

## ORIGINAL RESEARCH

## Experiences of Australian emergency doctors and nurses using advance care directives in the provision of care at the end of life

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## Abstract

**Objective:** An advance care directive is a legal document outlining the wishes made by a person about treatment options. However, there is increasing evidence that an advance care directive that has previously been documented may not always benefit the current prognosis of the patient. Therefore, the aim of the present study was to explore the experiences of Australian emergency doctors and nurses concerning the use of previously documented advance care directives at the point of care for patients and their families.

**Methods:** A qualitative study guided by a phenomenological interpretive approach was employed. Semi-structured interviews were conducted with ED doctors and nurses across Australia. Data were thematically analysed using a seven-stage data analysis framework.

**Results:** An analysis of the interview data resulted in four major themes: (i) Benefits of Advance Care Directives; (ii) Knowledge and Awareness; (iii) Communication; and (iv) Availability of Advance Care Directive Information.

**Conclusions:** From the findings, advance care directives were believed

to be beneficial in decision making when patients, families, and ED staff agreed with the decisions made. Advance care directives were often made a long time ago but were useful to start conversations around goals of care and end-of-life care relevant to the patient's current situation. Findings in the present study further reinforced that an advance care directive was beneficial when used alongside goals of care at the point of care in EDs.

**Key words:** *advance care directives, doctors, emergency, end-of-life care, nurses.*

## Introduction

Australians are living longer and according to the Australian Institute of Health and Welfare over 16% of the population are 65 years of age or older.<sup>1</sup> Over the next few decades, this population of older Australians is projected to rise to more than 4.5 million people and 1 in 5 of these will be aged 85 or more.<sup>1,2</sup> This rise is attributed to a high standard in health care provision that allows people with chronic

## Key findings

- ACDs had limited benefit for decision-making at the end of life but were useful for initiating end-of-life conversations.
- Goals of patient care were emphasised as complementary to ACDs.
- Sociodemographic factors such as level of income, education level, sex, and race impacted on the completion of an ACD.

illnesses and co-morbidities to live longer.<sup>3</sup> This trend has implications for healthcare nationally, especially within the ED as it is the first point of contact for many people needing health care and is often the setting in which people die. The ageing population has led to a rapid increase in the number of visits to the ED.<sup>4</sup> Therefore, the uptake and use of advance care directives (ACDs) is important in the ED so that timely decisions can be made and to prevent interventions that may not benefit the patient.<sup>5</sup>

Over 85% of older adults present to the ED due to rapid deterioration in the last 6 months of their life.<sup>6,7</sup> Although these older adults will often present to the ED at a critical point in their illness trajectory, an ACD documentation might not always be considered when planning treatment.<sup>8</sup> ED clinicians have been shown to be able to successfully predict prognosis at the end phase of life even up to a year before the dying phase.<sup>9</sup> Research has shown that a significant number of patients with advance illnesses

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could potentially benefit from advance care planning led by ED clinicians.<sup>8,10</sup> Despite this, a recent Australian study found that only 13% of older adults who present to the ED had an ACD in place.<sup>9</sup> Similar statistics were reported in other developed countries such as the USA, where only 21% of patients who presented to the ED had an ACD documented, and only 37% of patients with a terminal illness diagnosis had advance care discussions in the month before death, although there are known benefits of having an ACD.<sup>6,11</sup>

ACDs have been encouraged by the Australian government to ensure national leadership, engagement, availability of education resources, and advisory services.<sup>12</sup> In Australia, ACDs are supported by both common and statutory laws. The recently reviewed national framework for advance care planning discussed the legislation and principles that applied in each Australian state and jurisdictions.<sup>5,13</sup> For example, in South Australia, the Consent to Medical Treatment and Palliative Care Act (1995) was enacted as a legislation to provide regulation regarding medical interventions and consent to treatments that impact the care of people who are dying.<sup>14,15</sup> In Australia, the prevalence of a documented ACD is low and varies across jurisdictions, with only 25% of older Australians aged 65 and older reported to have an ACD.<sup>12</sup> In contrast to other states and territories, people living in South Australia, Queensland, and New South Wales are more likely to have an ACD.<sup>12</sup>

ACDs afford patients the opportunity to be actively involved in the decision-making before circumstances impede their ability to do so.<sup>9,16</sup> Patients who have ACDs in place are associated with fewer deaths in hospitals and less likely to receive aggressive and futile treatments.<sup>16–18</sup> Barriers to implementing an ACD, such as limited access to information needed at the point of care, are not uncommon even with the use of electronic records.<sup>8</sup> Having advance care planning and ACD information in electronic records would help clinician's

access important information.<sup>19</sup> Overall, conversations regarding advance care planning and goals of care are crucial in enabling interventions that are consistent with the patient's wishes and the ED is often the setting for these conversations. Currently, there is minimal evidence as to the experiences of Australian emergency doctors and nurses concerning their engagement with ACDs. The present study aims to explore the experiences of Australian emergency doctors and nurses in the use of advance care planning, ACDs, and goals of care in the provision of end-of-life care.

