

‘Can a relative override a patient’s Advance Care Directive?’: end-of-life legal worries of general practitioners and nurses working in aged care

Ben White^A, Rachel Feeney^{A,*} , Marcus Sellars^{A,C}, Penny Neller^A, Patsy Yates^B and Lindy Willmott^A

For full list of author affiliations and declarations see end of paper

***Correspondence to:**

Rachel Feeney
2 George Street, GPO Box 2434, Brisbane
Qld 4000, Australia
Email: rachel.feeney@qut.edu.au

Received: 12 December 2023

Accepted: 31 January 2024

Published: 15 February 2024

Cite this:

White B et al. (2024)
Australian Journal of Primary Health 30,
PY23213.
doi:[10.1071/PY23213](https://doi.org/10.1071/PY23213)

© 2024 The Author(s) (or their employer(s)). Published by CSIRO Publishing on behalf of La Trobe University.

This is an open access article distributed under the Creative Commons Attribution 4.0 International License (CC BY).

OPEN ACCESS

ABSTRACT

Background. This paper aimed to describe the legal worries of Australian general practitioners (GPs) and nurses regarding end-of-life care provided in the aged care setting. **Methods.** An analysis of responses to the final, open-ended question of a cross-sectional online survey of GPs and nurses practising in aged care settings in Queensland, New South Wales and Victoria was undertaken. **Results.** Of the 162 GPs and 61 nurses who gave valid responses to the survey, 92% (151 GPs and 55 nurses) responded to the open-ended question. Participants identified concerns across all relevant areas of end-of-life law. The most common concerns were substitute decision-makers or family member(s) wanting to overrule an Advance Care Directive, requests for futile or non-beneficial treatment and conflict about end-of-life decision-making. Participants often also identified concerns about their lack of legal knowledge and their fear of law or risk related to both end-of-life care generally and providing medication that may hasten death. **Conclusions.** Australian GPs and nurses working in aged care have broad-ranging legal concerns about providing end-of-life care. Legal concerns and knowledge gaps identified here highlight priority areas for future training of the aged care workforce.

Keywords: Advance Care Planning, aged, end-of-life care, general practitioners, health law, medical law, nurses, palliative care.

Introduction

Australians are now living longer than ever before ([Australian Institute of Health and Welfare 2023](#)). Advances in medicine have also meant that individuals are living longer with chronic diseases ([Australian Health Ministers’ Advisory Council 2017](#)). This trend has meant that it is increasingly likely that a person’s death will be the result of a decision about medical treatment, for example, whether to receive or refuse potentially life-sustaining treatment. Sometimes a person may have capacity to make this decision, but frequently medical decisions must be made on their behalf as they have lost decision-making capacity. An ageing population and limited availability of specialist health services has meant general practitioners (GPs) are increasingly involved in end-of-life decision-making with their patients. Sometimes these decisions are made with patients who are still living in the community, but often their patients will be residing in residential aged care facilities (RACFs) ([Johnson et al. 2010](#)). For individuals residing in RACFs, nurses also play a critical role in delivering end-of-life care both in terms of decision-making and providing emergency care when residents deteriorate.

The law establishes a broad framework for end-of-life decision-making and Advance Care Planning. End-of-life law covers legal issues that are relevant to medical decisions made at the end of life, including in the ‘last days and months of life’, as well as the planning and decision-making that happens well before this. The law supports good medical practice at the end of life by facilitating health care that aligns with a person’s values and goals. This includes respecting the decision of a competent resident to refuse treatment or a transfer to hospital. The law supports the provision of medication for pain and symptom relief for a

resident receiving end-of-life care. It also provides a framework for decision-making if a resident loses decision-making capacity.

The law that governs end-of-life decision-making is complex and, to add to that complexity, differs across Australian states and territories. Despite this complexity, to ensure a person's medical treatment is consistent with the above principles, knowledge of end-of-life law is essential for aged care clinical staff (White et al. 2017a; Willmott et al. 2021). Moreover, it is important that clinical staff also feel confident that decisions about the medical treatment of patients are compliant with the legal framework, and the staff are protected when these decisions are made.

