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Doctors’ perspectives on adhering to advance care directives when making medical decisions for patients: an Australian interview study

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Title: Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: an Australian interview study

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Abstract

Background

Advance care planning (ACP) assists people to identify their goals, values and treatment preferences for future care. Ideally, preferences are documented in an advance care directive (ACD), to be used by doctors to guide medical decision-making should patients subsequently lose their decision-making capacity. However, studies demonstrate that ACDs are not always adhered to by doctors in clinical practice.

Aim

To describe the attitudes and perspectives of doctors regarding ACD adherence and the utility of ACDs in clinical practice.

Methods

Doctors from a variety of medical specialties and with varying experience levels were recruited from a large tertiary hospital in Melbourne, Australia. Face-to-face semi-structured interviews were conducted using three case-based vignettes to explore doctors' decision-making and attitudes towards ACDs. Transcripts were analysed using thematic analysis.

Results

Twenty-one doctors were interviewed, 48% female (10/21). Most (19/21) reported having experience using ACDs. Four themes were identified: aligning with patient preferences (avoiding unwanted care, prioritising autonomy, navigating family opposition), advocating best interests (defining futile care, relying on clinical judgement, rejecting unreasonable decisions, disregarding legal consequences), establishing validity (doubting rigor of the decision-making process, questioning patients' ability to understand treatment decisions,

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distrusting outdated preferences, seeking confirmation) and translating written preferences into practice (contextualising patient preferences, applying subjective terminology, prioritising emergency medical treatment).

Conclusion

ACDs provide doctors with opportunities to align patient preferences with treatment and uphold patient autonomy. However, doctors experience decisional conflict when attempting to adhere to ACDs in practice, especially when they believe that adhering to the ACD is not in the patients' best interests, or if they have doubts about the validity of the ACD. Future ACP programs should consider approaches to improve the validity and applicability of ACDs. In addition, there is a need for ethical and legal education to support doctors' knowledge and confidence in ACP and enacting ACDs.

Keywords: advance care planning, advance care directives, autonomy, end-of-life, interviews, semi-structured interviews

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Article summary

Strengths and limitations of this study

- Purposive sampling used to promote inclusion of participants from a variety of medical specialties and experience levels
- Face-to-face semi-structured interviews used, providing a deeper understanding of participants attitudes and perspectives about ACD adherence
- Use of vignettes with hypothetical case scenarios to stimulate doctors' discussion about the use of ACDs in clinical practice
- Limitation: recruitment undertaken from a single metropolitan health service in Australia, which may limit the transferability of findings to other settings

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INTRODUCTION

Advance care planning (ACP) is a process where an individual makes his or her goals, values and preferences known in order to guide decision-making for healthcare, in the event he or she cannot make or communicate decisions in the future[1]. ACP conversations can be supported by the completion of an advance care directive (ACD), a document designed to inform medical decision-making in the event the patient loses capacity to make or communicate decisions[2]. The terminology, scope and legal status of ACDs varies considerably within Australia[3] and internationally[4-7], however they are commonly used to specify treatment preferences, express values, and/or to appoint a substitute decision-maker[2]. Completion of an ACD is considered to be a key component of ACP because ACDs provide written support and guidance for clinicians and family members when making decisions about end-of-life care[1, 8, 9].

ACP and ACD documentation are part of a broader shift in healthcare to promote person rights and autonomous decision-making. Legal frameworks have supported this evolution, providing greater emphasis on a substituted judgement approach to medical decision-making[10]. This approach requires decisions to be made according to what the patient would have wanted, rather than according to what others assume is in their "best interests". The emergence of ACP is largely a Western phenomenon and can be attributed to the rising value of autonomy in society, and increased legal emphasis on informed consent to medical treatment[11].

Research suggests that ACDs are not always adhered to by doctors in clinical practice. A 2007 study found that the presence of an ACD did not influence healthcare providers' decisions in using life-sustaining treatments or initiating comfort care plans[12]. More recently, Australian researchers presented 649 doctors from New South Wales and Victoria with a hypothetical case scenario to investigate compliance with ACDs[13]. In responding to

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the scenario, only 32% of doctors reported that they would adhere to the ACD in accordance with the law. Studies have identified a number of barriers to ACD adherence, including family opposition[14-16], lack of clinical relevance[15, 17-20], and concerns about the validity of ACDs[15, 18, 20].

The aim of this study is to describe the attitudes and perspectives of doctors involved in the care of patients with chronic disease at an Australian hospital. This study used qualitative interviews and vignettes to explore doctors' opinions regarding ACDs to gain a deeper understanding about ACD adherence and the utility of ACDs in clinical practice.

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METHODS

Study reporting is based on the Consolidated Criteria for Reporting Qualitative Health Research (COREQ)[21].

Participant selection and setting

Participants were doctors involved in the care of patients with chronic disease at Austin Health in Melbourne, Victoria, Australia. Participants were invited to participate through departmental meetings. Purposive sampling was used to ensure participants from a variety of medical specialties and with varying experience levels were included. All doctors who expressed interest in participating went on to participate in interviews. Ethical approval was obtained from the Austin Health Human Research Ethics Committee (LNR/16/Austin/528). Participants provided informed consent prior to being interviewed.

Data collection

Face-to-face semi-structured interviews were conducted from February to April of 2017 by two investigators (T.L., S.F.) until thematic saturation was reached, defined as the

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point at which few or no new concepts or themes were arising from subsequent interviews[21]. Participants were aware that the interviewers were a medical student and supervisor and some participants were known to the researchers in a collegial capacity, but otherwise a relationship was not established prior to interview. Interviews were audiorecorded and transcribed verbatim by T.L.

An interview guide was developed for this project by the research team (see Supplementary item S1). This guide consisted of three sections:

1. Demographics (gender, years of practice, area of practice) and prior experience with ACDs;
2. Three vignettes (see Box 1), each presented with a "values" then an "instructional" ACD; and
3. Questions regarding the perceived usefulness and importance of ACP.

In Section 2, participants were asked to outline their medical management plan for each case scenario. Extracts from ACDs were then used to determine whether the doctor would adhere to the ACDs in each scenario and how, if at all, the ACD would influence their management plan. Probing questions were then used to explore participants' perspectives with regards to ACD adherence and related issues such as legal concerns and family input.

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Box 1: Summary of hypothetical vignettes

Scenario 1: 73-year-old man with advanced chronic obstructive pulmonary disease and recurrent hospitalisations. Presents acutely breathless

- Values directive: places high value on his independence, doesn't want to become a burden to his family
- Instructional directive: not for intubation, intensive care unit intervention or inotropes

Scenario 2: 65-year-old previously well man presents with chest pain, then collapses with ventricular fibrillation

- Values directive: he values being an active and productive member of his community. He would "rather be dead" than unable to play golf
- Instructional directive: not for resuscitation, should be "allowed to pass away in peace"

Scenario 3: 68-year-old man on dialysis, with a history of metastatic pancreatic cancer. Presents febrile, tachypneic and hypotensive

- Values directive: he values life above everything – "God will take me when I'm ready"
- Instructional directive: not for intubation or cardiopulmonary resuscitation (signed 5 years ago)
- Additional information: patient's family disagree with directive and demand full treatment to be given

Note: values directive is defined as a general statement about a person's preferences and values[22]. Instructional directive is defined as an express statement in which a person may either consent to or refuse a particular medical treatment, which takes legal effect if the person loses decision-making capacity[22].

Data analysis

Transcripts were entered into HyperRESEARCH (ResearchWare Inc), a software package used to store and code qualitative data. Drawing from principles of grounded theory and thematic analysis[23], N.M. inductively identified concepts in the transcripts and then developed and refined the coding structure with assistance from M.S.. The analysis identified relationships between themes to develop a thematic framework to capture all concepts about participants' experiences and perspectives about ACD adherence. To further develop and enhance the analytical framework, interpretation of data and preliminary themes were discussed among the research team.

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Patient and public involvement

There was no patient or public involvement in the design and conduct of the study.

RESULTS

Participant demographics

Participant characteristics are provided in Table 1. In total, 21 doctors participated, from a broad range of medical specialties, with a range of experience levels. About half were women (10/21). Almost all participants (19/21) reported having used ACDs in their clinical practice. Interview duration ranged from 12 to 52 (mean, 26) minutes.

Themes

We identified four themes: aligning with patient preferences, advocating best interests, establishing validity and translating written preferences into practice. The themes were relevant to all scenarios unless otherwise specified. Selected quotations to illustrate themes are provided in Table 2. Conceptual links among themes are presented in Figure 1.

Aligning with patient preferences

Avoiding unwanted care

Doctors valued ACDs that supported them to understand “what the patient wants and why they want it” to be able to individualise treatments according to the patients’ preferences. They believed ACDs can help them make “the right decision for that particular patient” and avoid unwanted treatment. For instance, some doctors felt that ACDs provided patients with an opportunity to consider past treatment experiences, and have a say about “wanting or not wanting a certain kind of treatment”.

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Prioritising autonomy

Nonetheless, some doctors experienced deep conflict when weighing up decisions to follow ACDs, in scenarios where they disagreed with the patient's decision. This was because they felt "morally tied" to follow decisions to refuse treatment, because they believed it was important to respect the patients' autonomy. This was most evident in Scenario 2, involving a previously well patient presenting in a sudden cardiac arrest, who had an ACD which refused resuscitation. Even though participants acknowledged the situation was very difficult given the patient would likely have a good prognosis if treated, some felt obligated to adhere to the ACD, stating that "if you're going to allow people autonomy to decide things … you can't say, we will sometimes, we won't sometimes". These doctors felt that people deserve to maintain their own autonomy, provided the patient has made an informed choice as a competent adult. Thus despite their reservations, they decided they would adhere to the ACD and withhold resuscitation, reflecting that it would be "unethical to give [the patient] something that [they] never wanted".

Navigating family opposition

Doctors described potential difficulties of overcoming family opposition when making decisions based on patient preferences in ACDs. This was particularly in Scenario 3 in which participants were asked how they would respond if family members were not in agreement with the preferences described in the ACD. Some doctors felt that although they would "try to accommodate" the preferences of the family, they would draw the line at "causing harm to the patient". One participant argued against permitting family to override the ACD because the patient has "the right to make the decision" and "family don't necessarily play a part in that". However, other participants described scenarios from their own clinical experience where family members had requested more treatment than the patient

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wanted and doctors had felt obliged to comply with requests to avoid causing stress to the family. Thus, doctors reported that futile treatments are sometimes given, or treatments are continued for longer than they otherwise would be, to allow time for the family to come to terms with the situation.

Advocating best interests

Defining futile care

Doctors considered ACDs to be irrelevant to their decision-making if patients had requested treatment that the doctor perceived to be futile. Doctors felt it was their duty to determine "what [was] futile" to avoid "unnecessary and potentially harmful treatment". Because of this, some doctors refused to follow the treatment requests specified in the ACD, such as for cardiopulmonary resuscitation, intubation or mechanical ventilation, because they believed treatment would not be in the patient's "best interests". For example, in Scenario 3, a very unwell patient with a poor prognosis had an ACD that requested all available treatment to be given. Participants decided not to follow the ACD, identifying that "any advance care plan for treatment becomes irrelevant, because giving him treatment would be futile".

Relying on clinical judgement

In contrast to those participants who prioritised patient autonomy in decision-making, some doctors appeared most influenced by their assessment of the potential risks and benefits to patients rather than the preferences specified in the ACDs. They considered factors such as the patients' age and comorbidities, to make a judgement about prognosis and whether the condition was potentially reversible. As a result, some doctors refused to follow the ACD and instead proceeded with treatment because they felt it was not "right to withhold treatment especially when, based on your medical assessment, there is a great potential for

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reversibility". This was best illustrated in Scenario 2, where some doctors indicated they would be unwilling to withhold resuscitation on a relatively young, well patient, despite the patient having a valid ACD which stated they did not want resuscitation. Even though these doctors were aware of the patient's preference to "pass away in peace", they felt compelled to override the request because "[the patient] has an excellent prognosis … So you would be mischievous not to treat him".

Rejecting unreasonable decisions

Some doctors were reluctant to implement ACD requests that they considered to be unreasonable, or inconsistent with what a "normal" person might want. Doctors judged whether they thought the preferences specified in the ACD were "sensible" or acceptable for the situation, and some were unwilling to comply with those that they perceived as unreasonable or "unusual". These doctors were willing to respect patients' treatment choices but only if they conformed within the scope of treatment options that was felt to be reasonable or appropriate in that situation.

Disregarding legal consequences

Overall, doctors appeared to have minimal concerns regarding potential legal consequences of not following ACDs, choosing instead to prioritise ethical considerations in their decision-making. One participant explained that "the legal stuff never worried me. It'll be more about the moral thing to do". Doctors were more motivated to act in the patients' best interests, rather than uphold the ACD because of a legal obligation. Doctors dismissed the risk of legal consequences, believing they would be protected if they used "reasonable judgement" that could be justified in a way that their peers would agree, and if "the motivation for not following the plan was one of trying to do the best for the patient".

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Establishing validity

Doubting rigor of the decision-making process

Some doctors expressed concern because they were unable to verify whether a “proper” ACP discussion had occurred in the formation of an ACD, as they had not been “part of the [ACP] process.” Therefore they could not verify if the patient preferences specified in the ACD were accurate and/or informed. Doctors regarded best practice ACP as a formal discussion with a trained health professional in which issues could be explained, understood and discussed. Some doctors expressed scepticism regarding the rigor of ACP discussions in practice and therefore felt justified in dismissing any preferences specified in the ACD. For example, these doctors judged that patients’ may have been overly influenced or coerced by family members in making their decisions, or were concerned because they believed that ACP is sometimes completed as a “tick box” where important details about treatments are not discussed.

Questioning patients’ ability to understand treatment decisions

In considering treatment preferences specified in ACDs, some doctors questioned whether patients were capable of “fully understand[ing] the consequences” of their decisions, because they believed the general population lack required medical knowledge about the risks and benefits of specific treatments. One participant explained that “patients aren’t expected to understand all the minutiae or the nuances of what we can do”, especially given the fact that “every single sickness they have is going to be individual and different”. As a result, doctors suggested that medicalised instructional ACDs were not appropriate by themselves; instead, these doctors expressed a preference for ACDs that included the patient’s values because

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these ACDs allowed the medical team to interpret the patients' preferences in their own words.

Distrusting outdated preferences

Doctors also raised concern about adhering to ACDs that were created several years ago because they believed the preferences specified in the ACD were potentially outdated. They questioned whether the patients' views may have changed over time, especially if their health status had changed. Changes in the patients' circumstances that doctors believed may influence treatment preferences included receiving a new diagnosis or recovering from "acute unwellness". In contrast, some participants felt comfortable adhering to ACDs that were several years old if they judged it to be appropriate for the current situation. Some felt that if the ACD was already "conservative to start with" and the patients' prognosis had worsened, then they would still feel confident adhering to the ACD because they patient was unlikely to have changed their mind to opt for more aggressive treatment.

Seeking confirmation

To overcome concerns about the validity of ACDs, doctors believed they needed to seek confirmation of the ACD to establish its authenticity, such as from family members, before they would be willing to let it influence their management plan. This appeared mostly of concern when doctors disagreed with the preferences specified in the ACD, or if they believed the patient's treatment preferences were not in line with a reasonable medical course of action. Consequently if they could not clarify the reasons underlying the preferences specified in the ACD, some doctors decided not to adhere to the ACD.

Translating written preferences into practice

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Contextualising patient preferences

While doctors felt that ACDs are useful to help guide decision-making, some also highlighted the need for each ACD to be considered “in the context of what’s happening today”, rather than applied literally in every case. Doctors believed that they should have some leeway to determine whether the ACD was intended to apply to the given clinical scenario, feeling the ACD should be used as “a guide, rather than something that is compulsory” – allowing the clinician to have a more “nuanced” interpretation of the patients’ request. Some doctors believed that ACDs are unable to address every possible clinical scenario that might arise and therefore, clinicians should be able to “exercise judgement as to whether this will be the situation where values might be important to help guide [them]”. For this reason, some participants expressed a preference for ACDs that conveyed patients’ preferences in terms of broad values statements because they were “more general” and therefore usually “more flexible and more applicable across multiple scenarios”.

Applying subjective terminology

In contrast, doctors sometimes struggled to apply values-based ACDs because they were unsure how to interpret values statements. Doctors felt that values expressions were “vague” and “confusing” because they are subjective. For example, some doctors questioned the meaning of the word “independence”, with one participant stating that “how I interpret independence is different to how someone else might value his independence” because “values are different from person to person”. Doctors expressed difficulty knowing how to apply values to form a concrete treatment plan and therefore some participants regarded instructional ACDs as being easier to interpret and apply because they have “clear-cut” directions.

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Prioritising emergency medical treatment

Some doctors noted the importance of providing urgent medical treatment in a timely manner, and this was seen as a barrier to ACD adherence because there is not always time available to locate, read and interpret ACD documentation. Doctors reported that aggressive treatments are sometimes administered without consideration of patients' preferences because of the need to begin treatment immediately. Additionally, some doctors felt ill-equipped to make difficult decisions about end-of-life care, especially in time-pressured situations. Participants explained that in an emergency, they felt obliged to "err on the side of … treating" because "you certainly don't want to do it the wrong way around".