## Method

### *Study design and setting*

Guided by Hans-George Gadamer's phenomenological interpretive underpinnings (hermeneutics), the study used a qualitative exploration of emergency doctors and nurses' experiences using advance care planning, goals of care, and ACDs. The aim of the interpretive process was to create an understanding through the construction of ED doctors and nurses' subjective experiences (Fig. 1).<sup>20</sup> The process of understanding these experiences represents a movement away from pre-judgement of what the authors believed concerning ACD use in ED (understanding in parts) to the meaning of the whole (combined with the participants' own experiences).<sup>20–22</sup> Knowledge is created in the interactions between the authors and the participants through key aspects of the qualitative interpretive process of *language, prejudice, constant dialogue with the text, continual questioning of its (text) meaning, and the cultural and social forces that may have shaped the perspective of the individual.*<sup>23</sup>

The setting of the study was a mixture of metropolitan, rural, and regional EDs across Australia between June 2018 and January 2019. Regarding the level of services provided in the settings, some of the departments provided complex and critical care including major trauma service centres although others were smaller and provided fewer complex services.

### *Ethics approval*

Ethical approval for the study was given by the Social and Behavioural Research Ethics Committee at Flinders University (Project Number: 7909). Once ethical approval was granted, professional organisations assisted with participant recruitment by sending out an email advertisement.

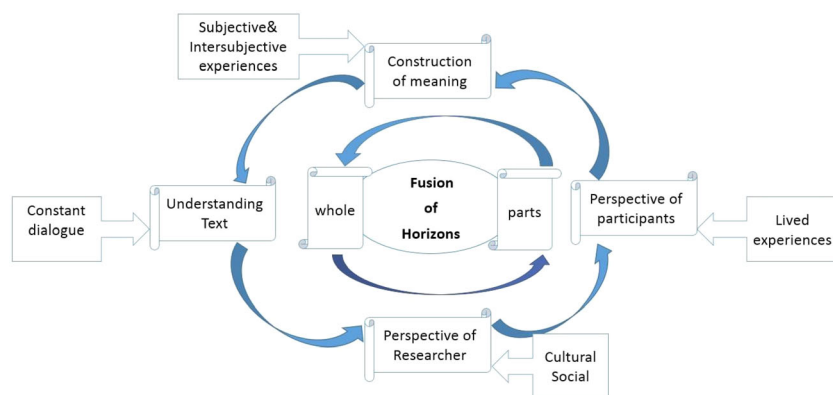
### *Participants*

Participants were emergency doctors and nurses who had ED experience of the issue being investigated. The sampling method was purposive so that the data obtained would address the aims of the study. The Australasian College for Emergency Medicine and the College of Emergency Nursing Australasia advertised the study and recruited participants across Australia via email. Data were collected using audiotaped semi-structured interviews over the phone and in person. Interview times ranged from 30 min to 2 h. Once all the interviews were completed and transcribed the transcripts were deidentified with pseudonyms to maintain anonymity and confidentiality.

### *Data analysis*

The focus on advance care planning, goals of care, and ACDs was part of a larger study about the experiences of ED doctors and nurses in providing end-of-life care. Demographical data were provided in numbers to describe the characteristics of the sample.<sup>7,10</sup> Qualitative data were analysed using seven stages of interpretive analysis (Table 1).<sup>24</sup> This method of analysis fits with the aims of a qualitative interpretive approach which is to fully understand people's lived experiences, in this case ED doctors and nurses, and the insights that arise from those experiences. 'The complexities of decision-making' emerged as a constitutive pattern that cuts across all the text due to the qualitative analysis approach.

Finally, the responses obtained from the ED doctors and nurses were thematically analysed for common meanings and shared practices.



**Figure 1.** Gadamer's Hermeneutic circle. In this hermeneutic phenomenological approach, the hermeneutic circle has been established through the coming together of two interpretive horizons (ED doctors and nurses, and the authors experiences) to create a fusion of these horizons into one. Within the hermeneutic circle, the process of understanding represents a movement away from the authors pre-judgement of what was believed were the major challenges of using an ACD in ED (understanding in parts) to the meaning of the whole (combined with the participants' own experiences).