To better understand perspectives about end-of-life law, we surveyed GPs and nurses from Queensland (Qld), New South Wales (NSW) and Victoria (Vic) who work within the aged care sector. There were two components of the survey. The first was an evaluation of the knowledge of GPs and nurses of the relevant laws. Our results, reported elsewhere, were that they had, on average, only low to moderate knowledge about end-of-life law (Sellars et al. 2022). The second component of the survey was an open-ended inquiry into a legal issue relating to end-of-life care that worried the participant. This article reports on the second component of the survey.

Methods

Study design

A cross-sectional online survey of GPs and nurses practising in aged care settings in Queensland, New South Wales and Victoria was conducted over 6 weeks from April 2020. The survey examined knowledge of end-of-life law and experiences in practice at the end of life. Sampling, survey design and development, recruitment and response rate has been detailed elsewhere (Sellars et al. 2022). This paper focuses on responses to the final, open-ended survey question: 'If you had to pick one legal issue in relation to providing end-of-life care that worries you, what would it be? Please provide an explanation for your response.'

Data analysis

Microsoft Excel was used to manage and code the data. Initially, coders (BW, MS and PN) reviewed the open-ended responses to get a holistic understanding of the data. Codes were identified in advance, drawing on a comprehensive mapping exercise of areas in the end-of-life legal field previously undertaken for a legal education program for clinicians (White et al. 2019). The preliminary coding system comprised 13 broad (sometimes overlapping) codes: capacity; consent to medical treatment; Advance Care Planning; Advance Care Directives; substitute decision-making; futile or non-beneficial treatment; withholding and withdrawing

life-sustaining medical treatment; providing pain and symptom relief; voluntary assisted dying; emergency treatment for adults; managing conflict; the role of law in end-of-life care; and 'other' issues. The coders documented the list of the codes along with descriptions of the meaning of each code. The coders then assigned codes to the dataset using the coding system, applying the 13 broad codes (more than one could be applied to a response) and identifying and applying new sub-codes which were then defined. Independent coding of responses was performed by BW, MS and PN and reviewed over multiple rounds. Discrepancies or areas of uncertainty were discussed and coding definitions revised to ensure coding consistency. After manual coding of all responses was complete, the researchers identified key areas of legal concern from the coded data (based on the frequency of concerns), and also examined differences in responses between GPs and nurses.

Ethics statement

Ethical approval for this study was obtained from the Queensland University of Technology Human Research Ethics Committee (reference number: 200000185). The research was undertaken with appropriate informed consent of participants.

Results

Of the 162 GPs and 61 nurses who gave valid responses to the survey, 92% (151 GPs and 55 nurses) responded to the open-ended question and were included in the current analysis. Of these, eight participants did not identify any legal worries ('not sure', 'not applicable', 'nil', 'none that I can think of at present'). The characteristics of the sample are shown in Table 1.

An overview of results is initially presented, mapping the issues raised to key areas of end-of-life law (Table 2). We then discuss in more detail participants' key areas of concern.

Key areas of end-of-life law

Capacity and consent to medical treatment

Participant responses about *capacity* often expressed apprehension about residents' capacity to make end-of-life decisions (including residents with dementia or reduced cognitive capacity). Some comments were about participants being unsure how to assess decision-making capacity.

Five comments (from both GPs and nurses) about *consent* related to treatment refusals. Four participants reported struggling with residents' decisions to refuse or stop treatment, including where the resident was seen as being 'well-functioning', 'giving up' or 'refusing treatment for a reversible cause, e.g. chest infection' (GP_224). These concerns appeared to arise because of clinicians' preferences to provide treatment,

Table 1. Participant characteristics (n = 206).

	n	Percent
Occupation		
General practitioner	151	73.3
Nurse	55	26.7
Gender		
Female	102	49.5
Male	101	49.0
Prefer not to say	3	1.5
Age (years)		
18–30	5	2.4
31–40	40	19.4
41–50	57	27.7
51–64	80	38.8
65+	24	11.7
Jurisdiction		
New South Wales	88	42.7
Victoria	72	35.0
Queensland	46	22.3
Aged care setting currently working in		
Residential care	53	25.7
Community/Home care	47	22.8
Both home care and residential care	106	51.5
Location		
City (100 000 or more people)	129	62.6
City (50 000–99 999 people)	17	8.3
City (20 000–49 999 people)	28	13.6
Town (10 000–19 999 people)	17	8.3
Rural or town (<10 000 people)	15	7.3
Years practising		
1–5	12	5.8
6–10	27	13.1
11–15	34	16.5
16–20	25	12.1
21–25	28	13.6
26–30	23	11.2
>30	57	27.7

e.g. ‘it is difficult to put to one side the instinctive desire to do all we can to preserve life’ (nurse_167). Two statements highlighted the importance of patient autonomy when making end-of-life decisions.

