

Palliative care health professionals' experiences of caring for patients with advance care directives

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Abstract

Objective. To explore the health professionals' (HPs) perceptions and experiences of advance care directives (ACDs) and advance care planning in Australian palliative care services.

Methods. A nationwide survey of 105 palliative care services was conducted, with two HPs from each service invited to participate. A qualitative analysis of open responses about advance care planning was undertaken.

Results. Sixty questionnaires were returned with open responses. Most responders were nurses (75%), aged ≥ 40 years (80%) and with a mean of 12 years palliative care experience. Data were grouped into four key themes: (1) the ACD; (2) the process of developing ACDs; (3) the process of using ACDs; and (4) the consequences of having ACDs. Participants were positive about advance care planning, commenting that ongoing communication about end-of-life care ensures mutual understanding between patients, family and HPs. Provision of care was considered easier and more efficient with an ACD in place. ACDs were perceived to reduce distrust and conflict between family, friends and HPs, and promote communication. Suboptimal documentation, clarity and explicitness limited the usefulness of ACDs when they were available.

Conclusions. Advance care planning benefits HPs, patients and their family. To maximise these benefits, ACDs need to be clear, comprehensive, medically relevant and transportable documents.

What is known about the topic? Ideally, advance care planning encompasses the identification and documentation of a person's preferences for future medical treatments and care in preparation for an occasion when the person cannot express their values and wishes. The uptake and practice of advance care planning is inconsistent, and the extent to which it is used by health professionals and patients is variable. Many people are cared for at the end of life in specialist palliative care services, but the intersection between palliative care and advance care planning remains under-researched.

What does this paper add? ACDs facilitate communication and advance care planning; help establish trust between health professionals, patients and their families; and make multiple aspects of care easier for HPs. Processes surrounding ACDs, particularly inadequate documentation, limit adherence and application.

What are the implications for practitioners? Clear communication is necessary for effective ACD development and application. The presence of an ACD makes communication and advance care planning easier, and improves trust between HPs, patients and their family. To be useful, ACDs must be clear, comprehensive, medically relevant, transportable documents.

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Introduction

Advance care planning is an ongoing process that encompasses the exploration and documentation of a person's preferences for future medical interventions and care, as well as ensuring the patient's understanding of their condition.¹ These conversations need to be tailored to the patient's circumstances, needs, wishes and concerns, and be facilitated by a health professional who has an understanding of the patient's psychosocial circumstances and medical condition.

Optimal and effective advance care planning involves several key components: conversation about, and consideration of, patient values and wishes surrounding end-of-life and life-sustaining treatment;² communication about, and documentation of, patient values and goals for treatment (including continuing and withdrawal of active treatment) in an advance care directive (ACD);³ presentation of information specific to patient preferences around unacceptable health and/or functional states and locations for care and death;⁴ and nomination, where possible, of a substitute decision maker for situations where the patient is unable to actively participate in care decisions.^{2,5} ACDs may be completed by healthy individuals in anticipation of a future time of physical deterioration or diminished decision-making capacity. Advance care planning may also be undertaken by people who have a life-limiting illness or when deterioration is imminent.⁶ The recent systematic review by Lovell and Yates explored the contextual factors influencing the uptake of advance care planning and development of ACDs.⁷ However, despite the reported benefits, our knowledge of the use of ACDs in the clinical setting is limited, particularly within specialist palliative care services.⁶ Specifically, little is known about how ACDs are implemented in palliative care or how advance care plans affect palliative care health professionals' experiences of caring for people at the end of life, especially in the Australian health context. The aim of the present study was to explore service providers' perceptions and experiences of advance care planning and the use of ACDs in Australian palliative care services.

Methods

A survey of Australian palliative care services was conducted using a self-report online questionnaire, consisting of closed and open-ended questions. This paper reports data from the latter. The directors of palliative care services involved in the Palliative Care Outcomes Collaboration (PCOC)⁸ were asked to nominate two health professionals who worked as clinicians within the service to complete the survey. Further details of the survey and results from the closed questions are provided elsewhere.⁶ Consent was implied by completion of the online questionnaire. Ethics approval was obtained from the University of Wollongong/Illawarra Shoalhaven Local Health District Human Research Ethics Committee (Approval no. HE12/471).