**TABLE 1.** Diekmann et al.'s (1989) phenomenological interpretative seven stages of data analysis

Stage	
1	All the interviews or texts are read for an overall understanding
2	Interpretive summaries of each interview were written, and excerpts provided
3	A (team) of researcher(s) analyses selected transcribed interviews or texts
4	Any disagreements on interpretation are resolved by going back to the text
5	Common meanings and shared practices are identified by comparing and contrasting text
6	Relationships among themes emerge
7	A draft of themes and exemplars from texts are presented to the team. Responses or suggestions are incorporated into the final draft

This research method was chosen because it fits with Gadamer's interpretive hermeneutic phenomenological approach which is to interpret and explore the lived experiences of people. This analytical method has been used extensively in nursing and education research.

A change from the initial meaning and understanding of the whole text was gained as the text was explored in detail. In other words, it involved the constant moving from parts of the text to the whole text, and then back to the parts of the text again, with consideration given to any preconceived ideas

until a conclusive interpretation of the text was obtained. At the end of the analysis, four major themes were identified (Fig. 2): (i) Benefits of Advance Care Directives; (ii) Knowledge and Awareness; (iii) Communication; and (iv) Availability of Advance Care Directive Information.

## Results

A total of 16 participants included seven doctors and nine nurses who provided an account of their experiences regarding advance care planning, goals of care, and ACDs. Of these, 14 participants had worked in emergency for 10 years or more, and 12 of the participants had engaged in postgraduate degrees or higher qualifications. There were 10 participants who occupied senior positions such as consultant/physician and/or senior nursing roles. Seven of the participants had previous education on the topic of death and dying (Table 2). A total of 13 themes were initially identified but were collapsed into four major themes focussing on advance care planning as described below. Advance care plans and ACDs were used interchangeably with the participants.

### Benefits of advance care directives

The participants believed that advance care planning was very beneficial for decision making. Even in some situations when urgent decisions at the end of life were required:

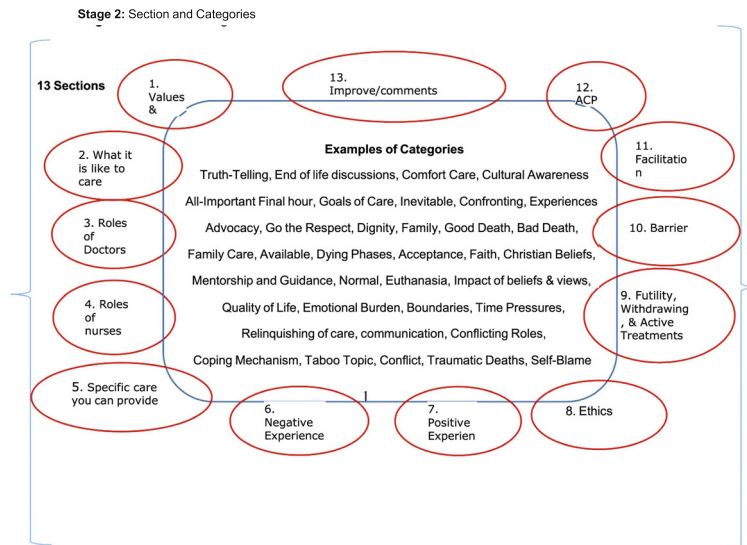
Absolutely, I love advance care planning, I think it's one of the greatest thing{s} in the world, because it takes into account the patient and their thoughts and wishes and what they want at a time that {they} are actually able to tell you. (Participant O)

Participants believed that an ACD was helpful even in situations where re-assessment of the document was required due to unforeseen changes in patient's current situation. It was still helpful because they were able to initiate conversations around end-of-life care and it took away the dilemma of 'how to start the conversation':

... so, it [ACP] can help me to start a discussion, its extremely rare that it actually guides me as

**Stage 1: An overall understanding of all the interviews**

Doctors	Nurses
1. Respect patient wishes (Participant F)	1. Dignity & Respect (Participant L)
2. Death is not to be prolonged (Participant K)	2. Christian Beliefs, Respect (Participant B)
3. Emotional and Clinical care (Participant D)	3. Dignity & Respect, Celebrate life (Participant M)
4. ACP conversations (Participant G)	4. Black and White, Natural, Respect (Participant I)
5. End of life care conversations (Participant C)	5. Inevitable, Natural, Christian Beliefs (Participant N)
6. Respecting patient wishes (Participant J)	6. Respect patient and family wishes (Participant E)
7. Emotional and clinical support (Participant A)	7. Respect for patient and family (Participant P)
	8. Patient advocacy (Participant O)
	9. Compassion and care (Participant H)