DISCUSSION

This qualitative interview study provides evidence regarding the attitudes and perspectives of doctors in relation to ACP and ACDs by exploring vignette scenarios and medical decision-making. The majority of participants valued ACDs that supported them to align with patient preferences in their treatment decisions. However, some doctors experienced conflict in adhering to ACDs when they believed the ACD did not represent the patients' best interests. Doctors tended to rely upon their own clinical judgement to make treatment decisions, sometimes overriding the ACD on the basis that the treatments requested were 'unreasonable', 'futile' or that the patients' condition was potentially 'reversible'. In addition, there were issues with validity and currency of ACDs, subjective terminology, patients' ability to understand consequences of preferences, family opposition, and time pressures. In this study, ethical considerations were found to be more influential in medical treatment decision-making than legal requirements.

From an ethical perspective, these findings challenge the widely held assumption that autonomy is the most important principle in healthcare decision-making[24]. Some

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participants preferred to follow their clinical judgement to make decisions that were in the patients' best interests, rather than uphold patient autonomy, although others felt obligated to adhere to patients' preferences despite this conflict. This is consistent with another vignette interview study conducted in the UK by Thompson and colleagues[25], who also found that some doctors wished to override the ACD and proceed with treatment consistent with the patient's best interests, whereas others believed it was most important to respect patient autonomy. Our findings reinforce past Australian and international qualitative studies demonstrating that, while doctors appear to have a shared understanding and respect for patient autonomy in theory, competing values and interests prevent doctors from prioritising patient autonomy in their clinical decisions in practice[17, 25, 26]. Doctors in an interview study by Johnson and colleagues[26] felt that there should be limits to patient autonomy, and patient preferences should not be respected if the treatment choice is 'unreasonable', 'futile' or 'medically inappropriate'.

Doctors in this study reported validity concerns to be a key barrier to ACD adherence, in accordance with past Australian and international research findings[15, 18, 20, 25]. Doubts about validity, including currency of decisions, were particularly prominent where participants disagreed with the treatment decision specified in the ACD. For instance, when the ACD refused treatment that doctors felt would be beneficial, they tended to question the authenticity of the ACD and wished to establish its validity, such as by confirming with family members. This is consistent with a model of end-of-life decision-making proposed by Willmott and White, suggesting that "the further the decision departs from responsible medical opinion, the clearer the evidence must be that this is what the adult wanted"[27]. On the other hand, participants in this study did not tend to raise validity concerns if they agreed with the decision in the ACD or thought it was appropriate for the situation. This suggests that doubts about validity were raised as a justification for overriding ACDs.

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Moreover, in this study some doctors questioned the ability of patients to accurately predict what they would want in future unknown circumstances. This is consistent with international research evidence suggesting that prognostic uncertainty is a barrier to the creation of useful, clinically relevant ACP documentation[28-30]. Some participants appeared to support the idea of using different ACD formats in tandem; instructional ACDs could be used for patients with an existing diagnosis and a predictable disease trajectory, to make advance decisions about anticipated situations. Values ACDs could provide broader context for the decision and act as general guidance to assist in decision-making for clinicians and substitute decision-makers. Further to this, legislation governing ACD adherence in Victoria states that doctors do not need to uphold ACDs that are not considered to have been intended to apply to the clinical scenario at hand[22]. This provides for some leeway in doctors interpretation of ACDs in clinical practice.

Interestingly, doctors in this study showed minimal concern about the potential legal consequences from overriding a patient's ACD, because they believed that making an ethical decision was the most important outcome for patients and families. This is concerning given that legal frameworks are moving toward greater support for patient autonomy, as reflected in current legislation[22] and the Medical Board of Australia code of conduct[31]. Doctors in this study may not have been aware of relevant law, and the consequences of not following the law which include civil and criminal liability[32]. Past research evidence examining compliance with ACDs has been mixed, with some survey studies in Australia[33] and overseas[34] describing high levels of self-reported adherence of doctors with ACDs. However, unlike the current study these surveys did not test doctors' adherence using sample vignette scenarios, and thus may be less reflective of actual clinical practice. In contrast, our study suggests that doctors prioritise ethical considerations and clinical judgement above law in decisions to follow ACDs. In addition, studies have demonstrated varying levels of legal

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knowledge among health professionals, and have concluded that more training and education is needed to address this gap in knowledge[33].

Strengths and limitations

In this study we utilised in-depth interviews and case vignettes to gain a deeper understanding about medical decision-making of doctors. We applied purposive sampling to recruit a cohort of doctors with a diverse range of experience levels and speciality backgrounds, from a hospital with a well-established ACP program. The majority of participating doctors had personal experience with the use of ACDs in their clinical practice, which strengthened our results by providing a real-world perspective on the utility and application of ACDs in clinical practice. However, doctors were recruited from a single metropolitan health service in Australia, which may limit the transferability of findings to other settings.

Implications for practice, policy, and future research

Our research highlights the importance of supporting patients to create relevant, up to date, and clear ACDs that are clinically useful for doctors. In addition, this study suggests a need for an integrated approach to ACP, including early involvement of doctors, and involvement of substitute decision-makers in discussions. This may minimise the likelihood that doctors will mistrust or question the validity of the ACD, or support family to override the patients' preferences. ACP implementation should support increased ethical and legal education and training for health professionals, in order to translate legislation into clinical practice. Future research may seek to track the influence of recent legislative change on ACD adherence; since these interviews were conducted, the law in Victoria was updated to provide greater legal support for ACDs which legislates substituted judgement decision-making[10].

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Conclusion

This study provides insight into doctors' attitudes and perspectives about the clinical utility of ACDs. Doctors found ACDs most useful when they were current, relevant to the scenario, consistent with clinical judgement, and contained what doctors considered to be 'reasonable' choices. Doctors were less supportive if an ACD conflicted with their treatment plan or if they doubted its validity. Consequently, some doctors decided to override the preferences in the ACD based on judgements that doing so was consistent with the best interests of the patient; whereas others felt morally obligated to respect the patient's autonomy, even if they disagreed with the decision. Future ACP programs should consider approaches to improve the validity and applicability of ACDs. In addition, there is an ongoing need for ethical and legal education to support doctors' knowledge and confidence in ACP and enacting ACDs.

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Contributors

Research idea and study design: KD, SF TL; data acquisition: TL, SF; data analysis/interpretation: NM, MS, TL, SF, KD, LN; thematic analysis: NM, MS; supervision or mentorship: SF, MS. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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Table 1. Participant characteristics (total participants = 21)

Characteristics	**No. of participants (%)**
*Area of practice**	
Cardiology	4 (19)
Gastroenterology	2 (10)
General medicine	7 (33)
Geriatric medicine	2 (10)
Infectious disease	1 (5)
Medical oncology	1 (5)
Nephrology	3 (14)
Palliative care	6 (29)
Relieving	1 (5)
Respiratory	1 (5)
Qualification	
Consultant	11 (52)
Resident OR registrar	10 (48)
Years of experience	
<5	5 (24)
5-10	7 (33)
11-20	3 (14)
>20	6 (29)
Gender	
Female	10 (48)
Male	11 (52)
Experience with advance care directives in clinical practice	
Yes	19 (90)
No	2 (10)

*some participants had more than one area of practice

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Table 2. Illustrative quotes by theme

Subthemes	*Quotations*
Aligning with patient preferences	
Avoiding unwanted care	"I think it's definitely quite valuable in knowing at what point they want you to pull back on certain treatments." (Respiratory medicine resident)
	"You'd like to know what their advance wishes were. And for example, maybe they were intubated in the last couple of months and they'd documented they don't want to do that again" (General medicine registrar)
	"Obviously, we can make decisions based on the clinical picture and that's reasonable, but to be sure that you're making the right decision for that particular patient, you absolutely need to know about the patient." (Palliative care consultant)
Prioritising autonomy	"If his advance care directive said, don't touch me, then, I mean, he's made that decision with his own hand and we would have to respect that, even if we don't agree with it from a physiological basis" (General medicine registrar)
	"As long as the patient is competent, I'd say it's the patient's right. We'll respect their choice to die." (Cardiology resident)
	"Who are we to say – who is anyone to say they know better than the patient what they want?" (Nephrology consultant)
	"If I was advising him while he was conscious, I might debate [the ACD] with him. But unless I've got evidence that he is incompetent mentally, I can't debate that with him while he's unconscious. I would think it was a great shame, it's the sort of thing an 85-year-old might do, but it's something which presumably has been considered

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	well and documented so I'm not the person to turn around and say, nuts to you I'm going to resuscitate you. It might be unexpected, but certainly makes it very clear." (Gastroenterology consultant)
	"The difficulty we're facing is exactly the problem of our mind, that he's got an excellent prognosis and he will do well if we resuscitate him. On the other hand, he's clearly instructed me not to do it. So, in that setting, I should not do it… I think he's making a dumb decision, but in the sense, he's morally tied my hands." (Geriatric medicine consultant)
Navigating family opposition	"Sometimes you persist with things a little longer than is appropriate, because you're trying to keep the patient alive so the relatives can see what is going on." (Gastroenterology consultant)
	"Sometimes people will end up doing the CPR because they really think the family are wanting it, or the patient's wanting it, and because they've been wanting it no one's said not to do it." (Nephrology consultant)
	"I could get you guys to help me with an advance care directive and say that I, at the age of 30, have no interest in being resuscitated, because at whatever point that my cardiac output stops and I am in an arrest situation, then I don't want to be resuscitated because that means something horrible's going on, and I have the right to make the decision and my family don't necessarily play a part in that." (General medicine registrar)
Advocating best interests	
Defining futile care	"The question would be, firstly, is it a futile treatment, and so the decision has to be made about whether we're offering the treatment before he has a chance to accept or decline it." (Palliative care consultant)
	"That's when I would say, unfortunately, resources are limited, it is a medical decision, in the Australian healthcare system we don't offer futile treatment. So if we think medically we can't help this patient, then we won't offer unnecessary and potentially harmful treatment. So in those situations I'll also emphasise that these treatments are not

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	without risk and harm and say that, you know, we do what's in the best interests of the patient, keeping them comfortable, we're focusing on quality not quantity of life." (General medicine registrar)
	"If treatment's futile, then that trumps an advance care plan. You can't say that you want treatment that isn't medically indicated or is futile. The patient can't write – I want this and this done in an advance care plan and it has to be done… That would be absurd. Medical futility obviously has to trump the desire of a patient to have a particular treatment" (Nephrology consultant)
Relying on clinical judgement	"If my judgement at the time is that this is going to be reversible, I would be inclined to not follow the plan and have a go at trying to reverse the ventricular fibrillation." (Nephrology consultant)
	"Being a doctor, your first rule would be to do no harm, and if I do believe that, in this case, it would be beneficial to the patient and, at the same time, there is a good chance he would be able to recover to the point of being able to live life as per his wishes, with significant independence and quality of life, then I don't think I'm doing anything wrong, in this case… I think it's not right to withhold treatment – especially when, based on your medical assessment, there is a great potential for reversibility. And the patient might not have that information. They are not expected to make that call. And you, as the doctor, should be. " (Nephrology consultant)
	"He has an excellent prognosis and you would reasonably anticipate that he would have potentially quite a number of years because basically he's got nothing wrong with him. So you would be mischievous not to treat him." (Geriatric medicine consultant)
	"It's very tricky, because sometimes you do have people who say they don't want to be resuscitated for a reversible condition, but, you know, patient autonomy is important… So this would be things the consultant would consider: autonomy versus, you know, reversing a reversible condition that will cost this patient their life otherwise." (General medicine registrar)

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Rejecting unreasonable decisions	“We are advocates for the patient, but at the same time, we advocate for treatment that we think is reasonable, within reasonable limits.” (Cardiology registrar)
	“In that situation, I would want more information, and for things to be clarified as to exactly what context he was referring to and things like that. I think you would need to know more information given that he’s 65 and otherwise well. That plan is not really in fitting with normal people’s wishes.” (Geriatric medicine resident)
	“It’s not that I’m saying that I normally disregard advance care plans, but this is an unusual advance care plan. You don’t have too much time to think about it. The details you’ve given me are really sketchy. Most of the time, when people make advance care plans about things they don’t want, it’s in pretty clear understandable reasons why probably a sensible person would not want that. You know, situations that are clearly untreatable. Situations where treatment is expected to give a bad outcome… Most people in this situation would want to be treated. So, it just feels a bit odd and you’ve got to make a quick decision” (Nephrology consultant)
Disregarding legal consequences	“(Interviewer: do any legal obligations come into it, at any stage?) No, I think it’s more – someone dying who doesn’t necessarily need to die. Like, for me, it’s not necessarily my legal ramifications as doing what’s best for the patient.” (Cardiology resident)
	“I think more the ethical side of things is a bigger play of things in my decision making than the legality of an advance care plan.” (Cardiology resident)
	“I don’t think I could be prosecuted for following or not following an advance care directive if I was using reasonable judgement, and that the interests of the patient are always at the forefront of everything I do, and so long as I can justify that in a way that my peers would agree with me, then I think I would be fairly safe from a legal perspective, and it’s certainly, fortunately, in this country, not at the forefront of my mind, ever.” (General medicine registrar)

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Establishing validity	
Doubting rigor of the decision-making process	"I guess with any documentation, you're presuming it was done under the right circumstances, without coercion and all of that… We can never verify that unless we were part of the process." (Gastroenterology consultant)
	"With an advance care plan, we're making the assumption that everything's been – the patient's had these discussions in a very formal way, things explained, they understand, and things have been discussed. Which may or may not be the case." (Respiratory medicine resident)
	"I know in some facilities, like some nursing homes, for example, they fill it in as their KPI… And it might be somebody who doesn't know the hospital system, or the healthcare system very well, like the nurse around, or the family member who's left to fill it in themselves, they might just write random things they don't really mean." (Palliative care, general medicine and medical oncology consultant)
Questioning patients' ability to understand treatment decisions	"you want what you want, but sometimes you don't understand – and I know that sounds quite condescending – people don't sometimes understand their conditions, and maybe that's a fault of clinicians, we don't explain what COPD means, what going on home oxygen means. People think that with home oxygen, they're going to be better and things are going to be better, but, no, it's one step closer towards the end. And sometimes we're really bad at explaining that" (General medicine and palliative care registrar)
	"I don't think patients necessarily understand what's going on, and I think – in as much an advance care plan is great, each situation is different. Some people say, I don't want to be resuscitated, I don't want to be brought back, because often they think their quality of life is going to be poor. But in some cases, things might not be as bad as they seem. We never know, so, I don't think they should be 100% binding." (General medicine and palliative care registrar)

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	"It's also useful to say, 'I don't want to be intubated', but it's kind of a harder one for some patients, who haven't had much experience with hospitals, who haven't had medical training, to kind of understand that. So, I think, it's probably, more for a patient-centred approach, 'I want a quality of life' or 'I don't want to be in a nursing home', because they can definitely understand that… If they happen to be a nurse or a doctor, then that's fine. If they haven't had much medical experience or medical training, you'd want to know, well, what is it about intubation you don't like? Or, what have you heard? Their understanding of intubation might be very different to my understanding of intubation." (Infectious disease and general medicine consultant)
Distrusting outdated preferences	"The advance care plan that was made five years ago could potentially be outdated, especially with the potentially new diagnoses of metastatic pancreatic cancer and end-stage kidney disease, that could very well change the patient's perspective about what he wants to do about limitations of treatment." (Nephrology consultant)
	"I mean, essentially, if the care plan was there, I would – I guess feel obliged to follow it. But my concern with the advance care plans is the timing that they're made, people – moods change, life changes all the time, advance care plans are rarely revisited to make sure that people still have the same opinion." (Nephrology consultant)
	"If they're conservative to start with, then I don't think they necessarily have to be updated. And that includes values. So if they're saying that fit and independent is how I want to be, then nothing changes. I think, if you've got someone asking for full resus who then develops metastatic pancreatic [cancer], so a new, significant comorbidity, then I think you should update it, to be less aggressive, if that's what you want." (Palliative care consultant)
Seeking confirmation	"I guess I don't really know the circumstances in which he said that. Maybe he was thinking about when he was an 80-year-old man with metastatic malignancy, or something like that. It doesn't really make sense to me if you're 65, you're young, you're playing golf, everything's fine, to say 'I don't want to have resuscitation'. So, if someone

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	really, really means it, then his family or spouse or whatever will know all about it and they'll be able to confirm it." (Palliative care consultant)
	"If it was like, he'd just said this yesterday during his admission, then it would be enough. And OK, stop. And if he's of sound mind, and he made that decision in the knowledge that he was going to die. But if, if there was any question about when it was made, or why it was made, then I would want to try and clarify. (Infectious disease and general medicine consultant)
	"If I was confident about the advance care plan, if my team was involved in it, then I'd respect it, regardless. But if there was a question then I'd have to try and revisit, have a family meeting, try and work out exactly what the situation is." (Infectious disease and general medicine consultant)
Translating written preferences into practice	
Contextualising patient preferences	"There's a generalness about [advance care directives], often, and all of a sudden, you're dealing with a specific. So you've got a general statement about what you want or don't want to do in a very specific situation, where you've got to make a decision in a hurry." (Nephrology consultant)
	"You need to have a bit of clinical judgement, in terms of interpreting, because obviously, when the advance care plan was made, as much as they try to cover all potential clinical scenarios, it is quite impossible to cover every clinical scenario, so I think, exercise judgement as to whether this will be the situation where values might be important to help guide you. Whether those values are achievable, or not, would help you plan your treatment." (Nephrology consultant)
	"The difficulty with the specific statement is, with a patient with multiple problems, but is stable at the time of your seeing them, you don't know what specific scenario you're thinking about. Like, you know, what if you had a stroke? What if you had an AMI? What if you had an arrhythmia? What if you aspirated? What if you fell over and