Advance Care Planning and Advance Care Directives

Responses about *Advance Care Planning* included two comments highlighting the need for Advance Care Planning and Advance Care Directives (ACDs) to facilitate or

mandate end-of-life decision-making, e.g. ‘advance care plans should be compulsory once people reach a certain age’ (nurse_92). It also included concerns from two participants about the limited utility of non-legally binding Advance Care Planning documents, particularly when a substitute decision-maker (SDM) or family member disagrees with wishes set out in these documents.

The largest volume of comments (15) about ACDs related to the sub-code *disagree/override* as they expressed concerns about cases where a SDM or family member(s) disagreed with an ACD and wanted to override it. Two participants commented that overruling wishes in an ACD can create conflict, e.g. ‘this is generally a family member who is obviously upset and potentially could become angry if their wishes are not carried out despite what the patient has requested’ (GP_102). A smaller number of statements were unspecified concerns with following ACDs, ACDs being unavailable, ACDs under the Mental Health Act, hospital transfers contrary to ACDs, families interpreting treatment refusals in ACDs as refusals of pain relief and conflict between wishes outlined in an ACD and ‘accepted medical practice’ or ‘medical advice’.

Treatment decisions

Substitute decision-making. Comments in the *substitute decision-making (who can decide)* sub-code generally related to situations where a family member queried the resident’s decision, e.g. as expressed in an ACD. A minority of statements related to uncertainty about a resident’s appropriate SDM, situations in which family members disagreed or there was no clear SDM. Comments in the *poor decision-making* sub-code primarily related to decisions that were seen as being against the best interests of the resident, inconsistent with good medical practice and/or refused pain relief. A minority of statements highlighted cases where financial interests drove poor decision-making: ‘guardians having control of the patient’s medical and financial matters and not necessarily acting always for the benefit of the patient’ (GP_44).

Futile or non-beneficial treatment. The prominent *futile or non-beneficial treatment (request for treatment)* sub-code encompassed situations where the family/SDM or resident requested or demanded treatment (e.g. hospital transfers, resuscitation, medication) that the participant believed was futile. A minority of statements in the *futile or non-beneficial treatment* code expressed the view that providing futile treatment leads to suffering or a ‘bad death’, or highlighted concerns about clinical assessments of futility, especially when a resident lacked capacity or had no family involvement.

Emergency medical treatment for adults. Most statements in the *emergency treatment for adults* code concerned ‘unnecessary’ hospital transfers, including transfers requested by the resident’s family in conflict with an ACD or seen as inappropriate by the GP/nurse participant. A smaller

Table 2. Summary of codes and sub-codes.