The three open-ended questions reported here asked participants about: (1) completing ACDs with patients from culturally and linguistically diverse backgrounds; (2) situations where ACDs were not followed; and (3) health professionals' experiences of caring for patients with an ACD. The questions were formulated and modified by the research team to gain a broad understanding of advance care planning and the use of ACDs within the palliative care setting. Questions were reviewed by

advance care planning and quality improvement facilitators from the Respecting Patient Choices and The Palliative Care Outcomes Collaboration programs^{8,9} to ensure they were understandable and applicable to palliative care services.

The responses were entered into NVivo (Version 10, QSR International Pty Ltd, Melbourne, Australia), whereupon thematic analysis was used to explore and categorise the data. The principle of constant comparison guided an inductive, iterative process of data analysis.¹⁰ Data were coded collaboratively by authors (RS, CJ), using a matrix that underwent several modifications until the final framework of themes was developed. Once thematic analysis was complete, the data were split into groups by service provider type to determine areas of discrepancy and consistency across the coding framework. Data analysis and interpretation undertaken by the authors RS and CJ was verified by the authors MS, MM and WS and reconciled where necessary.^{11,12}

Results

Sixty participants responded to at least one of the open-ended questions. This was 82% of health professionals who completed the full questionnaire.

The characteristics of participants are provided in Table 1. Most were female nurses, 40 years of age or older and from metropolitan services. Participants had spent a mean of 12 years working in palliative care. Less than half had received training in advance care planning and one-third reported completing an advance care planning discussion with a patient over the course of

Table 1. Participant characteristics (n = 60)

Note, data may not add to 100% due to rounding. CI, confidence interval

Characteristic	n	%	
Profession	Nursing	45	-75
	Medicine	9	-15
	Social work	4	-7
	Occupational therapy	2	-3
Gender	Female	57	-95
Age (years)	25-29	3	-5
	30-39	9	-15
	40-49	15	-25
	50-59	29	-48
	60+	4	-7
Service provider	In-patient palliative care	17	-28
	Community palliative care	14	-23
	Consultative service	9	-15
	Residential aged care facility	2	-3
	Combined	17	-28
	Other	1	-2
Location of service	City	34	-57
	Inner regional	10	-17
	Outer regional	13	-22
	Remote and very remote	3	-5
	Other	1	-2
	Completed advance care planning training	26	-43
Completed advance care planning discussion with patient	20	-33	
Mean (95% CI) time in palliative care (years)	12	(10.2-13.7)	

their career. Participants were similar in profession, age, service provider type and location of service to those who did not provide comments.

Key themes identified

The categories identified were grouped into four key themes: the ACD; the process of developing ACDs; the process of using ACDs; and the consequences of having ACDs.

The ACDs

Health professionals discussed advance care planning in several formats, including formal ACDs, informal advisory documentation (usually documented within a patient's medical record) and the appointment of medical guardians (Table 2). There was consensus that plans were useful only when they were documented, comprehensive, relevant and available. Inadequate levels of documentation were perceived to limit the usefulness of ACDs.

Consultant palliative care service participants were concerned that ACDs were of limited value if they were not explicit about medical situations encountered by the patients. Another participant noted that medical issues were sometimes poorly understood by patients and families and, unless ACDs were prepared with some medical input, they were often of little use.

Problems were reported when ACDs were prepared by people with little knowledge of the legal issues associated with the preparation and use of ACDs. This was a particular concern when advance care planning was left to junior medical staff who lacked the necessary skills and legal knowledge.

Another problem was the availability of ACDs, with several cases cited where patients were treated contrary to the patient's and family's wishes because patients were transferred to medical facilities without the appropriate original documentation. In these

instances, active treatment was reportedly instituted until a documented ACD was made available to the medical team.

Process of developing ACDs

In the experience of participants, the process of advance care planning was not routinely undertaken for patients, either in the community or in-patient setting. Patients admitted to services at the end of life frequently did not have an ACD and, in some instances, participants reported that advance care planning was not undertaken during an admission either (Table 3). Some health professionals described health settings where relevant policies were not in place and advance care planning was not routinely conducted.

Numerous participants identified advance care planning as an iterative process that needs to respond to changes in patients' circumstances and condition. Several participants identified that a patient's wishes may change as they are faced with circumstances that, up until that time, had been hypothetical.

Communication was central to the development of ACDs. The development of an ACD was perceived to support conversations within families and between the patient, family and healthcare team, and made communication about end-of-life care easier. Participants reflected upon the need for ongoing conversations to make sure ACDs were current and appropriate for changing circumstances, and to negotiate suitable goals of care. Even though such conversations were time-consuming, they were perceived to be important to build trust and to ensure that ACDs remained relevant.