**Stage 2 Extended:** Excerpts from the text to support each category.

Written interpretation of a Category	Excerpt supporting the category
1. A guideline but still need to assess each patient (Nurse)	And the <b>advance care directive itself is a useful guideline</b> to help us when we are doubt or we donot know which direction to look to that's why I think it's a good tool but always I feel that assess the patient on a case to case basis and that's is where we should always fall back to before we proceed (Nurse Chu p. 3, L 33-36)
2. Its extremely rare that it actually guides me as to what I should do (Doctor)	so it can help me to start a discussion <b>its extremely rare that it actually guides me as to what I should do</b> so if the patient is moribund and I can't get in touch with family I have left voice mails and no one is picking up then it canhelp me a little bit to guide my decision about treatment limitations whilst am waiting for the family to get back to me (Dr Turtle p. 5, L 40-43.

**Figure 2.** Stages of data analysis. This is a larger study about the experiences of ED doctors and nurses in providing end-of-life care. The process that led to the final four major themes that were identified from the larger study.

to what I should do ... They are helpful in as much as they tell me that the patient is very unlikely to want invasive therapies and will probably welcome a discussion about therapy limitations and

that's a nice door to open for me ... It's an awfully long way from so this person has now got a pneumonia, we think carefully about what we might do for them. (Participant D)

Hence, it was beneficial to have an ACD even if it did not inform the current clinical presentation as it still served as a guide to open conversations about end-of-life care, thereby removing the burden from

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**Stage 3 and 4:** An example of what occurred in stage 3.

Initial interpretation of excerpt below was categorised as Bad **Death**

*“And, for me personally, I guess the sadness you feel for a family who’s not a Christian is a lot deeper because you know that their separation is forever, as compared to a family who is a Christian” (Abigail P 5-6 L 35-45, 1-6)*

Interpretation now changed to **Feelings of Sadness** after further analysis with the team (ResearchSupervisors)

**Stage 4:** Similar themes were grouped together so that a link between multiple themes can be generated.

Similar themes grouped together	Excerpt supporting the themes
ACP still has its place, Still needs reassessment of ACP on each admission, Tricky for Family Pressure on Family Different opinions between family When there is no ACP Ensure ACP done for patient in GERRI & GEN MED ACP are important and useful (Doctors)	Yes, definitely. I think that if there’s not an advanced care directive that’s been made, it can be very tricky for family. And I mean, I sympathise with them in the sense that, you know, sometimes you panic at that situation and you’re, like (indistinct) et cetera. So it is hard. It’s a lot of pressure on a family to really know and decide as a collective, because there is often differing opinions between family members about what’s best for the patient (Participant F PP 6-7 L 43-45, 1-4). people who have got terminal diseases that are well established metastatic cancer end stage pulmonary lung disease, end stage heart disease <b>who either have never had a conversation</b> about it or there is documented discussion of what people want and or the family have no idea what that means or they are having chemotherapy, <b>“they are not dying” or “he was fine yesterday I spoke to her on the phone”</b> and lack of understanding which makes preparing people for the fact that you are not goanna intubate this person bigger than they are never goanna wake up they are goanna be dying soon and what that means Participant G p 4 L15-22
2. ACP HELPFUL wishes respected ACP done timely Have something set in place FIRST THING WE LOOK FOR USEFUL ATIMES ACP often unavailable Takes time Time consuming (Nurses)	I think everyone should have a right to decide what to do if they have ever find themselves position. So, I think it’s a really good way to know the level of treatment that someone wants (indistinct) someone wants, and that decision is up to them. <b>I don’t think we should be making that decision for them.</b> I think the patient should be able to make that decision by themselves, and I think that most people are quite sensible (Participant L p. 13, L 18-33) so I think there’s a very big place for <b>advance care planning</b> , and not just advance care planning but <b>for it to be done in a timely manner</b> (Participant H p. 25, L41-42).

At the end of this stage, an overarching relational theme of ‘Experiences of providing EOLC in ED’ was generated.