Code	Code frequency	Description	Sub-code(s)	Sub-code frequency	Description	Representative quotation(s)
Capacity	10	Capacity issues. Includes when there is a concern about assessing capacity or legal issues related to determining capacity. Excludes comments only mentioning capacity or commenting about whether the person has capacity or not.	–	–	–	‘What defines capacity ‘in legal decision-making?’ nurse_256 ‘Deciding if a person with dementia has capacity to make an informed decision or not.’ GP_162
Consent to medical treatment	10	Where a person with capacity is accepting or refusing treatment, which includes being informed (having been given adequate information and reasonable opportunity to make an informed decision).	–	–	–	‘A patient refusing treatment for a reversible cause, e.g. chest infection.’ GP_224
Advance Care Planning	6	Where comment is about undertaking Advance Care Planning or role of planning broadly, e.g. need for planning, including need for Advance Care Directives.	–	–	–	‘That still so many elderly Australians do not have Advance care plans and that they will die without their wishes being met.’ nurse_92
Advance Care Directives	32	Where comment is specifically about an Advance Care Directive, e.g. requirement to follow, documentation issues.	Disagree/override	17	Where a substitute decision-maker (SDM), family member or doctor disagrees with a valid Advance Care Directive (ACD) and wants to overrule it.	‘Advance care directives and conflicts with substitute decision-maker’s wishes.’ nurse_58
Substitute decision-making	23	Decision-making about medical treatment, by person or family (where they are framed as decision-makers even if not specifically labelled as a substitute decision-maker).	Who can decide	9	Where there’s uncertainty about who is the SDM. Includes where family member queries decision of person, e.g. decision made by a person in their ACD.	‘Always being able to recognise which person is ultimately able to make a decision on behalf of the patient.’ GP_344
			Poor decision-making	4	Bad decisions against best interests of the person, or refusing palliative care.	
Futile or non-beneficial treatment	21	Giving treatment or continuing to treat would be futile, not in person’s best interests.	Request for treatment	17	Where family/SDM or patient requests treatment that doctor/nurse believes is futile, inappropriate or non-beneficial.	‘Legal responsibilities when medically inappropriate treatments are demanded by patient or substitute decision-makers.’ GP_409
Emergency treatment for adults	7	Providing treatment in an emergency, including whether or not to transfer to hospital.	–	–	–	‘Doing the right thing in emergency situations with the paucity of time.’ GP_165
Withholding and withdrawing life-sustaining medical treatment	17	Withholding and withdrawing life-sustaining treatment from people who lack capacity. Excludes related issues about Advance Care Planning, substitute decision-making or futility.	Doctor to decide	6	Where comment is about a doctor deciding whether to withdraw or withhold treatment.	‘Some patients with inability to make decision due to acute episode, don’t have directive advance care plan and no power of attorney to their relatives and it is left to the doctor to decide what to do for this patient.’ GP_248
Providing pain and symptom relief	27	Providing medication for pain and symptom relief for a resident receiving end-of-life care; benefits of the palliative approach; palliative sedation.	Double effect	11	Concerns providing pain and symptom relief will hasten death.	‘The circumstances in which it is appropriate and legal to provide symptom relief if there is a risk of hastening death.’ GP_464
			Whether lawful	3	Concerns about whether giving pain and symptom relief or palliative care is lawful or not.	

(Continued on next page)

Table 2. (Continued).

Code	Code frequency	Description	Sub-code(s)	Sub-code frequency	Description	Representative quotation(s)
			No pain relief	5	Not giving pain relief despite need for it. Includes interpreting a direction to withhold or withdraw life-sustaining treatment to include not giving pain relief; family insisting pain relief not be given, lack of consent to or refusal of pain relief.	
Voluntary assisted dying	29	Includes lawful voluntary assisted dying (VAD) and unlawful practices; also includes requests to end suffering whether through medication to hasten death or requests for VAD.	Legality	10	Queries about the law on VAD, what is lawful, how it works (or will work) in practice.	'Voluntary euthanasia, and how it will work in practice when it comes to this state.' GP_263
			Hastening death	5	Request from patients to hasten their death by giving them VAD.	
Managing conflict	63	Where there is disagreement or conflict between patients, families, within families, with treating team about end-of-life decision-making and conflict management.	–	–	–	'The disagreement between family members about a patient's treatment when the patient does not have capacity to make his/her own decision.' GP_396
The role of law in end-of-life care	5	This includes comments about perceived relevance of the law to medical practice and whether the law should be followed.	–	–	–	'Do not think too much about the law when practising good palliative care.' GP_372
Other issues	57	Captures comments that do not fit into the other codes.	Legal knowledge	24	Queries about what the law is or says, not knowing the law, wanting to know more about end-of-life law generally or a specific topic, other than the legality of VAD or whether palliative care is lawful (have own sub-codes above).	'I don't know enough of the law governing end of life to be able to say.' GP_264
			Fear of law	9	Worries about being sued, civil or criminal liability, disciplinary proceedings, being chased by 'the law'; need for medico-legal protection.	'Many practitioners are nervous about end of life care because they fear litigation or repercussion.' nurse_62
			Community awareness	2	Comments highlighting that end-of-life law is not common knowledge and greater community awareness of this area of the law is needed.	
			Rationing/resources	2	Comments about rationing healthcare resources, including resource allocation and wasting resources.	

number of statements highlighted that decisions about emergency treatment were more difficult where there was no available SDM or ACD.

Withholding and withdrawing life-sustaining medical treatment. Comments in the *withholding and withdrawing life-sustaining medical treatment* code conveyed the clinical

and legal complexity of making these decisions for people who lack capacity, particularly for residents with mental health issues and where there is no available SDM or when family members disagree. The *doctor to decide* sub-code included comments about a doctor deciding whether to withhold or withdraw treatment, usually in the absence of an ACD and/or SDM.