Process of using ACDs

Participants recognised their legal and moral responsibilities to adhere to patients' wishes 'unless there is a clear and compelling

Table 2. Textual examples of participants' perspectives concerning advance care directives

N, nursing participants; M, medical participants; S, social worker participants

Any documentation is clearly followed. Discussions had but not documented are difficult to follow if it is unclear on what basis a decision had been made (whether it fits the current scenario or not). (N7)
[I had] a patient with directive. It was not explicit enough as to what the patient did and didn't want as far as medical input. Quite confusing. (N41)
[The] main problem is when it is written without help from medical practitioner and it doesn't make medical sense. (M8)
There are not many patients who have a medical power of attorney, there are not many advanced care plan documents. Medical staff seem to lack knowledge regarding the legal issues related to advanced care planning. Many of the conversations related to prognosis, treatment options etc. are often left to junior medical staff. (N28)
Relatively few patients have the 'whole package' of formal documentation, but when they do, it makes decision making much easier. (N7)
Pt [sic] had said they didn't want to have further chemotherapy, but was coerced into having further treatment. The result was admission to hospital with neutropenic sepsis. The patient deteriorated. (N17)

Table 3. Textual examples informing the theme about developing advance care directives

N, nursing participants; M, medical participants; S, social worker participants; ACDs, advanced care directives

Most patients presenting to our service have had little or no advance care planning done prior to admission and very little is done during the current admission. (N30)
Although I discuss ACDs with many clients most do not follow through with one. (S1)
A lot of our time is spent in conversations about end-of-life issues and sometimes this may involve re-negotiating goals of care. The documentation of these conversations is also continuous – through the medical notes. It can be a moving target. However we keep talking and explaining, so the initial plan can change, but usually consensually. (M3)
Clients change their mind, especially once admitted as an in-patient. (N37)
It offers conversation and opportunities to follow and patient can still change opinions. It offers ongoing dialogue. (S2)
I found it a rewarding process that helped me really establish what she wanted for her current care and needs in the event of her deterioration. (N7)

reason not to do so' (M6; Table 4), but situations were described where this did not occur (Table 4). Health professionals from all occupations recognised that the use of ACDs was limited, for varying reasons: the documentation was unavailable, incomplete, ignored, not discussed or no longer appropriate to the patient's circumstances. Nursing staff also commented on occasions when they had to challenge the treating team about not respecting an ACD.

Participants discussed several factors that were perceived to influence the use of ACDs. First, the lack of health service, state or national policy regarding ACDs was viewed as a confounding factor in their implementation. Several participants reported that their services did not recognise ACDs or have policies in place for their use.

Second, participants reported that ACDs were not always actively looked for when patients presented at the hospital. Cases were reported where a clinician was informed (either by family members or palliative care health professionals) that a patient had an ACD but active management was pursued until the ACD was produced.

Third, the usefulness of an ACD was perceived by participants to be influenced by its relevance to the patients' circumstances.

Medical issues are reportedly often poorly understood by patients and families and, hence, the usefulness and relevance of information contained in ACDs is variable. Changes in a patient's condition that were not addressed in the ACD were also believed to make the plan irrelevant.

Fourth, participants reported that compliance with a patient's wishes was more difficult when there was disagreement between interested parties (e.g. various family members or, in some cases, treating doctors). These situations were described by participants across all types of services, particularly in circumstances involving poor documentation.

Consequences of having ACDs

Health professionals observed that advance care planning was 'empowering for the patient and family' (S2; Table 5). Patients who had an ACD were perceived to be more proactive and in control of their care. Some participants reported that having clear documentation of a patient's expressed wishes helped health professionals to advocate on the patient's behalf. Participants reported that both families and health professionals were more confident about making treatment decisions when they had

Table 4. Textual examples informing the theme about the process of using advance care directive

N, nursing participants; M, medical participants; S, social worker participants; GP, general practitioner; CVA, cerebral vascular accident; abx, antibiotics; NG, nasogastric