Figure 2. Continued

family members to make the ‘right’ decision:

Yes, ACP (advance care planning) is definitely helpful. I think that if there’s not an advanced care directive that’s been made, it can be very tricky for family ... It’s a lot of pressure on a family to really know

and decide as a collective, because there is often differing opinions between family members about what’s best for the patient. (Participant F)

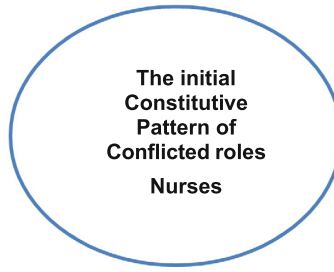
These participants highlighted the benefits of an ACD and yet also said that its implementation might also be dependent on the family

members agreeing with the documented goals of care:

But you do get families and the patient’s loved ones who are very much in denial about what’s happening, and whilst I understand it, it can be almost very obstructive to the process, so it can almost prevent us from

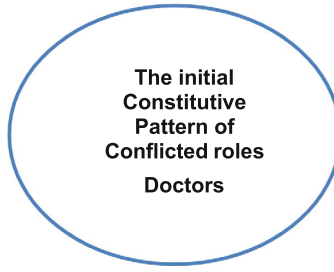
**Stage 5:** Common meanings and shared practices were identified (nurses).

- 10.) Conflicts & Disagreement**
  - 5 Reasons
  - 6 Resolution
  - 7 Mistrust
  - 8 Unacceptance/acceptance
- 11.) ACP**
  - 9 Helpful/unhelpful
  - 10 Preparedness for death
  - 11 Treating R.C



**Stage 5:** Common meanings and shared practices were identified (doctors)

- 9.) Conflicts**
  - 12 Reasons
  - 13 Consequences
  - 14 Resolving
  - 15 Role conflict
  - 16 Forced to provide treatment
  - 17 Acceptance/unacceptance
  - 18 Family power



**Stage 6:** Relationships among themes emerge (Doctors and nurses themes combined together for similarities and differences). An initial overarching theme of conflicted roles was generated.

- 9.) Conflicts and disagreements**
  - 19 Reasons
  - 20 Resolution
  - 21 Consequences
  - 22 Role of conflict
  - 23 Forced to provide treatment.
  - 24 Acceptance/unacceptance



**Stage 7:** A final overarching constitutive pattern of 'The Complexities of Decision Making' that cuts across all the identified major themes and subthemes was identified. These themes were part of a larger study about the experiences of ED doctors and nurses in providing end of life care.

The wordings and title of themes were re-worded to remove the negative slant that was stated in the feedback.

4. Conflicts and disagreement

1. Conflicting views on advance care plan- **Benefits of Advance care Directive**
2. Conflicts between families and the ED- **Knowledge and awareness**
3. Resolving Conflict- **Communication**
4. Time & the ED environment as a conflict- **Availability of Advance Care Directive Information**

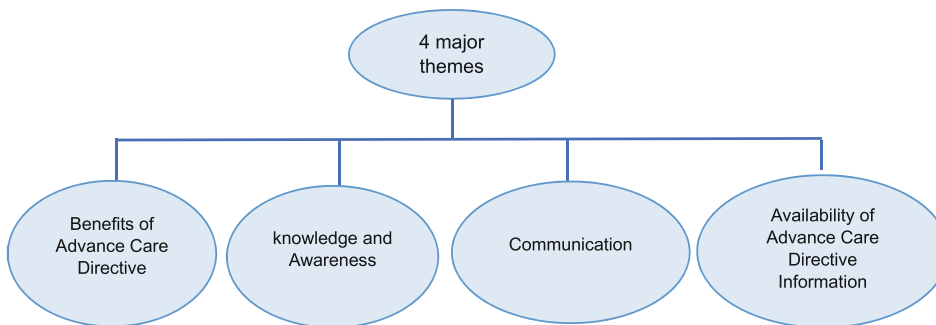


Figure 2. Continued

**TABLE 2.** *Characteristics of participants*

	Nurses	Doctors
Total, <i>n</i> = 16	9	7
Sex		
Male	4	2
Female	5	5
Age		
18–29	4	1
30–49	5	4
50–64		2
Education		
Undergraduate degree	2	2
Graduate diploma	6	
Master's degree	1	1
Doctoral degree		1
Professional degree		3
Years of working in ED		
<5 years	1	1
6–10 years	8	2
>11 years		4
Roles in ED		
Senior nursing roles (Triage, Resus, TL)	5	
Enrolled nurse	1	
Emergency physician		5
Intern		1
Medical officer		1
Nursing low acuity team leaders	3	
Education on death and dying		
Yes	4	3
No	5	4

Shows the characteristics and demographical information of ED staff who participated in the study.

making the patient comfortable ... (Participant M)

ED staff members observed that when families and loved ones had not accepted the imminence of death, end-of-life care could become counterproductive when the much-needed comfort care for the patient was omitted. Family members appeared to not understand the medical

condition and prognosis and this lack of understanding meant that sometimes, care could not be delivered in a timely manner.