Providing pain and symptom relief

Comments in the *providing pain and symptom relief* code highlighted the importance of providing adequate pain relief at the end of life, concerns about aspects of clinical decision-making and clinician's lack of knowledge about relevant law. The *double effect* sub-code included comments about the doctrine of double effect and its application in practice, namely that giving medication, usually by a clinician, to a person near death to relieve pain and symptoms is lawful even if it could hasten death. Most comments conveyed participants' concerns that medication may have the unintended effect of hastening death. Less common statements related to appropriate titration of medication to avoid hastening of death, worries that others (including families) may be unable to differentiate between the lawful provision of pain and symptom relief and voluntary assisted dying (VAD), and concerns over potential legal risks (e.g. court or disciplinary action) related to providing pain and symptom relief (including one comment about potential legal action from families). The *no pain relief* sub-code included comments about not giving pain relief despite the resident's need for it. These comments arose in relation to participants interpreting a direction to withhold or withdraw life-sustaining treatment as including withholding pain relief, families insisting pain relief be withheld and lack of consent to or refusal of pain relief. The *whether lawful* sub-code captured comments about whether giving pain and symptom relief or palliative care is lawful. Most comments reflected uncertainty about legal protection for providing pain and symptom relief and/or when double effect would apply.

Voluntary assisted dying

The survey was administered in April and May 2020, at which time VAD was only in operation in Victoria (although VAD laws had also been passed in Western Australia). At the time of writing this paper, VAD is in operation and is available (in limited circumstances) to people who meet the eligibility criteria in Victoria, Western Australia, Tasmania, Queensland and South Australia (VAD laws will commence in New South Wales on 28 November 2023).

A large volume of comments in the VAD code were statements for and against VAD (both generally and context specific), with comments expressing wide-ranging views. A smaller number of comments conveyed concerns about the eligibility criteria and processes for accessing VAD. The sub-code *legality* included ten comments about both lawful VAD and unlawful end-of-life practices. Most comments related to participants being unclear about the legal status of VAD or about aspects of VAD legislation. Other comments included concerns about the prohibition (in Victoria) on medical practitioners initiating a discussion about VAD and worries about nurses being unable to differentiate between VAD and the provision of pain and symptom relief. The sub-code *hastening death* related to five comments discussing requests to hasten death (including direct or indirect requests

from the resident or family). Comments typically expressed concern about such requests. Other worries were not knowing how to respond or struggling with being unable to provide assistance in response to these requests. Conversely, one GP stated 'being asked by patients to end their life, very rare to be asked and most understand reasons not to but work instead on pain relief' (GP_588).

Managing conflict

The broad *managing conflict* code included different views/opinions/decisions about medical treatment or care, and concerns about potential and actual conflict. Most comments related to conflict between the resident and family member(s) or SDMs, between the GP/nurse and a SDM or family member(s), and intra-family conflict. A minority of comments were about conflict between GPs/nurses and the resident, conflict between GPs and nurses and clinical or legal conflict resolution processes, e.g. second medical opinion, guardianship body dispute resolution avenues.

The role of law in end-of-life care

Many comments on the *role of law in end-of-life care* code reflected negative opinions of the role of law, e.g. 'do not think too much about the law when practising good palliative care' (GP_372), 'the law shouldn't impact on clinical judgement as often the treating doctor is in the best position to make the best decision for all concerned' (GP_231).

Other issues

The *other issues* code related to 57 comments that did not fit into another code. Many comments in the most frequent sub-code, *legal knowledge*, conveyed insufficient understanding of the role of ACDs and planning in end-of-life decision-making and the law relating to ACDs. Other comments related to the legal definition of capacity, uncertainty about when withholding and withdrawing life-sustaining treatment is lawful, legal obligations to provide futile treatment and conflict management. A related sub-code *community awareness* included two comments highlighting that end-of-life law is not common knowledge and greater community awareness of the law is needed.

The *fear of law* sub-code included worries about being sued, civil or criminal liability, disciplinary proceedings, being chased by 'the law' and the need for medico-legal protection. Concerns related to end-of-life care generally and providing medication that may hasten death.

The *rationing/resources* sub-code contained two statements about rationing healthcare resources. One regarded providing futile or non-beneficial treatment being wasteful of resources while the other queried rationing of intensive care resources in the COVID-19 context.