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	broke your hip? What if you were in a car accident? What if you had anaphylaxis? Do you want an antibiotic? You know, very different scenarios in some situations.” (Nephrology consultant)
	“Values statements let me do the medical stuff in the context of what they want. The problem with them saying, yes, I want haemodialysis and I want this and I want that is that we may be talking about a different situation. So it might be completely irrelevant. Whereas a values statement might be a lot more relevant for a lot more conditions” (Palliative care consultant)
Applying subjective terminology	“He said his independence is really important for him – that’s kind of a one sentence thing so I don’t really know what his independence means in this context” (Palliative care consultant)
	“When they say they don’t want to be resuscitated, what exactly do they mean. Do they not want [non-invasive ventilation], do they not want ICU, do they not want shocks?” (Nephrology consultant)
	“Some just say, ‘I don’t want to live if I can’t play golf’, then obviously it’s a bit tricky to work out which interventions might end up giving him the opportunity to play golf again. Whereas if it clearly states, ‘I don’t want to be intubated’, then your decision’s already made. So yeah, I guess that answers the previous question, it’s more helpful to have more specific treatments and interventions outlined, I would feel.” (Geriatric medicine resident)
	“Does it need to be interpreted literally? Well, as best one can. At the end of the day, people write funny things, and sometimes we’re not quite clear what they want, so you’ve sort of got to give it your best shot. Or they tell you things that appear to be contradictory, and then you’re struggling, so we run into a bit of that.” (Geriatric medicine consultant)
Prioritising emergency medical treatment	“You can always get that information available to you as quickly as possible, and you certainly don’t want to do it the wrong way around and say he might not want this and he does, and he did want that, and so yeah, I’d just treat it as a full code at this point.” (General medicine registrar)

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	"Mostly, we are trained to resuscitate, I think we struggle to let people die. But reading this scenario, and not being actually in the scenario, it's different when you're physically there, with all the stressors, and it's all noisy and everything… It's hard. It's hard in this case… We probably would resus in ICU. Probably, because we have the support – and I know it's not necessarily the right thing to do by the patient, but I actually think that would happen." (Cardiology resident)
	"In my experience, a 65-year-old with hypertension comes in and codes… They'd be in ICU and tubed before anyone looks at their scanned medical record to see what their advance care plan was." (General medicine registrar)

Abbreviations: ACDs, advance care directives; AMI, acute myocardial infarction; COPD, chronic obstructive pulmonary disease; CPR, cardiopulmonary resuscitation; ICU, intensive care unit; KPI, key performance indicator

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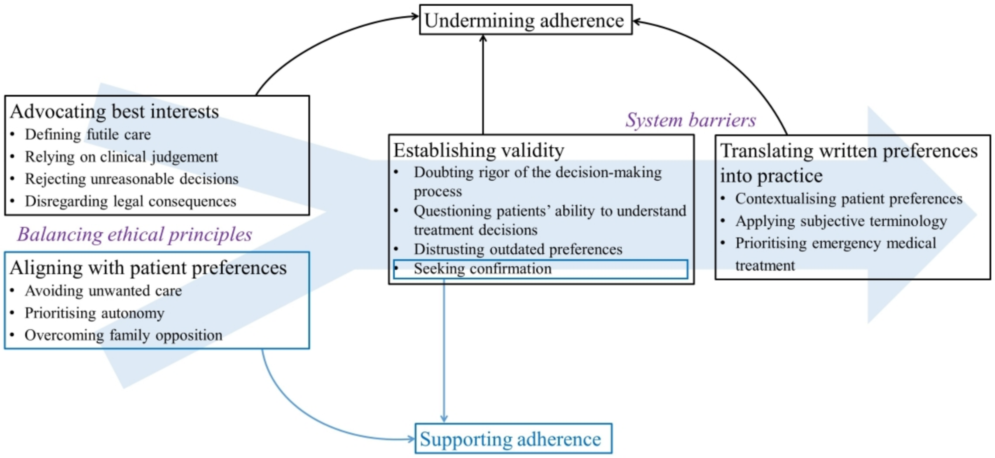

Figure 1. Thematic schema of doctors' perspectives of the use of ACDs in clinical decision-making. Doctors used two distinct ethical approaches to evaluate ACDs, and subsequently moved through their decision-making process towards a treatment decision. An autonomy-focused approach motivated doctors to align with patient preferences, and this supported doctors to adhere to ACDs, along with successful establishment of validity when confirmation of the ACD was sought. In contrast, decision-making based on patients' 'best interests' permitted doctors to override ACDs, as did validity concerns and issues with translating the ACD into practice.

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Supplementary Item S1: interview guide

Section 1: Basic demographics

- Please tell me a little about yourself:
    - Specialty/current rotation
    - Years of practice
- We are going to be talking about Advance Care Planning (ACP); have you ever used an advance care plan to guide the treatment you have delivered to a patient? Does ACP work for you?

Section 2: Vignettes

- OK, so what I want to do now is provide you with a case scenario, and what I would like is how you would intend to treat the patient. I will then add a little more information and see if and how that might alter your treatment plan.

Scenario 1: Mr X is a 73-year-old man with advanced chronic obstructive pulmonary disease (COPD). Over the last two years, he has become progressively breathless and is now breathless on even minimal exertion; he struggles with showering and dressing due to his breathing. He is on maximal therapy, including home oxygen. He has had three admissions for acute exacerbations of COPD in the past 6 months. During his last admission one month ago, he required non-invasive ventilation. This time, on arrival, he is breathless and has right heart failure. He is hypoxic and hypercapnic.

- Why would you choose this course of action?

- When examining the records, it was discovered that the patient had an Advance Care Plan, informing us that he places a high value on his independence, and does not want to become a burden to his family.
    - Would this alter your treatment plan?
    - Why would you alter/not alter the plan?
    - Would your treatment plan alter if the advance care plan actually informed us that the person was not for intubation, ICU intervention or inotropes?

(The first scenario explores the value of a goals based advance care plan in guiding treatment with a patient that is deteriorating due to chronic illness. Probing questions would examine how treatment options would affect the patients' independence etc. Other areas to

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examine would include the participants' views on the worth of values goals ACP and how they might go about interpreting them)

- Let's move onto to the second scenario. Again, I would like to know your treatment plan and the reasoning behind it, and then we will add a little more information.

Scenario 2: A 65-year-old patient with well-controlled hypertension arrives at the emergency department, complaining of "chest pain". A full work-up for cardiac ischemia is sorted. Before the work-up can be completed, he falls into ventricular fibrillation. A code is called and upon your arrival to the bedside, the patient is apnoeic and requiring mask ventilation by the nursing staff.

  - What would you do for this patient?

- Again, an advance care plan is present, which states that he values being an active and productive member of his community. He would rather be dead than miss his game of golf.
  - Would this alter your treatment plan? If so, how and why?
  - What if the advance care plan stated that he was not for resuscitation and should be "allowed to pass away in peace"? What treatments would you offer?

(This scenario explores the interaction between the acuity of the situation and the presence of an advance care plan. It may be expected that the patient here would make a full recovery however an advance care plan may mean that the treatment is not offered. Probing questions would include areas around the legal liability of honouring or not honouring an advance care directive)

- Now, if we can, I would like to move onto the final scenario.

Scenario 3: A 68-year-old patient with multiple co-morbidities – including diabetes, hypertension, end-stage renal disease (he is on dialysis) and metastatic pancreatic cancer – presents to the Emergency Department febrile, tachypnoeic and hypotensive. He is transferred to the intensive care unit (ICU), where you are covering. Upon arrival, his blood pressure falls to 40 systolic.

  - What would be your treatment plan? Why?

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- Let us imagine that the patient had an advance care directive stating that they value life above everything – God will take me when ready until then I must live.
    - How would this alter your treatment plan? Why?

- OK that was interesting but in actual fact they had an ACP that was signed 5 years ago stating that they were not for intubation or CPR.
    - Would that change your thinking and why?
    - How worried would you be about the ACP being dated 5 years ago?

- Let's stick with this scenario a little longer: so the patient has a blood pressure of 40, and the not for intubation or CPR ACP signed 5 years ago is in place. However, the wife of the patient is there, demanding that you do all you can to save her husband and that the ACP was not what her husband wanted anymore.
    - What action would you take and why?
    - Do legal considerations with regard to honouring the ACP or not honouring the ACP come into consideration?
    - Does the family or substitute decision maker have the right to override the ACP?

(This scenario first examines the situation where a patient opts in for treatment by the ACP and how that may change treatment provided in the dying phase. Some literature has suggested that a barrier for enacting ACP is that it may not represent current values this explores this by adding the old ACP with no evidence of an update. Finally, the question of family conflict with an ACP is explored and the knowledge of the legalities surrounding this)

Section 3: Questions regarding the perceived usefulness and importance of ACP.

- That is the end of our scenarios. Finally, I would like to ask just a couple more general questions:
    - How instructive do you find knowing a little bit about what the patient values in making a medical decision for them?
    - How important would you say an ACP has in providing person-centred care?
    - How binding should an ACP be – should they be interpreted literally?

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- That concludes the interview, thank you for your time. What I will do now is look over your responses, and collate them with other interviews and look for themes that are coming out. While there has been lots of research on how to generate more ACP documents, there is little known about enacting them and what we would consider valuable.
- If you would like a copy of the report once finalised, let me know and I will forward it to you. Alternatively, you can let Scott know; his contact details are on the information sheet.
- Again, thank you so much for your time.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: an Australian interview study

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Primary Subject Heading:	Ethics
Secondary Subject Heading:	Qualitative research
Keywords:	advance care planning, advance care directives, autonomy, end-of-life, interviews, semi-structured interviews

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Title: Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: an Australian interview study

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Abstract

Objective

Advance care planning (ACP) assists people to identify their goals, values and treatment preferences for future care. Ideally, preferences are documented in an advance care directive (ACD), used by doctors to guide medical decision-making should patients subsequently lose their decision-making capacity. However, studies demonstrate that ACDs are not always adhered to by doctors in clinical practice. We aim to describe the attitudes and perspectives of doctors regarding ACD adherence and the utility of ACDs in clinical practice.

Design

Face-to-face semi-structured interviews were conducted using three case-based vignettes to explore doctors' decision-making and attitudes towards ACDs. Transcripts were analysed using thematic analysis.

Setting

Doctors from a variety of medical specialties and with varying experience levels were recruited from a large tertiary hospital in Melbourne, Australia.

Participants

Twenty-one doctors were interviewed, 48% female (10/21). Most (19/21) reported having experience using ACDs.

Results

Four themes were identified: aligning with patient preferences (avoiding unwanted care, prioritising autonomy, anticipating family opposition), advocating best interests (defining

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futile care, relying on clinical judgement, rejecting unreasonable decisions, disregarding legal consequences), establishing validity (doubting rigor of the decision-making process, questioning patients' ability to understand treatment decisions, distrusting outdated preferences, seeking confirmation) and translating written preferences into practice (contextualising patient preferences, applying subjective terminology, prioritising emergency medical treatment).

Conclusions

ACDs provide doctors with opportunities to align patient preferences with treatment and uphold patient autonomy. However, doctors experience decisional conflict when attempting to adhere to ACDs in practice, especially when they believe that adhering to the ACD is not in the patients' best interests, or if they doubt the validity of the ACD. Future ACP programs should consider approaches to improve the validity and applicability of ACDs. In addition, there is a need for ethical and legal education to support doctors' knowledge and confidence in ACP and enacting ACDs.

Keywords: advance care planning, advance care directives, autonomy, end-of-life, interviews, semi-structured interviews

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Article summary

Strengths and limitations of this study

- Purposive sampling used to promote inclusion of participants from a variety of medical specialties and experience levels
- Face-to-face semi-structured interviews used, providing a deeper understanding of participants attitudes and perspectives about ACD adherence
- Use of vignettes with hypothetical case scenarios to stimulate doctors' discussion about the use of ACDs in clinical practice
- Limitation: recruitment undertaken from a single metropolitan health service in Australia, which may limit the transferability of findings to other settings

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INTRODUCTION

Advance care planning (ACP) is a process where an individual makes his or her goals, values and preferences known in order to guide decision-making for healthcare, in the event he or she cannot make or communicate decisions in the future[1]. ACP assists patients' personal reflection about their values and goals of care, and can be supported by the completion of an advance care directive (ACD), designed to inform medical decision-making in the event the patient loses capacity to make or communicate decisions[2]. The terminology and legal status of ACDs varies considerably within Australia[3] and internationally[4-7], however they are commonly used to specify treatment preferences, express values, and/or to appoint a substitute decision-maker[2] (see Box 1). Completion of an ACD is considered to be a key component of ACP because ACDs provide written support and guidance for clinicians and family members when making medical decisions on behalf of the person[1, 8, 9].

ACP and ACD documentation are part of a broader shift in healthcare to promote person rights and autonomous decision-making. Legal frameworks have supported this evolution, providing greater emphasis on approaches to medical decision-making which encompass substituted judgement, as well as relational autonomy[10]. Substituted judgement requires decisions to be made according to what the patient would have wanted, rather than according to what others assume is in their "best interests". The emergence of ACP can be attributed to the rising value of autonomy in society and increased legal emphasis on informed consent to medical treatment and shared decision-making[11].

Research suggests that ACDs are not always adhered to by doctors in clinical practice. A 2007 study found that the presence of an ACD did not influence healthcare providers' decisions in using life-sustaining treatments or initiating comfort care plans[12]. More recently, Australian researchers presented doctors from New South Wales and Victoria with a hypothetical case scenario to investigate compliance with ACDs[13]. In responding to the

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scenario, only 32% of doctors reported that they would adhere to the ACD in accordance with the law. Studies have identified a number of barriers to ACD adherence, including family opposition[14-16], lack of clinical relevance[15, 17-20], and concerns about the validity of ACDs[15, 18, 20].

The aim of this study is to describe the attitudes and perspectives of doctors involved in the care of patients with chronic disease at an Australian hospital. This study used qualitative interviews and vignettes to explore doctors' opinions regarding ACDs to gain a deeper understanding about ACD adherence and the utility of ACDs in clinical practice.

Box 1: Legal context in Victoria, Australia

Medical Treatment Act 1988[21]:

- A competent person can refuse treatment in relation to a current condition by completing a legally binding Refusal of Treatment Certificate.
- A competent person can appoint an enduring power of medical attorney with the powers to consent, refuse and/or withdraw treatment.

Guardianship and Administration Act 1986[22]:

- Person responsible, identified as default substitute decision-maker within the Act, can consent to or decline to consent to medical treatment; however they cannot refuse treatment.
- When making a decision the substitute decision-maker must act in the best interests of the person for whom they are making decisions. The paramount factor in determining the person's best interests is the wishes of the person, so far as they can be ascertained.[3, 23]

Common Law

- A person can complete a non-statutory advance care directive (inclusive of values and treatment preferences). It should be signed, dated and witnessed.[23] The legal standing of such documents has not been tested with Victoria, Australia. However, it was expected that given case law in New South Wales[24], common law directives would be upheld in Victoria.

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- Within the health service there are policies relating to advance care planning, informed consent (including where the patient lacks capacity) and limitation of life-prolonging treatment. These policies document clear explanation of the relevant legislation and the legal basis for statutory and non-statutory advance care directives. Information on the identification and role of the substitute decision-maker is also included in hospital policies

METHODS

Study reporting is based on the Consolidated Criteria for Reporting Qualitative Health Research (COREQ)[25].

Participant selection and setting

Participants were doctors involved in the care of patients with chronic disease at Austin Health in Melbourne, Victoria, Australia. Participants were invited to participate through departmental meetings. Purposive sampling was used to ensure participants from a variety of medical specialties and with varying experience levels were included. All doctors who expressed interest in participating went on to participate in interviews. Ethical approval was obtained from the Austin Health Human Research Ethics Committee (LNR/16/Austin/528). Participants provided informed consent prior to being interviewed.

Data collection

Face-to-face semi-structured interviews were conducted from February to April of 2017 by two investigators (T.L., S.F.) until thematic saturation was reached, defined as the point at which few or no new concepts or themes were arising from subsequent interviews[25]. Participants were aware that the interviewers were a medical student and supervisor and some participants were known to the researchers in a collegial capacity, but

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otherwise a relationship was not established prior to interview. Interviews were audiorecorded and transcribed verbatim by T.L.

An interview guide was developed for this project by the research team (see Supplementary item S1), based on literature review followed by discussion and consensus among the research team. This guide consisted of three sections:

1. Demographics and prior experience with ACDs;
2. Three vignettes (see Box 2), each presented with a "values" then an "instructional" ACD; and
3. Questions regarding the perceived usefulness and importance of ACP.