### *Knowledge and awareness*

Many of the participants reported that some patients did not understand what advance care planning entailed. Likewise, due to the family

member's inadequate knowledge of any ACD, they would often question why interventions and treatment were not ongoing, despite the documented ACD:

... but they (Families) didn't realise the extent of the condition the patient had. So, it becomes a back and forth where no decision is made. (Participant L)

The lack of education regarding a patient's prognosis was described as potentially causing suffering and a barrier to the promotion of quality end-of-life care:

In terms of things like ICU and CPR ... you know, a round of CPR, that is not going to fix anything. That will just kind of prolong their suffering ... And what families don't often understand is that it can be a lot more traumatising to the patient and their families than they expect. (Participant F)

Some of the participants suggested that ACDs should be performed as a routine assessment in primary care as they were not just about resuscitation:

ACP has an influence/impact in end of life care. It's part of my regular assessment and I just don't talk about CPR (cardiopulmonary resuscitation) and intubation, {I} talk about everything in-between and a lot of the time people say no and sometimes they say yes, it's important, I encourage people and do it with lots of patients. It clarifies the level of understanding of prognosis by patient and family, sometimes they don't have an idea of how bad their diagnosis is. It's a shock to realise from doing an ACP that they have never been told about the true extent of their diagnosis. (Participant A)

Undertaking an ACD with a patient and their family requires skills and knowledge and discussions

need to be undertaken by clinicians with advance care planning knowledge. Participants suggested that when ACDs are undertaken with clinicians who had the skills and knowledge, the information was clear, and it represented what was in the best interest of the patient:

ACP makes care a lot easier and its only helpful when it's been filled with guidance from someone who understands what quality end of life care means. Some ACP clearly when you see them have been filled with no guidance or by someone with no knowledge of good end of life care. While there is a significant awareness for nursing home patients to have ACP done but it appears as if no one follows through in terms of medical personnel to assist and guide with filling in ... (Participant C)

A participant stated that the lack of education regarding advance care planning and ACDs, as well as inadequate understanding of a patient's prognosis and condition by patient and families was generally reported in other ED settings, and was not experienced in their own setting:

So, I work in a really privileged environment which is pretty much just consultant based, its private emergency department ... I care for probably the wealthiest group in the country, but with that comes very good social connectedness and very high health literacy, and there is a few folks who have unreasonable expectations, but the vast majority have very reasonable expectations and are able to have discussions about end-of-life goals and so forth at a high level, so it makes it quite straightforward from a practice emergency medicine ... Well, I don't have communication barrier and I can almost always find certain family member. (Participant D)

This ED setting was a private hospital in a high socio-economic area with high levels of health literacy. Communication around end-of-life care goals was reported to be understood by patients and families and therefore expectations about what could and could not be achieved were realistic.

### Communication

Participants suggested that effective communication and working together as a team were important for ensuring that the patient's wishes for care were met. Open and honest communication about advance care and goals of care plans, whether as a team of doctors, nurses, social workers and also individually, were believed to be important. Some participants stated:

I think that if we had a medical doctor come along and actually be opened and honest from the get-go all of a sudden, it makes your job so much easier. Okay, cool, no worries, that's fine, everybody is on the same page and they know what's going on. (Participant O)

When communication with the dying patient and their family members was transparent, and all questions and concerns about the prognosis were clarified, end-of-life care was said to be 'easier'. Doctors believed that they were able to successfully predict when end of life was imminent, but barriers to end-of-life communication tended to be associated with time constraints and comfort levels of the individual clinician. A participant stated that:

... I think you find that experienced practitioners can probably pick (the 12 months life expectancy) ... therefore what's stopping them having these conversations it's not necessarily that they don't recognise the patient, it's probably that they don't want to have these conversations or they haven't got time or something else. (Participant D)

In some cases, participants used communication between the multidisciplinary team to effectively communicate prognosis. A multidisciplinary approach in communication about death and dying was believed to be important:

We are lucky from an ED perspective that ... We have got a really good relationship with the intensive care department where we don't have that conversations, saying to families 'well tough, we are going to do it anyway' {withdraw life-saving treatments} ... they can have this conversations sequentially, so I am very lucky that when there has been conflicts with different expectations, or different understandings of outcome, the reservation has often been intensive care kind of come in and take the patient to continue that process. (Participant G)

In some cases, the intensive care team was used as part of the multidisciplinary approach for agreement about transfers to the intensive care unit. Patient transfer to ICU allowed the slow removal of all aggressive interventions rather than an abrupt withdrawal of all treatments in ED. According to some participants, any slow removal of treatment was achieved through a process of open and honest communication with the family so they could all agree and accept the inevitability of their loved one's death.