The *other* sub-code included 20 comments that did not fit into other sub-codes. The largest group of comments related to residents' families, both generally ('the relatives' GP_413) and specifically in relation to 'family pressures' (GP_90),

'immediate and extended family issues' (GP_293) and 'ensuring family members all understand current treatment and the reasons behind this plan of action' (GP_125). Remaining comments related to challenges in supporting residents with dementia, varied concerns (and queries) about aspects of clinical practice and/or the law, and unrelated topics such as participants' own end-of-life documents.

Differences in GP and nurse responses

Aside from the sub-code *withholding and withdrawing life-sustaining medical treatment/Doctor to decide* (which included only GP comments), GP and nurse responses were generally similar. Exceptions were comments highlighting the importance of providing adequate pain relief at the end of life (made by nurses only) and comments about requests to hasten death (made by doctors only). Some sub-codes included only a small number of comments from nurses, which limited comparison.

Discussion

Most survey participants (92%) answered the optional open-ended question about their legal worries, and almost all identified at least one legal issue of concern, suggesting an interest in this topic. Collectively, participants identified concerns across all relevant areas of end-of-life law. They also identified concerns about their lack of legal knowledge (a very frequently made comment) and that of the community, and their fear of law or risk. These findings are consistent with earlier research that identifies a high level of legal anxiety around palliative and end-of-life care (Willmott *et al.* 2018; Mitchell *et al.* 2019; Gerber *et al.* 2022).

Key areas of concern (the highest frequency codes and sub-codes) were where: a SDM, family member or doctor wants to overrule a valid ACD; a SDM, family member or patient requests futile treatment; and there is conflict about decision-making. Sometimes these concerns overlapped; concerns about conflict were often in relation to the issues of overruling ACDs and seeking clinically futile or non-beneficial treatment. Notably, these concerns often related to what was perceived to be inappropriately providing active treatment. This may be related to families' grief and lack of understanding of likely clinical outcomes, a lack of community/family awareness of death and dying (Gurung 2018), and insufficient discussions with residents and families about expected disease course, goals of care, and resident wishes (Lane and Philip 2015). Conflict often arose where there was a lack of consensus regarding goals of care and uncertainly or family disagreement regarding decisional responsibility, which is often characteristic of practice in the provision of palliative care by aged care staff and GPs (Rainsford *et al.* 2020).

Significant gaps in legal knowledge were evident, particularly relating to the law on ACDs and legal protection for providing pain and symptom relief. These specific knowledge gaps align with the most commonly experienced end-of-life

areas reported by GPs in our earlier study (Sellars *et al.* 2022). These knowledge deficits are also consistent with earlier studies of specialist doctors and nurses (White *et al.* 2014; Shepherd *et al.* 2018; Willmott *et al.* 2020), including those working in aged care (Silvester *et al.* 2013). Similarly, previous research (Willmott *et al.* 2020) found that nurses had limited knowledge of the law on providing pain relief at the end of life and were concerned about legal liability, with less than half knowing about legal protection under the doctrine of double effect.

Implications

Knowledge gaps in relation to end-of-life law can result in futile or non-beneficial treatment being provided, increased hospital admissions and unnecessary transfers, ACDs not being followed, residents and SDMs being excluded from decision-making, conflict between families and aged care providers and residents dying in pain (Willmott *et al.* 2018; Mitchell *et al.* 2019; Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee 2020; Gerber *et al.* 2022). Legal knowledge can help prevent some of these adverse outcomes and can assist the aged care workforce with end-of-life decision-making, increase their confidence and ability to navigate legal issues and reduce their legal risk (Willmott *et al.* 2016, 2018, 2020; White *et al.* 2017b). This knowledge can also help to alleviate anxiety or worry about the law and provide reassurance that there are legal protections for health professionals who act within its boundaries (Willmott *et al.* 2020). The need for palliative care training as a core requirement for aged care health professionals and workers is consistent with the Aged Care Royal Commission's workforce development recommendations (Royal Commission into Aged Care Quality and Safety 2021). We argue that an essential component of such training is the law relating to palliative and end-of-life care, and that legal knowledge facilitates the implementation of recommendations from the Commission on the right of residents to exercise choice and control in their care planning and delivery (Royal Commission into Aged Care Quality and Safety 2021). Knowledge of end-of-life law is critical to GPs, nurses and other aged care health professionals and workers providing high-quality care consistent with residents' preferences and values; and complying with their legal obligations when providing end-of-life care.