In Section 2, participants were asked to outline their medical management plan for each case scenario. Extracts from ACDs were then used to determine whether the doctor would adhere to the ACDs in each scenario and how, if at all, the ACD would influence their management plan. Probing questions were then used to explore participants' perspectives with regards to ACD adherence and related issues such as legal concerns and family input.

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Box 2: Summary of hypothetical vignettes

Scenario 1: 73-year-old man with advanced chronic obstructive pulmonary disease and recurrent hospitalisations. Presents acutely breathless

- Values directive: places high value on his independence, doesn't want to become a burden to his family
- Instructional directive: not for intubation, intensive care unit intervention or inotropes

Scenario 2: 65-year-old previously well man presents with chest pain, then collapses with ventricular fibrillation

- Values directive: he values being an active and productive member of his community. He would "rather be dead" than unable to play golf
- Instructional directive: not for resuscitation, should be "allowed to pass away in peace"

Scenario 3: 68-year-old man on dialysis, with a history of metastatic pancreatic cancer. Presents febrile, tachypneic and hypotensive

- Values directive: he values life above everything – "God will take me when I'm ready"
- Instructional directive: not for intubation or cardiopulmonary resuscitation (signed 5 years ago)
- Additional information: patient's family disagree with directive and demand full treatment to be given

Note: values directive is defined as a general statement about a person's preferences and values[26]. Instructional directive is defined as an express statement in which a person may either consent to or refuse a particular medical treatment, which takes legal effect if the person loses decision-making capacity[26].

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Data analysis

Transcripts were entered into HyperRESEARCH (ResearchWare Inc), a software package used to store and code qualitative data. Drawing from principles of grounded theory and thematic analysis[27], N.M. inductively identified concepts in the transcripts and then developed and refined the coding structure with assistance from M.S.. The analysis identified relationships between themes to develop a thematic framework to capture all concepts about participants' experiences and perspectives about ACD adherence. To further develop and enhance the analytical framework, interpretation of data and preliminary themes were discussed among the research team.

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Patient and public involvement

There was no patient or public involvement in the design and conduct of the study.

RESULTS

Participant demographics

Participant characteristics are provided in Table 1. In total, 21 doctors participated, from a broad range of medical specialties, with a range of experience levels. About half were women (10/21). Almost all participants (19/21) reported having used ACDs in their clinical practice. Interview duration ranged from 12 to 52 (mean, 26) minutes.

Themes

We identified four themes: aligning with patient preferences, advocating best interests, establishing validity and translating written preferences into practice. The themes were relevant to all scenarios unless otherwise specified. Selected quotations to illustrate themes are provided in Table 2. Conceptual links among themes are presented in Figure 1.

Aligning with patient preferences

Avoiding unwanted care

Doctors valued ACDs that supported them to understand “what the patient wants and why they want it” to be able to individualise treatments according to the patients’ preferences. They believed ACDs can help them make “the right decision for that particular patient” and avoid unwanted treatment. For instance, some doctors felt that ACDs provided patients with an opportunity to have a say about “wanting or not wanting a certain kind of treatment”, after considering past treatment experiences.

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Prioritising autonomy

Nonetheless, some doctors experienced deep conflict when weighing up decisions to follow ACDs, in scenarios where they disagreed with the patient's decision. This was because they felt "morally tied" to follow decisions to refuse treatment, because they believed it was important to respect the patients' autonomy. This was most evident in Scenario 2, involving a previously well patient presenting in a sudden cardiac arrest, who had an ACD which refused resuscitation. Even though participants acknowledged the situation was very difficult given the patient would likely have a good prognosis if treated, some felt obligated to adhere to the ACD, stating that "if you're going to allow people autonomy to decide things … you can't say, we will sometimes, we won't sometimes". These doctors felt that people deserve to maintain their own autonomy, provided the patient has made an informed choice as a competent adult. Thus despite their reservations, they decided they would adhere to the ACD and withhold resuscitation, reflecting that it would be "unethical to give [the patient] something that [they] never wanted".

Anticipating family opposition

Doctors described potential difficulties of overcoming family opposition when making decisions based on patient preferences in ACDs. This was particularly evident in Scenario 3 in which participants were asked how they would respond if a family member requested more treatment to be given than stated in the ACD. Some doctors felt that although they would "try to accommodate" the preferences of the family, they would draw the line at "causing harm to the patient". One participant argued against permitting family to override the ACD because the patient has "the right to make the decision" and "family don't necessarily play a part in that". However, other participants reflected on scenarios from their own clinical experience where family members had requested more treatment than the patient

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wanted and doctors had felt obliged to comply with requests to avoid causing stress to the family.

Advocating best interests

Defining futile care

Doctors considered ACDs to be irrelevant to their decision-making if patients had requested treatment that the doctor perceived to be futile. Doctors felt it was their duty to determine “what [was] futile” to avoid “unnecessary and potentially harmful treatment”. Because of this, some doctors refused to follow the treatment requests specified in the ACD, such as for cardiopulmonary resuscitation, intubation or mechanical ventilation, because they believed treatment would not be in the patient’s “best interests”. For example, in Scenario 3, a very unwell patient with a poor prognosis had a values ACD that requested all available treatment to be given. Participants decided not to follow the ACD, identifying that “any advance care plan for treatment becomes irrelevant, because giving him treatment would be futile”.

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Relying on clinical judgement

In contrast to those participants who prioritised patient autonomy in decision-making, some doctors appeared most influenced by their assessment of the potential risks and benefits to patients rather than the preferences specified in the ACDs. They considered factors such as the patients’ age and comorbidities, to make a judgement about prognosis and whether the condition was potentially reversible. As a result, some doctors refused to follow the ACD and instead proceeded with treatment because they felt it was not “right to withhold treatment especially when, based on your medical assessment, there is a great potential for reversibility”. This was best illustrated in Scenario 2, where some doctors indicated they

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would be unwilling to withhold resuscitation on a relatively young, well patient, despite the patient having a valid ACD which stated they did not want resuscitation. Even though these doctors were aware of the patient's preference to "pass away in peace", they felt compelled to override the request because "[the patient] has an excellent prognosis … So you would be mischievous not to treat him".

Rejecting unreasonable decisions

Some doctors were reluctant to implement ACD requests that they considered to be unreasonable, or inconsistent with what a "normal" person might want. Doctors judged whether they thought the preferences specified in the ACD were "sensible" or acceptable for the situation, and some were unwilling to comply with those that they perceived as unreasonable or "unusual". These doctors were willing to respect patients' treatment choices but only if they conformed within the scope of treatment options that was felt to be reasonable or appropriate in that situation.

Disregarding legal consequences

Overall, doctors appeared to have minimal concerns regarding potential legal consequences of not following ACDs, choosing instead to prioritise what they believed to be the patients' best interests in their decision-making. One participant explained that "the legal stuff never worried me. It'll be more about the moral thing to do". Doctors were more motivated to act in the patients' best interests, rather than uphold the ACD because of a legal obligation. Doctors dismissed the risk of legal consequences, believing they would be protected if they used "reasonable judgement" that could be justified in a way that their peers would agree, and if "the motivation for not following the plan was one of trying to do the best for the patient".

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Establishing validity

Doubting rigor of the decision-making process

Some doctors expressed concern because they were unable to verify whether a "proper" ACP discussion had occurred in the formation of an ACD, as they had not been "part of the [ACP] process." Therefore they could not verify if the patient preferences specified in the ACD were accurate and/or informed. Doctors regarded best practice ACP as a formal discussion with a trained health professional in which issues could be explained, understood and discussed. Some doctors expressed scepticism regarding the rigor of ACP discussions in practice and therefore felt justified in dismissing any preferences specified in the ACD. For example, these doctors believed that ACP is sometimes completed as a "tick box" where important details about treatments are not discussed.

Questioning patients' ability to understand treatment decisions

In considering treatment preferences specified in ACDs, some doctors questioned whether patients were capable of "fully understand[ing] the consequences" of their decisions, because they believed the general population lack required medical knowledge about the risks and benefits of specific treatments. One participant explained that "patients aren't expected to understand all the minutiae or the nuances of what we can do", especially given the fact that "every single sickness they have is going to be individual and different". As a result, doctors suggested that medicalised instructional ACDs were not appropriate by themselves; instead, these doctors expressed a preference for ACDs that included the patient's values because these ACDs allowed the medical team to interpret the patients' preferences in their own words.

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Distrusting outdated preferences

Doctors also raised concern about adhering to ACDs that were created several years ago because they believed the preferences specified in the ACD were potentially outdated. They questioned whether the patients' views may have changed over time, especially if their health status had changed. Changes in the patients' circumstances that doctors believed may influence treatment preferences included receiving a new diagnosis or recovering from "acute unwellness". In contrast, some participants felt comfortable adhering to ACDs that were several years old if they judged it to be appropriate for the current situation. Some felt that if the ACD was already "conservative to start with" and the patients' prognosis had worsened, then they would still feel confident adhering to the ACD because they patient was unlikely to have changed their mind to opt for more aggressive treatment.

Seeking confirmation

To overcome concerns about the validity of ACDs, doctors believed they needed to seek confirmation of the ACD to establish its authenticity, such as from family members, before they would be willing to let it influence their management plan. This appeared mostly of concern when doctors disagreed with the preferences specified in the ACD, or if they believed the patient's treatment preferences were not in line with a reasonable medical course of action. Consequently, if they could not clarify the reasons underlying the preferences specified in the ACD, some doctors decided not to adhere to the ACD.

Translating written preferences into practice

Contextualising patient preferences

While doctors felt that ACDs are useful to help guide decision-making, some also highlighted the need for each ACD to be considered "in the context of what's happening

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today”, rather than applied literally in every case. Doctors believed that they should have some leeway to determine whether the ACD was intended to apply to the given clinical scenario, feeling the ACD should be used as “a guide, rather than something that is compulsory” – allowing the clinician to have a more “nuanced” interpretation of the patients’ request. Some doctors believed that ACDs are unable to address every possible clinical scenario that might arise and therefore, clinicians should be able to “exercise judgement as to whether this will be the situation where values might be important to help guide [them]”. For this reason, some participants expressed a preference for ACDs that conveyed patients’ preferences in terms of broad values statements because they were “more general” and therefore usually “more flexible and more applicable across multiple scenarios”.

Applying subjective terminology

In contrast, doctors sometimes struggled to apply values-based ACDs because they were unsure how to interpret values statements. Doctors felt that values expressions were “vague” and “confusing” because they are subjective. For example, some doctors questioned the meaning of the word “independence”, with one participant stating that “how I interpret independence is different to how someone else might value his independence” because “values are different from person to person”. Doctors expressed difficulty knowing how to apply values to form a concrete treatment plan and therefore some participants regarded instructional ACDs as being easier to interpret and apply because they have “clear-cut” directions.

Prioritising emergency medical treatment

Some doctors noted the importance of providing urgent medical treatment in a timely manner, and this was seen as a barrier to ACD adherence because there is not always time

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available to locate, read and interpret ACD documentation. Doctors reported that aggressive treatments are sometimes administered without consideration of patients’ preferences because of the need to begin treatment immediately. Additionally, some doctors felt ill-equipped to make difficult decisions about end-of-life care, especially in time-pressured situations. Participants explained that in an emergency, they felt obliged to “err on the side of … treating” because “you certainly don’t want to do it the wrong way around”.

DISCUSSION

This qualitative interview study provides evidence regarding the attitudes and perspectives of doctors in relation to ACP and ACDs by exploring vignette scenarios and medical decision-making. The majority of participants valued ACDs that supported them to align with patient preferences in their treatment decisions. However, some doctors experienced conflict in adhering to ACDs when they believed the ACD did not represent the patients’ best interests. Doctors tended to rely upon their own clinical judgement to make treatment decisions, sometimes overriding the ACD on the basis that the treatments requested were ‘unreasonable’, ‘futile’ or that the patients’ condition was potentially ‘reversible’. In addition, there were issues with validity and currency of ACDs, subjective terminology, patients’ ability to understand consequences of preferences, family opposition, and time pressures. In this study, consideration of what doctors perceived to be the patients’ best interests was found to be more influential in medical treatment decision-making than legal requirements.

From an ethical perspective, these findings challenge the widely held assumption that autonomy is the most important principle in healthcare decision-making[28]. Some participants preferred to follow their clinical judgement to make decisions that were in the patients’ best interests, rather than uphold patient autonomy, although others felt obligated to

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adhere to patients' preferences despite this conflict. This is consistent with another vignette interview study conducted in the UK by Thompson and colleagues[29], who also found that some doctors wished to override the ACD and proceed with treatment consistent with the patient's best interests, whereas others believed it was most important to respect patient autonomy. Our findings reinforce past Australian and international qualitative studies demonstrating that, while doctors appear to have a shared understanding and respect for patient autonomy in theory, competing values and interests prevent doctors from prioritising patient autonomy in their clinical decisions in practice[17, 29, 30]. Doctors in an interview study by Johnson and colleagues[30] felt that there should be limits to patient autonomy, and patient preferences should not be respected if the treatment choice is 'unreasonable', 'futile' or 'medically inappropriate'.

Doctors in this study reported validity concerns to be a key barrier to ACD adherence, in accordance with past Australian and international research findings[15, 18, 20, 29]. Doubts about validity, including currency of decisions, were particularly prominent where participants disagreed with the treatment decision specified in the ACD. For instance, when the ACD refused treatment that doctors felt would be beneficial, they tended to question the authenticity of the ACD and wished to establish its validity, such as by confirming with family members. This is consistent with a model of end-of-life decision-making proposed by Willmott and White, suggesting that "the further the decision departs from responsible medical opinion, the clearer the evidence must be that this is what the adult wanted"[31]. On the other hand, participants in this study did not tend to raise validity concerns if they agreed with the decision in the ACD or thought it was appropriate for the situation. This suggests that doubts about validity were raised as a justification for overriding ACDs. Many participants appeared to only question the validity of ACDs when they felt that the patient's choices were inappropriate or unreasonable for the situation.

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Moreover, in this study some doctors questioned the ability of patients to accurately predict what they would want in future unknown circumstances. This is consistent with international research evidence suggesting that prognostic uncertainty is a barrier to the creation of useful, clinically relevant ACP documentation[32-34]. Some participants appeared to support the idea of using different ACD formats in tandem; instructional ACDs could be used for patients with an existing diagnosis and a predictable disease trajectory, to make advance decisions about anticipated situations. Values ACDs could provide broader context for the decision and act as general guidance for substitute decision-makers. Further to this, legislation governing ACD adherence in Victoria states that doctors do not need to uphold ACDs that are not considered to have been intended to apply to the clinical scenario at hand[26]. This provides for some leeway in doctors interpretation of ACDs in clinical practice.

Interestingly, doctors in this study showed minimal concern about the potential legal consequences from overriding a patient's ACD, because they believed that making an ethical decision was the most important outcome for patients. This is concerning given that legal frameworks are moving toward greater support for patient autonomy, as reflected in current legislation[26] and the Medical Board of Australia code of conduct[35]. Doctors in this study may not have been aware of relevant law, and the consequences of not following the law which include civil and criminal liability[36]. Past research evidence examining compliance with ACDs has been mixed, with some survey studies in Australia[37] and overseas[38] describing high levels of self-reported adherence of doctors with ACDs. However, unlike the current study these surveys did not test doctors' adherence using sample vignette scenarios, and thus may be less reflective of actual clinical practice. In contrast, our study suggests that doctors prioritise ethical considerations and clinical judgement above law in decisions to follow ACDs. In addition, studies have demonstrated varying levels of legal knowledge

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among health professionals, and have concluded that more training and education is needed to address this gap in knowledge[37].

Strengths and limitations

In this study we utilised interviews and case vignettes to gain a deeper understanding about doctors' decision-making. We applied purposive sampling to recruit a cohort of doctors with a diverse range of experience levels and speciality backgrounds, from a hospital with a well-established ACP program. The majority of participating doctors had personal experience with the use of ACDs in their clinical practice, which strengthened our results by providing a real-world perspective on the utility and application of ACDs in clinical practice. However, doctors were recruited from a single metropolitan health service in Australia, which may limit the transferability of findings to other settings.

Implications for practice, policy, and future research

Our research highlights the importance of supporting patients to create relevant, up to date, and clear ACDs that are clinically useful for doctors. In addition, this study suggests a need for an integrated approach to ACP, including early involvement of doctors, and involvement of substitute decision-makers in discussions. This may minimise the likelihood that doctors will mistrust the validity of the ACD, or support family to override the patients' preferences. ACP implementation should support increased ethical and legal education and training for health professionals, in order to translate legislation into clinical practice. Future research may seek to track the influence of recent legislative change on ACD adherence; since these interviews were conducted, the law in Victoria was updated to provide greater legal support for ACDs which legislates substituted judgement decision-making[10]. In addition, future research could complement the current findings by characterising clinicians'

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perspectives and experiences regarding the role of family and legally appointed substitute decision-makers.