### Availability of ACD information

The participants stated that it was important to have the ACD information at the right time with all the right information but often they did not have a complete picture and history of the patient they were caring for:

The next stage of barrier is incomplete information, so it's rare that every bit of information you think you'd like about prognosis and current diagnosis and findings and patient preferences were available ... you are never



getting a complete picture ... and that's very difficult; indeed, it's much easier if you can find an oncology letter that says this patient's got stage 4 non-Hodgkin's lymphoma and have tried six rounds of different chemo, and we have made a joint decision that there is no role for palliative chemo anymore. They have been referred to palliative care, and they have had the conversation with the family, and they've all adjusted, and they have all met the pall care physician and so forth. But it's very rare to have that level of information. (Participant D)

Participants suggested that the referring doctor send a detailed letter stating both ongoing and ceased treatments, including future and goals of care. If this was done, ED staff would then know exactly what was happening and whether the patient had previously had any discussions about end-of-life care. Participants stated that it was rare to have this level of information, but it would be helpful. The unavailability of resuscitation and ACD documentation at the time of presentation to the ED may lead to providing treatments that did not align with the patient's wishes:

... a lack of communication in one case where the patient was obviously dying, but end of life care was not discussed appropriately ... but there was no clear order as to not perform CPR, and we still did obviously on a patient who should not have had CPR performed ... because often we have patients coming in from aged care homes unresponsive and there's no clear end of life care terms written out and the next of kin is unaware and they want everything done, and then that's when we start providing unnecessary care to a patient who obviously is dying. (Participant H)

They also recommended having discussions regarding the goals of

care that are made at the time of patient's presentation with some clear distinctions relating to the differences between goals of care and ACDs. One participant stated that:

If you have a look at the academic models for what an advance care plan and GOPC is, they are very different; the advance care planning is simply patient preferences sometimes even two decades ago. Usually, they haven't ticked anything other than if I get sick, I want to go to the hospital. I'd like everything done ... It's quite different to deciding on therapies for the current presentation ... there are overlaps between advance care plan and goals of care that there's a bit of overlap and it's an opening to a conversation ... but it's an awfully long way from getting to the other end ... {Current presentation} ... (Participant D)

In comparison to an ACD that has been made prior to presentation at an ED, goals of care were often documented at the bedside based on the current presentation. Thus, even when an ACD had been made, a goal of care is still needed to be established alongside any previously documented preferences. Having both ACDs and documented goals of care were beneficial as they demonstrated that a patient might be willing to have end-of-life conversations.

## Discussion

The experiences of emergency doctors and nurses concerning the use of ACDs explored in this qualitative study were conceptualised as complexities experienced in the decision-making process. The discussion of advance care planning, goals of care, and ACDs by study participants indicated that ACDs were beneficial depending on a range of factors that could either facilitate or be a barrier to the uptake or use of ACDs. The benefits of advance care planning

were tied to the presence of an ACD that had been prepared in the presence of someone with the skills and knowledge for having these discussions. The presence of family members and loved ones were pivotal during any goals of care discussion so that they are aware of decisions about treatment. Family members who were aware of ACDs were more likely to participate in the decision-making process and agree with the contents of the ACD, making the treatment decisions easier to apply.

Participants' experiences of ACDs, advance care planning, and goals of care were more effective when communication around end-of-life care treatments and decisions were in agreement. Like the findings in the current study, research has shown that advance care planning is beneficial for decision making at the end of life.<sup>24–26</sup> Even in circumstances, where there might be mismatched end-of-life expectations between the dying patient, the family, and staff members, ACDs were still able to provide some guidance into initiating conversations and communication of treatments goals.<sup>25–27</sup> Studies have shown that having ACDs and goals of care conversations in the ED setting with patients who were terminally ill but clinically stable are beneficial because it can set precedence for future management although preventing unwarranted treatments.<sup>28,29</sup> Similar to the research literature, participants in this current study stated that ED doctors were able to successfully predict the patients who had less than 12 months to live and yet an ACD was not always available.<sup>29,30</sup>

End-of-life care as a collaborative approach between doctors, nurses, patients, and families has been shown to improve care outcomes.<sup>31</sup> Nurses in ED were well positioned to collaborate with doctors in initiating advance care planning, goals of care, and ACD conversations as they generally spend more time at the bedside. ED staff have skills in communication with a marked ability to develop rapport and therapeutic interactions with patients and families.<sup>32</sup> Recent studies exploring ED

nurse led initiated conversations at the end of life showed improved communications between patients and clinicians.<sup>9,28,33,34</sup> Results of these studies indicate that nurses in ED have an expressed interest in taking an active role in helping patients at the end of life clarify their preferences.<sup>35,36</sup> A recent scoping review of articles exploring nurse led ACD training showed that there were numerous training modules available for nurses and doctors.<sup>31</sup> ED nurses and doctors require formal training in initiating end-of-life communication and difficult discussions so that they can improve the quality of care for patients who may require end-of-life care rather than futile active treatment.