Legal concerns and knowledge gaps identified by participants here can and should inform end-of-life legal training for aged care GPs and nurses. Future training could also be informed by the results of the first component of our survey (relating to GP knowledge), which highlighted the need for education about determining the legal validity of consent to treatment and the law relating to withholding or withdrawing futile or non-beneficial life-sustaining treatment (Sellars *et al.* 2022). These findings will be used to inform the development of resources, including for the End of Life Directions for Aged

Care (ELDAC) national palliative care project ([End of Life Directions for Aged Care 2023](#)), which aims to provide information, guidance and resources to Australian health professionals and aged care workers on palliative care topics including end-of-life law.

Strengths and limitations

The primary limitation of this work is it draws on a single open-ended question. A strength is its focus on a broad range of legal areas as previous studies have focused primarily on Advance Care Planning with insufficient coverage of other areas of end-of-life law. Survey participants included GPs and nurses across three jurisdictions and 92% responded to the open-ended question.

Conclusions

Australian GPs and nurses working in aged care have broad-ranging legal concerns about providing end-of-life care. The most commonly identified concerns were SDMs or family member(s) wanting to overrule an ACD, requests for futile or non-beneficial treatment, and differences of opinion and/or conflict about end-of-life decision-making. Lack of consensus and conflict among decision-makers was seen by participants as driving adverse outcomes such as decisions being made that were inconsistent with residents' wishes (including ACDs not being followed) and futile or non-beneficial treatment being provided.

Many GP and nurse participants reported wanting to know more about end-of-life law. Education on this topic has established benefits for residents, families/SDMs and clinicians themselves and is consistent with the Aged Care Royal Commission recommendations. Legal concerns and knowledge gaps identified here highlight priority areas for future training initiatives.