Conclusion

This study provides insight into doctors' attitudes and perspectives about the clinical utility of ACDs. Doctors found ACDs most useful when they were current, relevant to the scenario, consistent with clinical judgement, and contained what doctors considered to be 'reasonable' choices. Doctors were less supportive if an ACD conflicted with their treatment plan or if they doubted its validity. Consequently, some doctors decided to override the preferences in the ACD based on judgements that doing so was consistent with the best interests of the patient; whereas others felt morally obligated to respect the patient's autonomy, even if they disagreed with the decision. Future ACP programs should consider approaches to improve the validity and applicability of ACDs. In addition, there is an ongoing need for ethical and legal education to support doctors' knowledge and confidence in ACP and enacting ACDs.

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Contributors

Research idea and study design: KD, SF TL; data acquisition: TL, SF; data analysis/interpretation: NM, MS, TL, SF, KD, LN; thematic analysis: NM, MS; supervision or mentorship: SF, MS. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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Competing Interests Statement

None declared

Data Availability Statement

No additional data available

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Table 1. Participant characteristics (total participants = 21)

Characteristics	**No. of participants (%)**
*Area of practice**	
Cardiology	4 (19)
Gastroenterology	2 (10)
General medicine	7 (33)
Geriatric medicine	2 (10)
Infectious disease	1 (5)
Medical oncology	2 (10)
Nephrology	3 (14)
Palliative care	7 (33)
Haematology	1 (5)
Respiratory	1 (5)
Qualification	
Consultant	11 (52)
Resident OR registrar	10 (48)
Years of experience	
<5	5 (24)
5-10	7 (33)
11-20	3 (14)
>20	6 (29)
Gender	
Female	10 (48)
Male	11 (52)
Experience with advance care directives in clinical practice	
Yes	19 (90)
No	2 (10)

*some participants had more than one area of practice

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Table 2. Illustrative quotes by theme

Subthemes	*Quotations*
Aligning with patient preferences	
Avoiding unwanted care	"I think it's definitely quite valuable in knowing at what point they want you to pull back on certain treatments." (Respiratory medicine resident)
	"You'd like to know what their advance wishes were. And for example, maybe they were intubated in the last couple of months and they'd documented they don't want to do that again" (General medicine registrar)
	"Obviously, we can make decisions based on the clinical picture and that's reasonable, but to be sure that you're making the right decision for that particular patient, you absolutely need to know about the patient." (Palliative care consultant)
Prioritising autonomy	"If his advance care directive said, don't touch me, then, I mean, he's made that decision with his own hand and we would have to respect that, even if we don't agree with it from a physiological basis" (General medicine registrar)
	"As long as the patient is competent, I'd say it's the patient's right. We'll respect their choice to die." (Cardiology resident)
	"Who are we to say – who is anyone to say they know better than the patient what they want?" (Nephrology consultant)
	"If I was advising him while he was conscious, I might debate [the ACD] with him. But unless I've got evidence that he is incompetent mentally, I can't debate that with him while he's unconscious. I would think it was a great shame, it's the sort of thing an 85-year-old might do, but it's something which presumably has been considered

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	well and documented so I'm not the person to turn around and say, nuts to you I'm going to resuscitate you. It might be unexpected, but certainly makes it very clear." (Gastroenterology consultant)
	"The difficulty we're facing is exactly the problem of our mind, that he's got an excellent prognosis and he will do well if we resuscitate him. On the other hand, he's clearly instructed me not to do it. So, in that setting, I should not do it… I think he's making a dumb decision, but in the sense, he's morally tied my hands." (Geriatric medicine consultant)
Anticipating family opposition	"Sometimes you persist with things a little longer than is appropriate, because you're trying to keep the patient alive so the relatives can see what is going on." (Gastroenterology consultant)
	"Sometimes people will end up doing the CPR because they really think the family are wanting it, or the patient's wanting it, and because they've been wanting it no one's said not to do it." (Nephrology consultant)
	"I could get you guys to help me with an advance care directive and say that I, at the age of 30, have no interest in being resuscitated, because at whatever point that my cardiac output stops and I am in an arrest situation, then I don't want to be resuscitated because that means something horrible's going on, and I have the right to make the decision and my family don't necessarily play a part in that." (General medicine registrar)
Advocating best interests	
Defining futile care	"The question would be, firstly, is it a futile treatment, and so the decision has to be made about whether we're offering the treatment before he has a chance to accept or decline it." (Palliative care consultant)
	"That's when I would say, unfortunately, resources are limited, it is a medical decision, in the Australian healthcare system we don't offer futile treatment. So if we think medically we can't help this patient, then we won't offer unnecessary and potentially harmful treatment. So in those situations I'll also emphasise that these treatments are not

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	without risk and harm and say that, you know, we do what's in the best interests of the patient, keeping them comfortable, we're focusing on quality not quantity of life." (General medicine registrar)
	"If treatment's futile, then that trumps an advance care plan. You can't say that you want treatment that isn't medically indicated or is futile. The patient can't write – I want this and this done in an advance care plan and it has to be done… That would be absurd. Medical futility obviously has to trump the desire of a patient to have a particular treatment" (Nephrology consultant)
Relying on clinical judgement	"If my judgement at the time is that this is going to be reversible, I would be inclined to not follow the plan and have a go at trying to reverse the ventricular fibrillation." (Nephrology consultant)
	"Being a doctor, your first rule would be to do no harm, and if I do believe that, in this case, it would be beneficial to the patient and, at the same time, there is a good chance he would be able to recover to the point of being able to live life as per his wishes, with significant independence and quality of life, then I don't think I'm doing anything wrong, in this case… I think it's not right to withhold treatment – especially when, based on your medical assessment, there is a great potential for reversibility. And the patient might not have that information. They are not expected to make that call. And you, as the doctor, should be. " (Nephrology consultant)
	"He has an excellent prognosis and you would reasonably anticipate that he would have potentially quite a number of years because basically he's got nothing wrong with him. So you would be mischievous not to treat him." (Geriatric medicine consultant)
	"It's very tricky, because sometimes you do have people who say they don't want to be resuscitated for a reversible condition, but, you know, patient autonomy is important… So this would be things the consultant would consider: autonomy versus, you know, reversing a reversible condition that will cost this patient their life otherwise." (General medicine registrar)

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Rejecting unreasonable decisions	“We are advocates for the patient, but at the same time, we advocate for treatment that we think is reasonable, within reasonable limits.” (Cardiology registrar)
	“In that situation, I would want more information, and for things to be clarified as to exactly what context he was referring to and things like that. I think you would need to know more information given that he’s 65 and otherwise well. That plan is not really in fitting with normal people’s wishes.” (Geriatric medicine resident)
	“It’s not that I’m saying that I normally disregard advance care plans, but this is an unusual advance care plan. You don’t have too much time to think about it. The details you’ve given me are really sketchy. Most of the time, when people make advance care plans about things they don’t want, it’s in pretty clear understandable reasons why probably a sensible person would not want that. You know, situations that are clearly untreatable. Situations where treatment is expected to give a bad outcome… Most people in this situation would want to be treated. So, it just feels a bit odd and you’ve got to make a quick decision” (Nephrology consultant)
Disregarding legal consequences	“(Interviewer: do any legal obligations come into it, at any stage?) No, I think it’s more – someone dying who doesn’t necessarily need to die. Like, for me, it’s not necessarily my legal ramifications as doing what’s best for the patient.” (Cardiology resident)
	“I think more the ethical side of things is a bigger play of things in my decision making than the legality of an advance care plan.” (Cardiology resident)
	“I don’t think I could be prosecuted for following or not following an advance care directive if I was using reasonable judgement, and that the interests of the patient are always at the forefront of everything I do, and so long as I can justify that in a way that my peers would agree with me, then I think I would be fairly safe from a legal perspective, and it’s certainly, fortunately, in this country, not at the forefront of my mind, ever.” (General medicine registrar)

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Establishing validity	
Doubting rigor of the decision-making process	"I guess with any documentation, you're presuming it was done under the right circumstances, without coercion and all of that… We can never verify that unless we were part of the process." (Gastroenterology consultant)
	"With an advance care plan, we're making the assumption that everything's been – the patient's had these discussions in a very formal way, things explained, they understand, and things have been discussed. Which may or may not be the case." (Respiratory medicine resident)
	"I know in some facilities, like some nursing homes, for example, they fill it in as their KPI… And it might be somebody who doesn't know the hospital system, or the healthcare system very well, like the nurse around, or the family member who's left to fill it in themselves, they might just write random things they don't really mean." (Palliative care, general medicine and medical oncology consultant)
Questioning patients' ability to understand treatment decisions	"you want what you want, but sometimes you don't understand – and I know that sounds quite condescending – people don't sometimes understand their conditions, and maybe that's a fault of clinicians, we don't explain what COPD means, what going on home oxygen means. People think that with home oxygen, they're going to be better and things are going to be better, but, no, it's one step closer towards the end. And sometimes we're really bad at explaining that" (General medicine and palliative care registrar)
	"I don't think patients necessarily understand what's going on, and I think – in as much an advance care plan is great, each situation is different. Some people say, I don't want to be resuscitated, I don't want to be brought back, because often they think their quality of life is going to be poor. But in some cases, things might not be as bad as they seem. We never know, so, I don't think they should be 100% binding." (General medicine and palliative care registrar)

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	"It's also useful to say, 'I don't want to be intubated', but it's kind of a harder one for some patients, who haven't had much experience with hospitals, who haven't had medical training, to kind of understand that. So, I think, it's probably, more for a patient-centred approach, 'I want a quality of life' or 'I don't want to be in a nursing home', because they can definitely understand that… If they happen to be a nurse or a doctor, then that's fine. If they haven't had much medical experience or medical training, you'd want to know, well, what is it about intubation you don't like? Or, what have you heard? Their understanding of intubation might be very different to my understanding of intubation." (Infectious disease and general medicine consultant)
Distrusting outdated preferences	"The advance care plan that was made five years ago could potentially be outdated, especially with the potentially new diagnoses of metastatic pancreatic cancer and end-stage kidney disease, that could very well change the patient's perspective about what he wants to do about limitations of treatment." (Nephrology consultant)
	"I mean, essentially, if the care plan was there, I would – I guess feel obliged to follow it. But my concern with the advance care plans is the timing that they're made, people – moods change, life changes all the time, advance care plans are rarely revisited to make sure that people still have the same opinion." (Nephrology consultant)
	"If they're conservative to start with, then I don't think they necessarily have to be updated. And that includes values. So if they're saying that fit and independent is how I want to be, then nothing changes. I think, if you've got someone asking for full resus who then develops metastatic pancreatic [cancer], so a new, significant comorbidity, then I think you should update it, to be less aggressive, if that's what you want." (Palliative care consultant)
Seeking confirmation	"I guess I don't really know the circumstances in which he said that. Maybe he was thinking about when he was an 80-year-old man with metastatic malignancy, or something like that. It doesn't really make sense to me if you're 65, you're young, you're playing golf, everything's fine, to say 'I don't want to have resuscitation'. So, if someone

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	really, really means it, then his family or spouse or whatever will know all about it and they'll be able to confirm it." (Palliative care consultant)
	"If it was like, he'd just said this yesterday during his admission, then it would be enough. And OK, stop. And if he's of sound mind, and he made that decision in the knowledge that he was going to die. But if, if there was any question about when it was made, or why it was made, then I would want to try and clarify. (Infectious disease and general medicine consultant)
	"If I was confident about the advance care plan, if my team was involved in it, then I'd respect it, regardless. But if there was a question then I'd have to try and revisit, have a family meeting, try and work out exactly what the situation is." (Infectious disease and general medicine consultant)
Translating written preferences into practice	
Contextualising patient preferences	"There's a generalness about [advance care directives], often, and all of a sudden, you're dealing with a specific. So you've got a general statement about what you want or don't want to do in a very specific situation, where you've got to make a decision in a hurry." (Nephrology consultant)
	"You need to have a bit of clinical judgement, in terms of interpreting, because obviously, when the advance care plan was made, as much as they try to cover all potential clinical scenarios, it is quite impossible to cover every clinical scenario, so I think, exercise judgement as to whether this will be the situation where values might be important to help guide you. Whether those values are achievable, or not, would help you plan your treatment." (Nephrology consultant)
	"The difficulty with the specific statement is, with a patient with multiple problems, but is stable at the time of your seeing them, you don't know what specific scenario you're thinking about. Like, you know, what if you had a stroke? What if you had an AMI? What if you had an arrhythmia? What if you aspirated? What if you fell over and

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	broke your hip? What if you were in a car accident? What if you had anaphylaxis? Do you want an antibiotic? You know, very different scenarios in some situations.” (Nephrology consultant)
	“Values statements let me do the medical stuff in the context of what they want. The problem with them saying, yes, I want haemodialysis and I want this and I want that is that we may be talking about a different situation. So it might be completely irrelevant. Whereas a values statement might be a lot more relevant for a lot more conditions” (Palliative care consultant)
Applying subjective terminology	“He said his independence is really important for him – that’s kind of a one sentence thing so I don’t really know what his independence means in this context” (Palliative care consultant)
	“When they say they don’t want to be resuscitated, what exactly do they mean. Do they not want [non-invasive ventilation], do they not want ICU, do they not want shocks?” (Nephrology consultant)
	“Some just say, ‘I don’t want to live if I can’t play golf’, then obviously it’s a bit tricky to work out which interventions might end up giving him the opportunity to play golf again. Whereas if it clearly states, ‘I don’t want to be intubated’, then your decision’s already made. So yeah, I guess that answers the previous question, it’s more helpful to have more specific treatments and interventions outlined, I would feel.” (Geriatric medicine resident)
	“Does it need to be interpreted literally? Well, as best one can. At the end of the day, people write funny things, and sometimes we’re not quite clear what they want, so you’ve sort of got to give it your best shot. Or they tell you things that appear to be contradictory, and then you’re struggling, so we run into a bit of that.” (Geriatric medicine consultant)
Prioritising emergency medical treatment	“You can always get that information available to you as quickly as possible, and you certainly don’t want to do it the wrong way around and say he might not want this and he does, and he did want that, and so yeah, I’d just treat it as a full code at this point.” (General medicine registrar)

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	“Mostly, we are trained to resuscitate, I think we struggle to let people die. But reading this scenario, and not being actually in the scenario, it’s different when you’re physically there, with all the stressors, and it’s all noisy and everything… It’s hard. It’s hard in this case… We probably would resus in ICU. Probably, because we have the support – and I know it’s not necessarily the right thing to do by the patient, but I actually think that would happen.” (Cardiology resident)
	“In my experience, a 65-year-old with hypertension comes in and codes… They’d be in ICU and tubed before anyone looks at their scanned medical record to see what their advance care plan was.” (General medicine registrar)

Abbreviations: ACDs, advance care directives; AMI, acute myocardial infarction; COPD, chronic obstructive pulmonary disease; CPR, cardiopulmonary resuscitation; ICU, intensive care unit; KPI, key performance indicator

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Caption: Figure 1. Thematic schema of doctors’ perspectives of the use of ACDs in clinical decision-making. Doctors used two distinct ethical approaches to evaluate ACDs, and subsequently moved through their decision-making process towards a treatment decision. An autonomy-focused approach motivated doctors to align with patient preferences, and this supported doctors to adhere to ACDs, along with successful establishment of validity when confirmation of the ACD was sought. In contrast, decision-making based on patients’ ‘best interests’ permitted doctors to override ACDs, as did validity concerns and issues with translating the ACD into practice.

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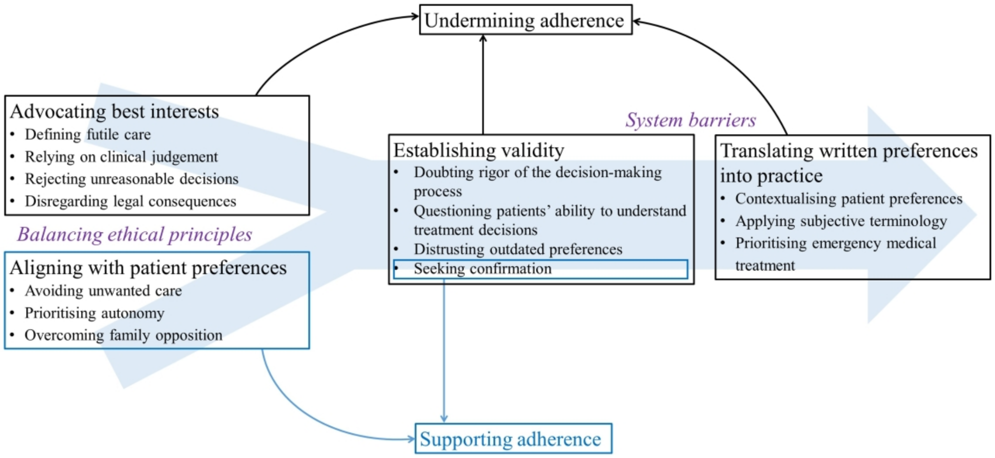

Figure 1. Thematic schema of doctors' perspectives of the use of ACDs in clinical decision-making. Doctors used two distinct ethical approaches to evaluate ACDs, and subsequently moved through their decision-making process towards a treatment decision. An autonomy-focused approach motivated doctors to align with patient preferences, and this supported doctors to adhere to ACDs, along with successful establishment of validity when confirmation of the ACD was sought. In contrast, decision-making based on patients' 'best interests' permitted doctors to override ACDs, as did validity concerns and issues with translating the ACD into practice.