More recently in Australia, the aim of goals of patient care (GOPC) was to change the culture of medical and nursing decision-making.<sup>37</sup> GOPC (Fig. 3) made at the point of care identified the patient who wished to decline treatment and assigned them to one of four phases of care: (i) curative (life prolongation), (ii) restorative, (iii) palliative (no intervention designed to prolong life) and (iv) terminal (care of the dying).<sup>37</sup> As opposed to ACDs, decisions about goals of care at the end of life are designed to be beneficial in making treatment decisions during a crisis, and especially in an emergency when difficult decisions were needed to be made at the point of care.<sup>30,37-41</sup> Once GOPC were determined at the point of care, then ACDs and treatment limitations were instituted. However, for patients who

already had an ACD in place, goals of care were still discussed, but with consideration to their ACD wishes. A study by Brimblecombe *et al.* (2014) exploring the prevalence of emergency calls in patient at the end of life argued that in patients who had GOPC summaries, calls for emergency medical review were lower compared to the overall cohort of their study.<sup>42</sup>

Findings in the present study showed that sociodemographic factors such as individuals with high socioeconomic status and high literacy levels had a better understanding of ACDs than those with lower SES and literacy. Research exploring the influence of sociodemographic factors on ACDs showed factors such as high-income levels, education, being Caucasian and female were associated with higher ACD completion rates.<sup>34,43-45</sup> Most financially affluent individuals will often have their financial will completed with an ACD. People with low income and assets might not have been exposed to information about ACDs. Research has shown that people, especially women who have suffered a traumatic and sudden loss of loved ones or spouses, were more likely to have ACD in place because they have already experienced the need to have a plan in place to provide quality end-of-life care.<sup>43,44,46</sup>

### Limitations

The main limitation of the present study lay in the characteristics of the sample. There was an over

representation of senior ED doctors, and from the findings the experiences of senior doctors were different from those of junior doctors. Although many of the senior doctors did discuss the experiences of the junior doctors, more research focusing specifically on the experiences of junior ED staff is warranted.

### Conclusion

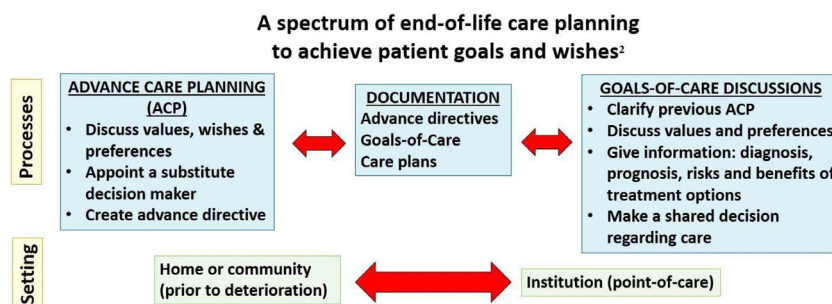
The present study found four main themes in discussion of ACDs with ED doctors and nurses. These themes centred around the advantages of having ACDs, the knowledge and awareness of ACDs by all concerned, the need for clear communication in regard to ACDs, and the availability of ACD information. Overall, ACDs appeared to be valuable for decision making in the ED when discussing the goals of care with a patient and their family. When goals of care assessments were unavailable or not able to be undertaken, decisions were made collaboratively between the patient, their family members, and the ED staff at the point of care. Goals of care at the end of life is an area that has yet to be widely introduced to the ED staff, despite the perceived benefits. More research is needed in the area of goals of care to further establish the benefits, however, ACDs should be on the radar of all ED staff as they may be beneficial in end-of-life care discussions in determining goals of care.

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### Competing interests

None declared.



**Figure 3.** A spectrum of end-of-life care planning to achieve patient goals and wishes. Provides a visual representation of the differences that exist between the processes involved in ACP and GOCP. ACP were made prior to deterioration and GOCP were implemented at the point of care.

### Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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