References

- Australian Health Ministers' Advisory Council (2017) National strategic framework for chronic conditions. Australian Government, Canberra, ACT, Australia. Available at <https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf> [Verified 11 December 2023]
- Australian Institute of Health and Welfare (2023) How long can Australians live? Australian Government, Canberra, ACT, Australia. Available at <https://www.aihw.gov.au/getmedia/da6b92c7-60c2-4c66-aab7-63bb26fc71fd/aihw-phe-324.pdf?v=20230711085556&inline=true> [Verified 11 December 2023]
- End of Life Directions for Aged Care (2023) ELDAC: end of life directions for aged care. Available at <https://www.eldac.com.au/> [Verified 11 December 2023]
- Gerber K, Willmott L, White B, Yates P, Mitchell G, Currow DC, Piper D (2022) Barriers to adequate pain and symptom relief at the end of life: a qualitative study capturing nurses' perspectives. *Collegian* **29**, 1–8. doi:10.1016/j.colegn.2021.02.008
- Gurung A (2018) Deciding to transfer a resident to the emergency department: a phenomenographic examination of decision-making in residential aged care. PhD Thesis, Queensland University of Technology, Brisbane, Qld, Australia. Available at https://eprints.qut.edu.au/120022/1/Apil_Gurung_Thesis.pdf [Verified 11 December 2023]
- Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (2020) Aged care, end-of-life and palliative care: findings and recommendations. Queensland Parliament, Brisbane, Qld, Australia. Available at <https://documents.parliament.qld.gov.au/tableoffice/tablepapers/2020/5620t466.pdf> [Verified 11 December 2023]
- Johnson CE, Mitchell G, Thomas K (2010) The potential for a structured approach to palliative and end of life care in the community in Australia. *Australasian Medical Journal* **3**, 313–317. doi:10.4066/AMJ.2010.329
- Lane H, Philip J (2015) Managing expectations: providing palliative care in aged care facilities. *Australasian Journal on Ageing* **34**, 76–81. doi:10.1111/ajag.12085
- Mitchell GK, Willmott L, White BP, Piper D, Currow DC, Yates PM (2019) A perfect storm: fear of litigation for end of life care. *Medical Journal of Australia* **210**, 441–441.e1. doi:10.5694/mja2.50164
- Rainsford S, Johnston N, Liu W-M, Glasgow N, Forbat L (2020) Palliative care needs rounds in rural residential aged care: a mixed-methods study exploring experiences and perceptions of staff and general practitioners. *Progress in Palliative Care* **28**, 308–317. doi:10.1080/09699260.2019.1698177
- Royal Commission into Aged Care Quality and Safety (2021) Final report: care, dignity and respect. Volume 1, summary and recommendations. Commonwealth of Australia, Canberra, ACT, Australia. Available at <https://www.royalcommission.gov.au/system/files/2021-03/final-report-volume-1.pdf> [Verified 11 December 2023]
- Sellars M, White B, Yates P, Willmott L (2022) Knowledge of end-of-life law: a cross-sectional survey of general practitioners working in aged care. *Australasian Journal on Ageing* **41**, 265–273. doi:10.1111/ajag.13018
- Shepherd J, Waller A, Sanson-Fisher R, Clark K, Ball J (2018) Knowledge of, and participation in, advance care planning: a cross-sectional study of acute and critical care nurses' perceptions. *International Journal of Nursing Studies* **86**, 74–81. doi:10.1016/j.ijnurstu.2018.06.005
- Silvester W, Fullam RS, Parslow RA, Lewis VJ, Sjanta R, Jackson L, White V, Gilchrist J (2013) Quality of advance care planning policy and practice in residential aged care facilities in Australia. *BMJ Supportive & Palliative Care* **3**, 349–357. doi:10.1136/bmjspcare-2012-000262
- White B, Willmott L, Cartwright C, Parker MH, Williams G (2014) Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment. *Medical Journal of Australia* **201**, 229–232. doi:10.5694/mja13.00217
- White BP, Willmott L, Williams G, Cartwright C, Parker M (2017a) The role of law in decisions to withhold and withdraw life-sustaining treatment from adults who lack capacity: a cross-sectional study. *Journal of Medical Ethics* **43**, 327–333. doi:10.1136/medethics-2016-103543
- White B, Willmott L, Cartwright C, Parker M, William G (2017b) Withholding and withdrawing life-sustaining medical treatment from adults who lack capacity: the role of law in medical practice. Australian Centre for Health Law Research, Brisbane, Qld, Australia. Available at https://eprints.qut.edu.au/118303/13/WWLST_from_adults_who_lack_capacity_FINAL.pdf [Verified 11 December 2023]
- White BP, Willmott L, Yates P, Then S-N, Neller P (2019) ELLC – end of life law for clinicians. End of Life Law for Clinicians, Brisbane, Qld, Australia. Available at <https://ellc.edu.au/> [Verified 11 December 2023]
- Willmott L, White B, Close E, Gallois C, Parker M, Graves N, Winch S, Callaway L, Shepherd N (2016) Futility and the law: knowledge, practice and attitudes of doctors in end of life care. *QUT Law Review* **16**, 55–75. doi:10.5204/qutlr.v16i1.622
- Willmott L, White B, Piper D, Yates P, Mitchell G, Currow D (2018) Providing palliative care at the end of life: should health professionals fear regulation? *Journal of Law and Medicine* **26**, 214–245.
- Willmott L, White B, Yates P, Mitchell G, Currow DC, Gerber K, Piper D (2020) Nurses' knowledge of law at the end of life and implications for practice: a qualitative study. *Palliative Medicine* **34**, 524–532. doi:10.1177/0269216319897550
- Willmott L, White B, Feeney R, Tilse C, Wilson J, Aitken J (2021) Role of law in end-of-life decision-making: perspectives of patients, substitute decision-makers and families. *Journal of Law and Medicine* **28**, 813–830. doi:10.2139/ssrn.3909636

Data availability. Data is not available due to third party privacy and copyright agreement requirements.

Conflicts of interest. The authors are affiliated with or employed by End of Life Direction for Aged Care (ELDAC), which funded the project. The authors have no other potential financial or personal interests that may constitute a source of bias.

Declaration of funding. This study was undertaken as part of the ELDAC: End of Life Direction for Aged Care project which is funded by the Australian Government, Department of Health and Aged Care. The funder had no involvement in the preparation of the data or manuscript or the decision to submit for publication.

Author affiliations

^AAustralian Centre for Health Law Research, Queensland University of Technology, Brisbane, Qld, Australia.

^BFaculty of Health, Office of the Executive Dean, Queensland University of Technology, Brisbane, Qld, Australia.

^CPresent address: Department of Health Services Research & Policy, Research School of Population Health, College of Health & Medicine, The Australian National University, Canberra, ACT, Australia.