303x140mm (300 x 300 DPI)

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Supplementary Item S1: interview guide

Section 1: Basic demographics

- Please tell me a little about yourself:
    - Specialty/current rotation
    - Years of practice
- We are going to be talking about Advance Care Planning (ACP); have you ever used an advance care plan to guide the treatment you have delivered to a patient? Does ACP work for you?

Section 2: Vignettes

- OK, so what I want to do now is provide you with a case scenario, and what I would like is how you would intend to treat the patient. I will then add a little more information and see if and how that might alter your treatment plan.

Scenario 1: Mr X is a 73-year-old man with advanced chronic obstructive pulmonary disease (COPD). Over the last two years, he has become progressively breathless and is now breathless on even minimal exertion; he struggles with showering and dressing due to his breathing. He is on maximal therapy, including home oxygen. He has had three admissions for acute exacerbations of COPD in the past 6 months. During his last admission one month ago, he required non-invasive ventilation. This time, on arrival, he is breathless and has right heart failure. He is hypoxic and hypercapnic.

- Why would you choose this course of action?

- When examining the records, it was discovered that the patient had an Advance Care Plan, informing us that he places a high value on his independence, and does not want to become a burden to his family.
    - Would this alter your treatment plan?
    - Why would you alter/not alter the plan?
    - Would your treatment plan alter if the advance care plan actually informed us that the person was not for intubation, ICU intervention or inotropes?

(The first scenario explores the value of a goals based advance care plan in guiding treatment with a patient that is deteriorating due to chronic illness. Probing questions would examine how treatment options would affect the patients' independence etc. Other areas to

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examine would include the participants' views on the worth of values goals ACP and how they might go about interpreting them)

- Let's move onto to the second scenario. Again, I would like to know your treatment plan and the reasoning behind it, and then we will add a little more information.

Scenario 2: A 65-year-old patient with well-controlled hypertension arrives at the emergency department, complaining of "chest pain". A full work-up for cardiac ischemia is sorted. Before the work-up can be completed, he falls into ventricular fibrillation. A code is called and upon your arrival to the bedside, the patient is apnoeic and requiring mask ventilation by the nursing staff.

- What would you do for this patient?

- Again, an advance care plan is present, which states that he values being an active and productive member of his community. He would rather be dead than miss his game of golf.
    - Would this alter your treatment plan? If so, how and why?
    - What if the advance care plan stated that he was not for resuscitation and should be "allowed to pass away in peace"? What treatments would you offer?

(This scenario explores the interaction between the acuity of the situation and the presence of an advance care plan. It may be expected that the patient here would make a full recovery however an advance care plan may mean that the treatment is not offered. Probing questions would include areas around the legal liability of honouring or not honouring an advance care directive)

- Now, if we can, I would like to move onto the final scenario.

Scenario 3: A 68-year-old patient with multiple co-morbidities – including diabetes, hypertension, end-stage renal disease (he is on dialysis) and metastatic pancreatic cancer – presents to the Emergency Department febrile, tachypnoeic and hypotensive. He is transferred to the intensive care unit (ICU), where you are covering. Upon arrival, his blood pressure falls to 40 systolic.

- What would be your treatment plan? Why?

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- Let us imagine that the patient had an advance care directive stating that they value life above everything – God will take me when ready until then I must live.
    - How would this alter your treatment plan? Why?

- OK that was interesting but in actual fact they had an ACP that was signed 5 years ago stating that they were not for intubation or CPR.
    - Would that change your thinking and why?
    - How worried would you be about the ACP being dated 5 years ago?

- Let's stick with this scenario a little longer: so the patient has a blood pressure of 40, and the not for intubation or CPR ACP signed 5 years ago is in place. However, the wife of the patient is there, demanding that you do all you can to save her husband and that the ACP was not what her husband wanted anymore.
    - What action would you take and why?
    - Do legal considerations with regard to honouring the ACP or not honouring the ACP come into consideration?
    - Does the family or substitute decision maker have the right to override the ACP?

(This scenario first examines the situation where a patient opts in for treatment by the ACP and how that may change treatment provided in the dying phase. Some literature has suggested that a barrier for enacting ACP is that it may not represent current values this explores this by adding the old ACP with no evidence of an update. Finally, the question of family conflict with an ACP is explored and the knowledge of the legalities surrounding this)

Section 3: Questions regarding the perceived usefulness and importance of ACP.

- That is the end of our scenarios. Finally, I would like to ask just a couple more general questions:
    - How instructive do you find knowing a little bit about what the patient values in making a medical decision for them?
    - How important would you say an ACP has in providing person-centred care?
    - How binding should an ACP be – should they be interpreted literally?

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- That concludes the interview, thank you for your time. What I will do now is look over your responses, and collate them with other interviews and look for themes that are coming out. While there has been lots of research on how to generate more ACP documents, there is little known about enacting them and what we would consider valuable.
- If you would like a copy of the report once finalised, let me know and I will forward it to you. Alternatively, you can let Scott know; his contact details are on the information sheet.
- Again, thank you so much for your time.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: an Australian interview study

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Primary Subject Heading:	Ethics
Secondary Subject Heading:	Qualitative research
Keywords:	advance care planning, advance care directives, autonomy, end-of-life, interviews, semi-structured interviews

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Title: Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: an Australian interview study

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Abstract

Objective

Advance care planning (ACP) assists people to identify their goals, values and treatment preferences for future care. Ideally, preferences are documented in an advance care directive (ACD), used by doctors to guide medical decision-making should patients subsequently lose their decision-making capacity. However, studies demonstrate that ACDs are not always adhered to by doctors in clinical practice. We aim to describe the attitudes and perspectives of doctors regarding ACD adherence and the utility of ACDs in clinical practice.

Design

Face-to-face semi-structured interviews were conducted using three case-based vignettes to explore doctors' decision-making and attitudes towards ACDs. Transcripts were analysed using thematic analysis.

Setting

Doctors from a variety of medical specialties and with varying experience levels were recruited from a large tertiary hospital in Melbourne, Australia.

Participants

Twenty-one doctors were interviewed, 48% female (10/21). Most (19/21) reported having experience using ACDs.

Results

Four themes were identified: aligning with patient preferences (avoiding unwanted care, prioritising autonomy, anticipating family opposition), advocating best interests (defining

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futile care, relying on clinical judgement, rejecting unreasonable decisions, disregarding legal consequences), establishing validity (doubting rigor of the decision-making process, questioning patients' ability to understand treatment decisions, distrusting outdated preferences, seeking confirmation) and translating written preferences into practice (contextualising patient preferences, applying subjective terminology, prioritising emergency medical treatment).

Conclusions

ACDs provide doctors with opportunities to align patient preferences with treatment and uphold patient autonomy. However, doctors experience decisional conflict when attempting to adhere to ACDs in practice, especially when they believe that adhering to the ACD is not in the patients' best interests, or if they doubt the validity of the ACD. Future ACP programs should consider approaches to improve the validity and applicability of ACDs. In addition, there is a need for ethical and legal education to support doctors' knowledge and confidence in ACP and enacting ACDs.

Keywords: advance care planning, advance care directives, autonomy, end-of-life, interviews, semi-structured interviews

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Article summary

Strengths and limitations of this study

- Purposive sampling used to promote inclusion of participants from a variety of medical specialties and experience levels
- Face-to-face semi-structured interviews used, providing a deeper understanding of participants attitudes and perspectives about ACD adherence
- Use of vignettes with hypothetical case scenarios to stimulate doctors' discussion about the use of ACDs in clinical practice
- Limitation: recruitment undertaken from a single metropolitan health service in Australia, which may limit the transferability of findings to other settings

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INTRODUCTION

Advance care planning (ACP) is a process where an individual makes his or her goals, values and preferences known in order to guide decision-making for healthcare, in the event he or she cannot make or communicate decisions in the future[1]. ACP assists patients' personal reflection about their values and goals of care, and can be supported by the completion of an advance care directive (ACD), designed to inform medical decision-making in the event the patient loses capacity to make or communicate decisions[2]. The terminology and legal status of ACDs varies considerably within Australia[3] and internationally[4-7], however they are commonly used to specify treatment preferences, express values, and/or to appoint a substitute decision-maker[2] (see Box 1). Completion of an ACD is considered to be a key component of ACP because ACDs provide written support and guidance for clinicians and family members when making medical decisions on behalf of the person[1, 8, 9].

ACP and ACD documentation are part of a broader shift in healthcare to promote person rights and autonomous decision-making. Legal frameworks have supported this evolution, providing greater emphasis on a substituted judgement approach to medical decision-making[10]. Substituted judgement requires decisions to be made according to what the patient would have wanted, rather than according to what others assume is in their "best interests". The emergence of ACP can be attributed to the rising value of autonomy in society and increased legal emphasis on informed consent to medical treatment and shared decision-making[11].

Research suggests that ACDs are not always adhered to by doctors in clinical practice. A 2007 study found that the presence of an ACD did not influence healthcare providers' decisions in using life-sustaining treatments or initiating comfort care plans[12]. More recently, Australian researchers presented doctors from New South Wales and Victoria with a hypothetical case scenario to investigate compliance with ACDs[13]. In responding to the

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scenario, only 32% of doctors reported that they would adhere to the ACD in accordance with the law. Studies have identified a number of barriers to ACD adherence, including family opposition[14-16], lack of clinical relevance[15, 17-20], and concerns about the validity of ACDs[15, 18, 20].

The aim of this study is to describe the attitudes and perspectives of doctors involved in the care of patients with chronic disease at an Australian hospital. This study used qualitative interviews and vignettes to explore doctors' opinions regarding ACDs to gain a deeper understanding about ACD adherence and the utility of ACDs in clinical practice.

Box 1: Legal context in Victoria, Australia

Medical Treatment Act 1988[21]:

- A competent person can refuse treatment in relation to a current condition by completing a legally binding Refusal of Treatment Certificate.
- A competent person can appoint an enduring power of medical attorney with the powers to consent, refuse and/or withdraw treatment.

Guardianship and Administration Act 1986[22]:

- Person responsible, identified as default substitute decision-maker within the Act, can consent to or decline to consent to medical treatment; however they cannot refuse treatment.
- When making a decision the substitute decision-maker must act in the best interests of the person for whom they are making decisions. The paramount factor in determining the person's best interests is the wishes of the person, so far as they can be ascertained.[3, 23]

Common Law

- A person can complete a non-statutory advance care directive (inclusive of values and treatment preferences). It should be signed, dated and witnessed.[23] The legal standing of such documents has not been tested with Victoria, Australia. However, it was expected that given case law in New South Wales[24], common law directives would be upheld in Victoria.

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- Within the health service there are policies relating to advance care planning, informed consent (including where the patient lacks capacity) and limitation of life-prolonging treatment. These policies document clear explanation of the relevant legislation and the legal basis for statutory and non-statutory advance care directives. Information on the identification and role of the substitute decision-maker is also included in hospital policies

METHODS

Study reporting is based on the Consolidated Criteria for Reporting Qualitative Health Research (COREQ)[25].

Participant selection and setting

Participants were doctors involved in the care of patients with chronic disease at Austin Health in Melbourne, Victoria, Australia. Participants were invited to participate through departmental meetings. Purposive sampling was used to ensure participants from a variety of medical specialties and with varying experience levels were included. All doctors who expressed interest in participating went on to participate in interviews. Ethical approval was obtained from the Austin Health Human Research Ethics Committee (LNR/16/Austin/528). Participants provided informed consent prior to being interviewed.

Data collection

Face-to-face semi-structured interviews were conducted from February to April of 2017 by two investigators (T.L., S.F.) until thematic saturation was reached, defined as the point at which few or no new concepts or themes were arising from subsequent interviews[25]. Participants were aware that the interviewers were a medical student and supervisor and some participants were known to the researchers in a collegial capacity, but

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otherwise a relationship was not established prior to interview. Interviews were audiorecorded and transcribed verbatim by T.L.

An interview guide was developed for this project by the research team (see Supplementary item S1), based on literature review followed by discussion and consensus among the research team. This guide consisted of three sections:

1. Demographics and prior experience with ACDs;
2. Three vignettes (see Box 2), each presented with a “values” then an “instructional” ACD; and
3. Questions regarding the perceived usefulness and importance of ACP.

In Section 2, participants were asked to outline their medical management plan for each case scenario. Extracts from ACDs were then used to determine whether the doctor would adhere to the ACDs in each scenario and how, if at all, the ACD would influence their management plan. Probing questions were then used to explore participants’ perspectives with regards to ACD adherence and related issues such as legal concerns and family input.

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Box 2: Summary of hypothetical vignettes

Scenario 1: 73-year-old man with advanced chronic obstructive pulmonary disease and recurrent hospitalisations. Presents acutely breathless

- Values directive: places high value on his independence, doesn’t want to become a burden to his family
- Instructional directive: not for intubation, intensive care unit intervention or inotropes

Scenario 2: 65-year-old previously well man presents with chest pain, then collapses with ventricular fibrillation

- Values directive: he values being an active and productive member of his community. He would “rather be dead” than unable to play golf
- Instructional directive: not for resuscitation, should be “allowed to pass away in peace”

Scenario 3: 68-year-old man on dialysis, with a history of metastatic pancreatic cancer. Presents febrile, tachypneic and hypotensive

- Values directive: he values life above everything – “God will take me when I’m ready”
- Instructional directive: not for intubation or cardiopulmonary resuscitation (signed 5 years ago)
- Additional information: patient’s family disagree with directive and demand full treatment to be given

Note: values directive is defined as a general statement about a person’s preferences and values[26]. Instructional directive is defined as an express statement in which a person may either consent to or refuse a particular medical treatment, which takes legal effect if the person loses decision-making capacity[26].

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Data analysis

Transcripts were entered into HyperRESEARCH (ResearchWare Inc), a software package used to store and code qualitative data. Drawing from principles of grounded theory and thematic analysis[27], N.M. inductively identified concepts in the transcripts and then developed and refined the coding structure with assistance from M.S.. The analysis identified relationships between themes to develop a thematic framework to capture all concepts about participants’ experiences and perspectives about ACD adherence. To further develop and enhance the analytical framework, interpretation of data and preliminary themes were discussed among the research team.

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Patient and public involvement

There was no patient or public involvement in the design and conduct of the study.

RESULTS

Participant demographics

Participant characteristics are provided in Table 1. In total, 21 doctors participated, from a broad range of medical specialties, with a range of experience levels. About half were women (10/21). Almost all participants (19/21) reported having used ACDs in their clinical practice. Interview duration ranged from 12 to 52 (mean, 26) minutes.

Themes

We identified four themes: aligning with patient preferences, advocating best interests, establishing validity and translating written preferences into practice. The themes were relevant to all scenarios unless otherwise specified. Selected quotations to illustrate themes are provided in Table 2. Conceptual links among themes are presented in Figure 1.

Aligning with patient preferences

Avoiding unwanted care

Doctors valued ACDs that supported them to understand "what the patient wants and why they want it" to be able to individualise treatments according to the patients' preferences. They believed ACDs can help them make "the right decision for that particular patient" and avoid unwanted treatment. For instance, some doctors felt that ACDs provided patients with an opportunity to have a say about "wanting or not wanting a certain kind of treatment", after considering past treatment experiences.

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Prioritising autonomy

Nonetheless, some doctors experienced deep conflict when weighing up decisions to follow ACDs, in scenarios where they disagreed with the patient's decision. This was because they felt "morally tied" to follow decisions to refuse treatment, because they believed it was important to respect the patients' autonomy. This was most evident in Scenario 2, involving a previously well patient presenting in a sudden cardiac arrest, who had an ACD which refused resuscitation. Even though participants acknowledged the situation was very difficult given the patient would likely have a good prognosis if treated, some felt obligated to adhere to the ACD, stating that "if you're going to allow people autonomy to decide things … you can't say, we will sometimes, we won't sometimes". These doctors felt that people deserve to maintain their own autonomy, provided the patient has made an informed choice as a competent adult. Thus despite their reservations, they decided they would adhere to the ACD and withhold resuscitation, reflecting that it would be "unethical to give [the patient] something that [they] never wanted".

Anticipating family opposition

Doctors described potential difficulties of overcoming family opposition when making decisions based on patient preferences in ACDs. This was particularly evident in Scenario 3 in which participants were asked how they would respond if a family member requested more treatment to be given than stated in the ACD. Some doctors felt that although they would "try to accommodate" the preferences of the family, they would draw the line at "causing harm to the patient". One participant argued against permitting family to override the ACD because the patient has "the right to make the decision" and "family don't necessarily play a part in that". However, other participants reflected on scenarios from their own clinical experience where family members had requested more treatment than the patient

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wanted and doctors had felt obliged to comply with requests to avoid causing stress to the family.

