorem GF, Nortvedt P, et al. Family members’ experiences of “wait and see” as a communication strategy in end-of-life decisions. *Intensive Care Med* 2011; 37(7): 1143–1150.

18. Brown M, Brooksbank MA, Burgess TA, et al. The experience of patients with advanced chronic obstructive pulmonary disease and advance care-planning: a South Australian perspective. *J Law Med* 2012; 20(2): 400–409.

19. Lawson D, Davoren S and Cordes-Holland R. *Making the law work better for people affected by cancer*. Melbourne: McCabe Centre for Law & Cancer, 2013.

20. Brown M, Fisher JW, Brumley DJ, et al. Advance directives in action in a regional palliative care service: “road testing” the provisions of the Medical Treatment Act 1988 (VIC). *J Law Med* 2005; 13(2): 186–190.

21. White B, Willmott L, Tilse C, et al. Community knowledge of law at the end of life: availability and accessibility of web-based resources. *Aust Health Rev* 2018; 42(3): 266–271.

22. Richie J. The application of qualitative methods to social research. In: Richie J and Lewis J (eds) *Qualitative research practice: a guide for social science students and researchers*. London: SAGE, 2003, pp.24–46.

23. Spencer L, Richie J and O’Connor W. Analysis: practices, principles and process. In: Richie J and Lewis J (eds) *Qualitative research practice: a guide for social science students and researchers*. London: SAGE, 2003, pp.199–218.

24. Payne S, Tanner M and Hughes S. Digitisation and the patient-professional relationship in palliative care. *Palliat Med* 2020; 34(4): 441–443.

25. Pieterse AH, Stiggelbout AM and Montori VM. Shared decision making and the importance of time. *JAMA* 2019; 322(1): 25–26.

26. Waller A, Hall A, Sanson-Fisher R, et al. Do medical oncology patients and their support persons agree about end-of-life issues? *Intern Med J* 2018; 48(1): 60–66.

27. Tran J, Sellars M, Nolte L, et al. Systematic review and content analysis of Australian health care substitute decision making online resources. *Aust Health Rev* 2021; 45: 317–327.

28. Office of the Chief Health Officer. NSW Health. Conflict resolution in end of life settings project: working report, https://www.health.nsw.gov.au/patients/acp/Publications/conflict-resolution.pdf (2009, accessed 29 September 2020).

29. Pignatiello G, Hickman RL Jr and Hetland B. End-of-life decision support in the ICU: where are we now? *West J Nurs Res* 2018; 40(1): 84–120.

30. Virdun C, Luckett T, Davidson PM, et al. Dying in the hospital setting: a systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliat Med* 2015; 29(9): 774–796.

31. Gott M, Robinson J, Moeke-Maxwell T, et al. ‘It was peaceful, it was beautiful’: a qualitative study of family understandings of good end-of-life care in hospital for people dying in advanced age. *Palliat Med* 2019; 33(7): 793–801.

32. Lombard J. Bridging the divide between law and palliative medicine. *Palliat Med* 2020; 34(1): 3–4.