Advocating best interests

Defining futile care

Doctors considered ACDs to be irrelevant to their decision-making if patients had requested treatment that the doctor perceived to be futile. Doctors felt it was their duty to determine “what [was] futile” to avoid “unnecessary and potentially harmful treatment”. Because of this, some doctors refused to follow the treatment requests specified in the ACD, such as for cardiopulmonary resuscitation, intubation or mechanical ventilation, because they believed treatment would not be in the patient’s “best interests”. For example, in Scenario 3, a very unwell patient with a poor prognosis had a values ACD that requested all available treatment to be given. Participants decided not to follow the ACD, identifying that “any advance care plan for treatment becomes irrelevant, because giving him treatment would be futile”.

Relying on clinical judgement

In contrast to those participants who prioritised patient autonomy in decision-making, some doctors appeared most influenced by their assessment of the potential risks and benefits to patients rather than the preferences specified in the ACDs. They considered factors such as the patients’ age and comorbidities, to make a judgement about prognosis and whether the condition was potentially reversible. As a result, some doctors refused to follow the ACD and instead proceeded with treatment because they felt it was not “right to withhold treatment especially when, based on your medical assessment, there is a great potential for reversibility”. This was best illustrated in Scenario 2, where some doctors indicated they

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would be unwilling to withhold resuscitation on a relatively young, well patient, despite the patient having a valid ACD which stated they did not want resuscitation. Even though these doctors were aware of the patient's preference to "pass away in peace", they felt compelled to override the request because "[the patient] has an excellent prognosis … So you would be mischievous not to treat him".

Rejecting unreasonable decisions

Some doctors were reluctant to implement ACD requests that they considered to be unreasonable, or inconsistent with what a "normal" person might want. Doctors judged whether they thought the preferences specified in the ACD were "sensible" or acceptable for the situation, and some were unwilling to comply with those that they perceived as unreasonable or "unusual". These doctors were willing to respect patients' treatment choices but only if they conformed within the scope of treatment options that was felt to be reasonable or appropriate in that situation.

Disregarding legal consequences

Overall, doctors appeared to have minimal concerns regarding potential legal consequences of not following ACDs, choosing instead to prioritise what they believed to be the patients' best interests in their decision-making. One participant explained that "the legal stuff never worried me. It'll be more about the moral thing to do". Doctors were more motivated to act in the patients' best interests, rather than uphold the ACD because of a legal obligation. Doctors dismissed the risk of legal consequences, believing they would be protected if they used "reasonable judgement" that could be justified in a way that their peers would agree, and if "the motivation for not following the plan was one of trying to do the best for the patient".

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Establishing validity

Doubting rigor of the decision-making process

Some doctors expressed concern because they were unable to verify whether a "proper" ACP discussion had occurred in the formation of an ACD, as they had not been "part of the [ACP] process." Therefore they could not verify if the patient preferences specified in the ACD were accurate and/or informed. Doctors regarded best practice ACP as a formal discussion with a trained health professional in which issues could be explained, understood and discussed. Some doctors expressed scepticism regarding the rigor of ACP discussions in practice and therefore felt justified in dismissing any preferences specified in the ACD. For example, these doctors believed that ACP is sometimes completed as a "tick box" where important details about treatments are not discussed.

Questioning patients' ability to understand treatment decisions

In considering treatment preferences specified in ACDs, some doctors questioned whether patients were capable of "fully understand[ing] the consequences" of their decisions, because they believed the general population lack required medical knowledge about the risks and benefits of specific treatments. One participant explained that "patients aren't expected to understand all the minutiae or the nuances of what we can do", especially given the fact that "every single sickness they have is going to be individual and different". As a result, doctors suggested that medicalised instructional ACDs were not appropriate by themselves; instead, these doctors expressed a preference for ACDs that included the patient's values because these ACDs allowed the medical team to interpret the patients' preferences in their own words.

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Distrusting outdated preferences

Doctors also raised concern about adhering to ACDs that were created several years ago because they believed the preferences specified in the ACD were potentially outdated. They questioned whether the patients' views may have changed over time, especially if their health status had changed. Changes in the patients' circumstances that doctors believed may influence treatment preferences included receiving a new diagnosis or recovering from "acute unwellness". In contrast, some participants felt comfortable adhering to ACDs that were several years old if they judged it to be appropriate for the current situation. Some felt that if the ACD was already "conservative to start with" and the patients' prognosis had worsened, then they would still feel confident adhering to the ACD because they patient was unlikely to have changed their mind to opt for more aggressive treatment.

Seeking confirmation

To overcome concerns about the validity of ACDs, doctors believed they needed to seek confirmation of the ACD to establish its authenticity, such as from family members, before they would be willing to let it influence their management plan. This appeared mostly of concern when doctors disagreed with the preferences specified in the ACD, or if they believed the patient's treatment preferences were not in line with a reasonable medical course of action. Consequently, if they could not clarify the reasons underlying the preferences specified in the ACD, some doctors decided not to adhere to the ACD.

Translating written preferences into practice

Contextualising patient preferences

While doctors felt that ACDs are useful to help guide decision-making, some also highlighted the need for each ACD to be considered "in the context of what's happening

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today", rather than applied literally in every case. Doctors believed that they should have some leeway to determine whether the ACD was intended to apply to the given clinical scenario, feeling the ACD should be used as "a guide, rather than something that is compulsory" – allowing the clinician to have a more "nuanced" interpretation of the patients' request. Some doctors believed that ACDs are unable to address every possible clinical scenario that might arise and therefore, clinicians should be able to "exercise judgement as to whether this will be the situation where values might be important to help guide [them]". For this reason, some participants expressed a preference for ACDs that conveyed patients' preferences in terms of broad values statements because they were "more general" and therefore usually "more flexible and more applicable across multiple scenarios".

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Applying subjective terminology

In contrast, doctors sometimes struggled to apply values-based ACDs because they were unsure how to interpret values statements. Doctors felt that values expressions were "vague" and "confusing" because they are subjective. For example, some doctors questioned the meaning of the word "independence", with one participant stating that "how I interpret independence is different to how someone else might value his independence" because "values are different from person to person". Doctors expressed difficulty knowing how to apply values to form a concrete treatment plan and therefore some participants regarded instructional ACDs as being easier to interpret and apply because they have "clear-cut" directions.

Prioritising emergency medical treatment

Some doctors noted the importance of providing urgent medical treatment in a timely manner, and this was seen as a barrier to ACD adherence because there is not always time

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available to locate, read and interpret ACD documentation. Doctors reported that aggressive treatments are sometimes administered without consideration of patients' preferences because of the need to begin treatment immediately. Additionally, some doctors felt ill-equipped to make difficult decisions about end-of-life care, especially in time-pressured situations. Participants explained that in an emergency, they felt obliged to "err on the side of … treating" because "you certainly don't want to do it the wrong way around".

DISCUSSION

This qualitative interview study provides evidence regarding the attitudes and perspectives of doctors in relation to ACP and ACDs by exploring vignette scenarios and medical decision-making. The majority of participants valued ACDs that supported them to align with patient preferences in their treatment decisions. However, some doctors experienced conflict in adhering to ACDs when they believed the ACD did not represent the patients' best interests. Doctors tended to rely upon their own clinical judgement to make treatment decisions, sometimes overriding the ACD on the basis that the treatments requested were 'unreasonable', 'futile' or that the patients' condition was potentially 'reversible'. In addition, there were issues with validity and currency of ACDs, subjective terminology, patients' ability to understand consequences of preferences, family opposition, and time pressures. In this study, consideration of what doctors perceived to be the patients' best interests was found to be more influential in medical treatment decision-making than legal requirements.

From an ethical perspective, these findings challenge the widely held assumption that autonomy is the most important principle in healthcare decision-making[28]. Some participants preferred to follow their clinical judgement to make decisions that were in the patients' best interests, rather than uphold patient autonomy, although others felt obligated to

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adhere to patients' preferences despite this conflict. This is consistent with another vignette interview study conducted in the UK by Thompson and colleagues[29], who also found that some doctors wished to override the ACD and proceed with treatment consistent with the patient's best interests, whereas others believed it was most important to respect patient autonomy. Our findings reinforce past Australian and international qualitative studies demonstrating that, while doctors appear to have a shared understanding and respect for patient autonomy in theory, competing values and interests prevent doctors from prioritising patient autonomy in their clinical decisions in practice[17, 29, 30]. Doctors in an interview study by Johnson and colleagues[30] felt that there should be limits to patient autonomy, and patient preferences should not be respected if the treatment choice is 'unreasonable', 'futile' or 'medically inappropriate'.

Doctors in this study reported validity concerns to be a key barrier to ACD adherence, in accordance with past Australian and international research findings[15, 18, 20, 29]. Doubts about validity, including currency of decisions, were particularly prominent where participants disagreed with the treatment decision specified in the ACD. For instance, when the ACD refused treatment that doctors felt would be beneficial, they tended to question the authenticity of the ACD and wished to establish its validity, such as by confirming with family members. This is consistent with a model of end-of-life decision-making proposed by Willmott and White, suggesting that "the further the decision departs from responsible medical opinion, the clearer the evidence must be that this is what the adult wanted"[31]. On the other hand, participants in this study did not tend to raise validity concerns if they agreed with the decision in the ACD or thought it was appropriate for the situation. This suggests that doubts about validity were raised as a justification for overriding ACDs. Many participants appeared to only question the validity of ACDs when they felt that the patient's choices were inappropriate or unreasonable for the situation.

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Moreover, in this study some doctors questioned the ability of patients to accurately predict what they would want in future unknown circumstances. This is consistent with international research evidence suggesting that prognostic uncertainty is a barrier to the creation of useful, clinically relevant ACP documentation[32-34]. Some participants appeared to support the idea of using different ACD formats in tandem; instructional ACDs could be used for patients with an existing diagnosis and a predictable disease trajectory, to make advance decisions about anticipated situations. Values ACDs could provide broader context for the decision and act as general guidance for substitute decision-makers. Further to this, legislation governing ACD adherence in Victoria states that doctors do not need to uphold ACDs that are not considered to have been intended to apply to the clinical scenario at hand[26]. This provides for some leeway in doctors interpretation of ACDs in clinical practice.

Interestingly, doctors in this study showed minimal concern about the potential legal consequences from overriding a patient’s ACD, because they believed that making an ethical decision was the most important outcome for patients. This is concerning given that legal frameworks are moving toward greater support for patient autonomy, as reflected in current legislation[26] and the Medical Board of Australia code of conduct[35]. Doctors in this study may not have been aware of relevant law, and the consequences of not following the law which include civil and criminal liability[36]. Past research evidence examining compliance with ACDs has been mixed, with some survey studies in Australia[37] and overseas[38] describing high levels of self-reported adherence of doctors with ACDs. However, unlike the current study these surveys did not test doctors’ adherence using sample vignette scenarios, and thus may be less reflective of actual clinical practice. In contrast, our study suggests that doctors prioritise ethical considerations and clinical judgement above law in decisions to follow ACDs. In addition, studies have demonstrated varying levels of legal knowledge

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among health professionals, and have concluded that more training and education is needed to address this gap in knowledge[37].

Strengths and limitations

In this study we utilised interviews and case vignettes to gain a deeper understanding about doctors' decision-making. We applied purposive sampling to recruit a cohort of doctors with a diverse range of experience levels and speciality backgrounds, from a hospital with a well-established ACP program. The majority of participating doctors had personal experience with the use of ACDs in their clinical practice, which strengthened our results by providing a real-world perspective on the utility and application of ACDs in clinical practice. However, doctors were recruited from a single metropolitan health service in Australia, which may limit the transferability of findings to other settings.

Implications for practice, policy, and future research

Our research highlights the importance of supporting patients to create relevant, up to date, and clear ACDs that are clinically useful for doctors. In addition, this study suggests a need for an integrated approach to ACP, including early involvement of doctors, and involvement of substitute decision-makers in discussions. This may minimise the likelihood that doctors will mistrust the validity of the ACD, or support family to override the patients' preferences. ACP implementation should support increased ethical and legal education and training for health professionals, in order to translate legislation into clinical practice. Future research may seek to track the influence of recent legislative change on ACD adherence; since these interviews were conducted, the law in Victoria was updated to provide greater legal support for ACDs which legislates substituted judgement decision-making[10]. In addition, future research could complement the current findings by characterising clinicians'

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perspectives and experiences regarding the role of family and legally appointed substitute decision-makers.

Conclusion

This study provides insight into doctors' attitudes and perspectives about the clinical utility of ACDs. Doctors found ACDs most useful when they were current, relevant to the scenario, consistent with clinical judgement, and contained what doctors considered to be 'reasonable' choices. Doctors were less supportive if an ACD conflicted with their treatment plan or if they doubted its validity. Consequently, some doctors decided to override the preferences in the ACD based on judgements that doing so was consistent with the best interests of the patient; whereas others felt morally obligated to respect the patient's autonomy, even if they disagreed with the decision. Future ACP programs should consider approaches to improve the validity and applicability of ACDs. In addition, there is an ongoing need for ethical and legal education to support doctors' knowledge and confidence in ACP and enacting ACDs.

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Contributors

Research idea and study design: KD, SF TL; data acquisition: TL, SF; data analysis/interpretation: NM, MS, TL, SF, KD, LN; thematic analysis: NM, MS; supervision or mentorship: SF, MS. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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Competing Interests Statement

None declared

Data Availability Statement

No additional data available

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Table 1. Participant characteristics (total participants = 21)

Characteristics	**No. of participants (%)**
*Area of practice**	
Cardiology	4 (19)
Gastroenterology	2 (10)
General medicine	7 (33)
Geriatric medicine	2 (10)
Infectious disease	1 (5)
Medical oncology	2 (10)
Nephrology	3 (14)
Palliative care	7 (33)
Haematology	1 (5)
Respiratory	1 (5)
Qualification	
Consultant	11 (52)
Resident OR registrar	10 (48)
Years of experience	
<5	5 (24)
5-10	7 (33)
11-20	3 (14)
>20	6 (29)
Gender	
Female	10 (48)
Male	11 (52)
Experience with advance care directives in clinical practice	
Yes	19 (90)
No	2 (10)

*some participants had more than one area of practice

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Table 2. Illustrative quotes by theme

Subthemes	*Quotations*
Aligning with patient preferences	
Avoiding unwanted care	"I think it's definitely quite valuable in knowing at what point they want you to pull back on certain treatments." (Respiratory medicine resident)
	"You'd like to know what their advance wishes were. And for example, maybe they were intubated in the last couple of months and they'd documented they don't want to do that again" (General medicine registrar)
	"Obviously, we can make decisions based on the clinical picture and that's reasonable, but to be sure that you're making the right decision for that particular patient, you absolutely need to know about the patient." (Palliative care consultant)
Prioritising autonomy	"If his advance care directive said, don't touch me, then, I mean, he's made that decision with his own hand and we would have to respect that, even if we don't agree with it from a physiological basis" (General medicine registrar)
	"As long as the patient is competent, I'd say it's the patient's right. We'll respect their choice to die." (Cardiology resident)
	"Who are we to say – who is anyone to say they know better than the patient what they want?" (Nephrology consultant)
	"If I was advising him while he was conscious, I might debate [the ACD] with him. But unless I've got evidence that he is incompetent mentally, I can't debate that with him while he's unconscious. I would think it was a great shame, it's the sort of thing an 85-year-old might do, but it's something which presumably has been considered

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	well and documented so I'm not the person to turn around and say, nuts to you I'm going to resuscitate you. It might be unexpected, but certainly makes it very clear." (Gastroenterology consultant)
	"The difficulty we're facing is exactly the problem of our mind, that he's got an excellent prognosis and he will do well if we resuscitate him. On the other hand, he's clearly instructed me not to do it. So, in that setting, I should not do it… I think he's making a dumb decision, but in the sense, he's morally tied my hands." (Geriatric medicine consultant)
Anticipating family opposition	"Sometimes you persist with things a little longer than is appropriate, because you're trying to keep the patient alive so the relatives can see what is going on." (Gastroenterology consultant)
	"Sometimes people will end up doing the CPR because they really think the family are wanting it, or the patient's wanting it, and because they've been wanting it no one's said not to do it." (Nephrology consultant)
	"I could get you guys to help me with an advance care directive and say that I, at the age of 30, have no interest in being resuscitated, because at whatever point that my cardiac output stops and I am in an arrest situation, then I don't want to be resuscitated because that means something horrible's going on, and I have the right to make the decision and my family don't necessarily play a part in that." (General medicine registrar)
Advocating best interests	
Defining futile care	"The question would be, firstly, is it a futile treatment, and so the decision has to be made about whether we're offering the treatment before he has a chance to accept or decline it." (Palliative care consultant)
	"That's when I would say, unfortunately, resources are limited, it is a medical decision, in the Australian healthcare system we don't offer futile treatment. So if we think medically we can't help this patient, then we won't offer unnecessary and potentially harmful treatment. So in those situations I'll also emphasise that these treatments are not

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	without risk and harm and say that, you know, we do what's in the best interests of the patient, keeping them comfortable, we're focusing on quality not quantity of life." (General medicine registrar)
	"If treatment's futile, then that trumps an advance care plan. You can't say that you want treatment that isn't medically indicated or is futile. The patient can't write – I want this and this done in an advance care plan and it has to be done… That would be absurd. Medical futility obviously has to trump the desire of a patient to have a particular treatment" (Nephrology consultant)
Relying on clinical judgement	"If my judgement at the time is that this is going to be reversible, I would be inclined to not follow the plan and have a go at trying to reverse the ventricular fibrillation." (Nephrology consultant)
	"Being a doctor, your first rule would be to do no harm, and if I do believe that, in this case, it would be beneficial to the patient and, at the same time, there is a good chance he would be able to recover to the point of being able to live life as per his wishes, with significant independence and quality of life, then I don't think I'm doing anything wrong, in this case… I think it's not right to withhold treatment – especially when, based on your medical assessment, there is a great potential for reversibility. And the patient might not have that information. They are not expected to make that call. And you, as the doctor, should be. " (Nephrology consultant)
	"He has an excellent prognosis and you would reasonably anticipate that he would have potentially quite a number of years because basically he's got nothing wrong with him. So you would be mischievous not to treat him." (Geriatric medicine consultant)
	"It's very tricky, because sometimes you do have people who say they don't want to be resuscitated for a reversible condition, but, you know, patient autonomy is important… So this would be things the consultant would consider: autonomy versus, you know, reversing a reversible condition that will cost this patient their life otherwise." (General medicine registrar)

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Rejecting unreasonable decisions	“We are advocates for the patient, but at the same time, we advocate for treatment that we think is reasonable, within reasonable limits.” (Cardiology registrar)
	“In that situation, I would want more information, and for things to be clarified as to exactly what context he was referring to and things like that. I think you would need to know more information given that he’s 65 and otherwise well. That plan is not really in fitting with normal people’s wishes.” (Geriatric medicine resident)
	“It’s not that I’m saying that I normally disregard advance care plans, but this is an unusual advance care plan. You don’t have too much time to think about it. The details you’ve given me are really sketchy. Most of the time, when people make advance care plans about things they don’t want, it’s in pretty clear understandable reasons why probably a sensible person would not want that. You know, situations that are clearly untreatable. Situations where treatment is expected to give a bad outcome… Most people in this situation would want to be treated. So, it just feels a bit odd and you’ve got to make a quick decision” (Nephrology consultant)
Disregarding legal consequences	“(Interviewer: do any legal obligations come into it, at any stage?) No, I think it’s more – someone dying who doesn’t necessarily need to die. Like, for me, it’s not necessarily my legal ramifications as doing what’s best for the patient.” (Cardiology resident)
	“I think more the ethical side of things is a bigger play of things in my decision making than the legality of an advance care plan.” (Cardiology resident)
	“I don’t think I could be prosecuted for following or not following an advance care directive if I was using reasonable judgement, and that the interests of the patient are always at the forefront of everything I do, and so long as I can justify that in a way that my peers would agree with me, then I think I would be fairly safe from a legal perspective, and it’s certainly, fortunately, in this country, not at the forefront of my mind, ever.” (General medicine registrar)

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Establishing validity	
Doubting rigor of the decision-making process	"I guess with any documentation, you're presuming it was done under the right circumstances, without coercion and all of that… We can never verify that unless we were part of the process." (Gastroenterology consultant)
	"With an advance care plan, we're making the assumption that everything's been – the patient's had these discussions in a very formal way, things explained, they understand, and things have been discussed. Which may or may not be the case." (Respiratory medicine resident)
	"I know in some facilities, like some nursing homes, for example, they fill it in as their KPI… And it might be somebody who doesn't know the hospital system, or the healthcare system very well, like the nurse around, or the family member who's left to fill it in themselves, they might just write random things they don't really mean." (Palliative care, general medicine and medical oncology consultant)
Questioning patients' ability to understand treatment decisions	"you want what you want, but sometimes you don't understand – and I know that sounds quite condescending – people don't sometimes understand their conditions, and maybe that's a fault of clinicians, we don't explain what COPD means, what going on home oxygen means. People think that with home oxygen, they're going to be better and things are going to be better, but, no, it's one step closer towards the end. And sometimes we're really bad at explaining that" (General medicine and palliative care registrar)
	"I don't think patients necessarily understand what's going on, and I think – in as much an advance care plan is great, each situation is different. Some people say, I don't want to be resuscitated, I don't want to be brought back, because often they think their quality of life is going to be poor. But in some cases, things might not be as bad as they seem. We never know, so, I don't think they should be 100% binding." (General medicine and palliative care registrar)

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	"It's also useful to say, 'I don't want to be intubated', but it's kind of a harder one for some patients, who haven't had much experience with hospitals, who haven't had medical training, to kind of understand that. So, I think, it's probably, more for a patient-centred approach, 'I want a quality of life' or 'I don't want to be in a nursing home', because they can definitely understand that… If they happen to be a nurse or a doctor, then that's fine. If they haven't had much medical experience or medical training, you'd want to know, well, what is it about intubation you don't like? Or, what have you heard? Their understanding of intubation might be very different to my understanding of intubation." (Infectious disease and general medicine consultant)
Distrusting outdated preferences	"The advance care plan that was made five years ago could potentially be outdated, especially with the potentially new diagnoses of metastatic pancreatic cancer and end-stage kidney disease, that could very well change the patient's perspective about what he wants to do about limitations of treatment." (Nephrology consultant)
	"I mean, essentially, if the care plan was there, I would – I guess feel obliged to follow it. But my concern with the advance care plans is the timing that they're made, people – moods change, life changes all the time, advance care plans are rarely revisited to make sure that people still have the same opinion." (Nephrology consultant)
	"If they're conservative to start with, then I don't think they necessarily have to be updated. And that includes values. So if they're saying that fit and independent is how I want to be, then nothing changes. I think, if you've got someone asking for full resus who then develops metastatic pancreatic [cancer], so a new, significant comorbidity, then I think you should update it, to be less aggressive, if that's what you want." (Palliative care consultant)
Seeking confirmation	"I guess I don't really know the circumstances in which he said that. Maybe he was thinking about when he was an 80-year-old man with metastatic malignancy, or something like that. It doesn't really make sense to me if you're 65, you're young, you're playing golf, everything's fine, to say 'I don't want to have resuscitation'. So, if someone

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	really, really means it, then his family or spouse or whatever will know all about it and they'll be able to confirm it." (Palliative care consultant)
	"If it was like, he'd just said this yesterday during his admission, then it would be enough. And OK, stop. And if he's of sound mind, and he made that decision in the knowledge that he was going to die. But if, if there was any question about when it was made, or why it was made, then I would want to try and clarify." (Infectious disease and general medicine consultant)
	"If I was confident about the advance care plan, if my team was involved in it, then I'd respect it, regardless. But if there was a question then I'd have to try and revisit, have a family meeting, try and work out exactly what the situation is." (Infectious disease and general medicine consultant)
Translating written preferences into practice	
Contextualising patient preferences	"There's a generalness about [advance care directives], often, and all of a sudden, you're dealing with a specific. So you've got a general statement about what you want or don't want to do in a very specific situation, where you've got to make a decision in a hurry." (Nephrology consultant)
	"You need to have a bit of clinical judgement, in terms of interpreting, because obviously, when the advance care plan was made, as much as they try to cover all potential clinical scenarios, it is quite impossible to cover every clinical scenario, so I think, exercise judgement as to whether this will be the situation where values might be important to help guide you. Whether those values are achievable, or not, would help you plan your treatment." (Nephrology consultant)
	"The difficulty with the specific statement is, with a patient with multiple problems, but is stable at the time of your seeing them, you don't know what specific scenario you're thinking about. Like, you know, what if you had a stroke? What if you had an AMI? What if you had an arrhythmia? What if you aspirated? What if you fell over and

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	broke your hip? What if you were in a car accident? What if you had anaphylaxis? Do you want an antibiotic? You know, very different scenarios in some situations.” (Nephrology consultant)
	“Values statements let me do the medical stuff in the context of what they want. The problem with them saying, yes, I want haemodialysis and I want this and I want that is that we may be talking about a different situation. So it might be completely irrelevant. Whereas a values statement might be a lot more relevant for a lot more conditions” (Palliative care consultant)
Applying subjective terminology	“He said his independence is really important for him – that’s kind of a one sentence thing so I don’t really know what his independence means in this context” (Palliative care consultant)
	“When they say they don’t want to be resuscitated, what exactly do they mean. Do they not want [non-invasive ventilation], do they not want ICU, do they not want shocks?” (Nephrology consultant)
	“Some just say, ‘I don’t want to live if I can’t play golf’, then obviously it’s a bit tricky to work out which interventions might end up giving him the opportunity to play golf again. Whereas if it clearly states, ‘I don’t want to be intubated’, then your decision’s already made. So yeah, I guess that answers the previous question, it’s more helpful to have more specific treatments and interventions outlined, I would feel.” (Geriatric medicine resident)
	“Does it need to be interpreted literally? Well, as best one can. At the end of the day, people write funny things, and sometimes we’re not quite clear what they want, so you’ve sort of got to give it your best shot. Or they tell you things that appear to be contradictory, and then you’re struggling, so we run into a bit of that.” (Geriatric medicine consultant)
Prioritising emergency medical treatment	“You can always get that information available to you as quickly as possible, and you certainly don’t want to do it the wrong way around and say he might not want this and he does, and he did want that, and so yeah, I’d just treat it as a full code at this point.” (General medicine registrar)

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	“Mostly, we are trained to resuscitate, I think we struggle to let people die. But reading this scenario, and not being actually in the scenario, it’s different when you’re physically there, with all the stressors, and it’s all noisy and everything… It’s hard. It’s hard in this case… We probably would resus in ICU. Probably, because we have the support – and I know it’s not necessarily the right thing to do by the patient, but I actually think that would happen.” (Cardiology resident)
	“In my experience, a 65-year-old with hypertension comes in and codes… They’d be in ICU and tubed before anyone looks at their scanned medical record to see what their advance care plan was.” (General medicine registrar)

Abbreviations: ACDs, advance care directives; AMI, acute myocardial infarction; COPD, chronic obstructive pulmonary disease; CPR, cardiopulmonary resuscitation; ICU, intensive care unit; KPI, key performance indicator

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Caption: Figure 1. Thematic schema of doctors' perspectives of the use of ACDs in clinical decision-making. Doctors used two distinct ethical approaches to evaluate ACDs, and subsequently moved through their decision-making process towards a treatment decision. An autonomy-focused approach motivated doctors to align with patient preferences, and this supported doctors to adhere to ACDs, along with successful establishment of validity when confirmation of the ACD was sought. In contrast, decision-making based on patients' 'best interests' permitted doctors to override ACDs, as did validity concerns and issues with translating the ACD into practice.

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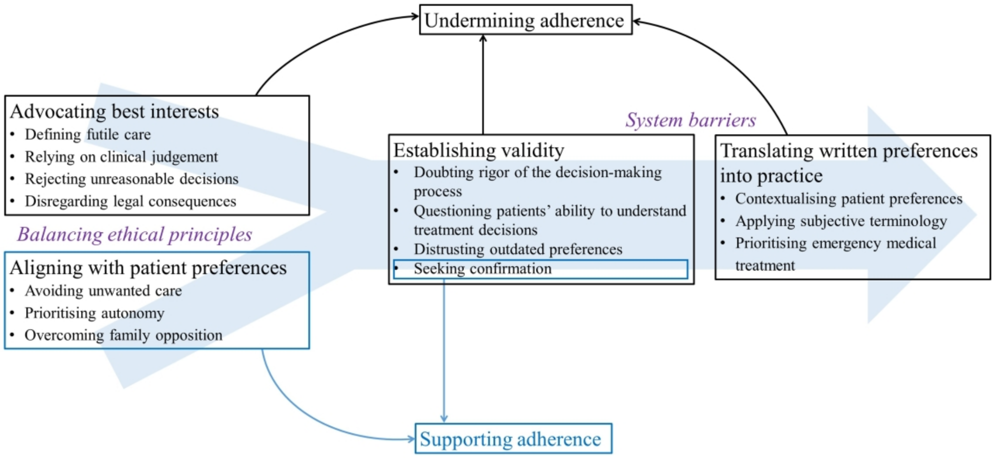

Figure 1. Thematic schema of doctors' perspectives of the use of ACDs in clinical decision-making. Doctors used two distinct ethical approaches to evaluate ACDs, and subsequently moved through their decision-making process towards a treatment decision. An autonomy-focused approach motivated doctors to align with patient preferences, and this supported doctors to adhere to ACDs, along with successful establishment of validity when confirmation of the ACD was sought. In contrast, decision-making based on patients' 'best interests' permitted doctors to override ACDs, as did validity concerns and issues with translating the ACD into practice.

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Supplementary Item S1: interview guide

Section 1: Basic demographics

- Please tell me a little about yourself:
  - Specialty/current rotation
  - Years of practice
- We are going to be talking about Advance Care Planning (ACP); have you ever used an advance care plan to guide the treatment you have delivered to a patient? Does ACP work for you?

Section 2: Vignettes

- OK, so what I want to do now is provide you with a case scenario, and what I would like is how you would intend to treat the patient. I will then add a little more information and see if and how that might alter your treatment plan.

Scenario 1: Mr X is a 73-year-old man with advanced chronic obstructive pulmonary disease (COPD). Over the last two years, he has become progressively breathless and is now breathless on even minimal exertion; he struggles with showering and dressing due to his breathing. He is on maximal therapy, including home oxygen. He has had three admissions for acute exacerbations of COPD in the past 6 months. During his last admission one month ago, he required non-invasive ventilation. This time, on arrival, he is breathless and has right heart failure. He is hypoxic and hypercapnic.

  - Why would you choose this course of action?

- When examining the records, it was discovered that the patient had an Advance Care Plan, informing us that he places a high value on his independence, and does not want to become a burden to his family.
  - Would this alter your treatment plan?
  - Why would you alter/not alter the plan?
  - Would your treatment plan alter if the advance care plan actually informed us that the person was not for intubation, ICU intervention or inotropes?

(The first scenario explores the value of a goals based advance care plan in guiding treatment with a patient that is deteriorating due to chronic illness. Probing questions would examine how treatment options would affect the patients' independence etc. Other areas to

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examine would include the participants' views on the worth of values goals ACP and how they might go about interpreting them)

- Let's move onto to the second scenario. Again, I would like to know your treatment plan and the reasoning behind it, and then we will add a little more information.

Scenario 2: A 65-year-old patient with well-controlled hypertension arrives at the emergency department, complaining of "chest pain". A full work-up for cardiac ischemia is sorted. Before the work-up can be completed, he falls into ventricular fibrillation. A code is called and upon your arrival to the bedside, the patient is apnoeic and requiring mask ventilation by the nursing staff.

  - What would you do for this patient?

- Again, an advance care plan is present, which states that he values being an active and productive member of his community. He would rather be dead than miss his game of golf.
  - Would this alter your treatment plan? If so, how and why?
  - What if the advance care plan stated that he was not for resuscitation and should be "allowed to pass away in peace"? What treatments would you offer?

(This scenario explores the interaction between the acuity of the situation and the presence of an advance care plan. It may be expected that the patient here would make a full recovery however an advance care plan may mean that the treatment is not offered. Probing questions would include areas around the legal liability of honouring or not honouring an advance care directive)

- Now, if we can, I would like to move onto the final scenario.

Scenario 3: A 68-year-old patient with multiple co-morbidities – including diabetes, hypertension, end-stage renal disease (he is on dialysis) and metastatic pancreatic cancer – presents to the Emergency Department febrile, tachypnoeic and hypotensive. He is transferred to the intensive care unit (ICU), where you are covering. Upon arrival, his blood pressure falls to 40 systolic.

  - What would be your treatment plan? Why?

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- Let us imagine that the patient had an advance care directive stating that they value life above everything – God will take me when ready until then I must live.
    - How would this alter your treatment plan? Why?

- OK that was interesting but in actual fact they had an ACP that was signed 5 years ago stating that they were not for intubation or CPR.
    - Would that change your thinking and why?
    - How worried would you be about the ACP being dated 5 years ago?

- Let's stick with this scenario a little longer: so the patient has a blood pressure of 40, and the not for intubation or CPR ACP signed 5 years ago is in place. However, the wife of the patient is there, demanding that you do all you can to save her husband and that the ACP was not what her husband wanted anymore.
    - What action would you take and why?
    - Do legal considerations with regard to honouring the ACP or not honouring the ACP come into consideration?
    - Does the family or substitute decision maker have the right to override the ACP?

(This scenario first examines the situation where a patient opts in for treatment by the ACP and how that may change treatment provided in the dying phase. Some literature has suggested that a barrier for enacting ACP is that it may not represent current values this explores this by adding the old ACP with no evidence of an update. Finally, the question of family conflict with an ACP is explored and the knowledge of the legalities surrounding this)

Section 3: Questions regarding the perceived usefulness and importance of ACP.

- That is the end of our scenarios. Finally, I would like to ask just a couple more general questions:
    - How instructive do you find knowing a little bit about what the patient values in making a medical decision for them?
    - How important would you say an ACP has in providing person-centred care?
    - How binding should an ACP be – should they be interpreted literally?

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- That concludes the interview, thank you for your time. What I will do now is look over your responses, and collate them with other interviews and look for themes that are coming out. While there has been lots of research on how to generate more ACP documents, there is little known about enacting them and what we would consider valuable.
- If you would like a copy of the report once finalised, let me know and I will forward it to you. Alternatively, you can let Scott know; his contact details are on the information sheet.
- Again, thank you so much for your time.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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