When we actually know what they [patients' wishes] are we are bound (legally and morally) to follow them unless there is a clear and compelling reason not to do so. (M6)
In a consultative role I have seen the treating team pursue treatment that patients may not have understood or did not want. (N38)
The local health service had not yet developed a policy or process to recognise advance care plans. . .they were not worth the paper they were written on. (N20)
Depends on the treating medical team and their philosophy/knowledge of advance care planning, willingness to implement; some doctors (especially surgical), are less willing to shift focus from 'treating at all costs' to 'caring for patients comfort and wishes'. (N10)
On other occasions the question wasn't asked as to whether the patient had an advanced care plan prior to the treatment being instigated. (N28)
The patient was taken to hospital with a CVA and received i.v. fluids, i.v. abx and NG feeds despite the family's clear instructions that this was against the patient's wishes. Our palliative care team got hold of the advance care plan and took it to the ward to discuss with the physician. The physician said 'I heard that she had one of those. We got away with it for a little while but now we'll have to stop treating her'. I have no idea why the plan was not followed other than the plan was not on hand at the relevant time and the physician chose to ignore the substitute decision makers. (M6)
Happy to comply with an advance care plan if the circumstances fit those that the patient anticipated. Will allow patients to die if I believe they are fully informed and competent if that is their wish. (M9)
Family have enduring power of guardianship and have overridden the patients advanced directive and given permission for them to be ventilated post a seizure caused by a brain tumour. (N32)
Lack of rigorous documentation and conflicting wishes from family and GP. (N1)

Table 5. Textual examples informing the theme 'Consequences of having an advance care directive'

N, nursing participants; M, medical participants; S, social worker participants

Having an advance care plan in place ensured that the patient's wishes were followed. When some family members became upset that life saving measures were being withheld we were able to honestly reassure them that that is what their loved one wanted. It helps us as nurses to advocate for the patient. (N31)
By having the advance care plan completed, all parties involved were fully informed of all wishes/needs. By being informed, it took away the distress of what to do, as it was already set out what the client wanted. It made the care for the client in the end stages of their disease, a bit easier for the family and care givers. (N2)
Empowering for the patient and family. (S3)
Even though patients do come in with advance care plan already, it is still challenging to explain to some patients (mostly relatives) about their condition and prognosis. It is also rather difficult sometimes to break bad news to inform them that they are in dying process. (M2)
The client was able to discuss what interventions she wanted and was therefore more relaxed. (N15)
Usually because family are aware of the patient's wishes the whole approach to care is more cohesive and smooth, removing distrust and conflict. Families usually feel comfortable with knowing what the person's wishes are and complying with them. (N36)
Symptom management is carried out with ease knowing what the patient really wants. End-of-life care is comfortable for the patient knowing they do not want any invasive treatments to prolong life uncomfortably. The families and friends are more comfortable and accepting of the imminent death. (N21)
Caring for patients with an advanced care plan is rewarding as you know that the patient has made their own decision regarding their treatment, and end-of-life care. (N13)

insight into ‘...what the patient really wants’ (N21). Family members were perceived to be more comfortable and accepting, knowing that the decisions made were what the patient wanted or reflected the patient’s values and priorities. Many participants mentioned a sense of relief when treatment decisions reflected the wishes and priorities of their patients. Several participants reported a sense of satisfaction when they were able to provide the care patients desired. Providing end-of-life care in such a context was described as a rewarding process.

Participants also reported that advance care planning made communication about end-of-life care easier with both the patient and the family, knowing that the person had already thought about these issues. However, one doctor stated that conversations about end-of-life care were still difficult, even when previous conversations about advance care planning had been documented. Patients were not always perceived to be in control and, in some situations, reportedly received treatment that was contrary to their expressed wishes.

Discussion

This paper reports the advance care planning experiences of palliative care health professionals and highlights the role of ACDs in facilitating communication, decision making and providing care for dying patients. ACDs promoted greater understanding between family, friends and staff, and reduced distrust and conflict. However, the use and applicability of ACDs was dependent on the availability, relevance and quality of the documentation.

Participants primarily reported positive experiences for health professionals and patients when advance care planning was undertaken, and both the development and use of ACDs in practice was perceived to be rewarding.

The present study identified several barriers to the advance care planning process and use of ACDs in practice that are similar to previous research.⁷ The need for ACDs to be accessible and available to all health professionals involved in the patient’s care and across health jurisdictions has consistently highlighted concerns about ownership of the ACD and sharing of patient information in a fragmented health system.⁷ To be effective, formal ACDs need to be available to the patient and their family, as well as to relevant health providers when health care decisions are made. Particular difficulties in accessing ACDs have been observed when health professionals become involved in the care late in an illness or in an emergency situation.¹³ In such situations, it is important for information to be immediately available, current and relevant to the patient’s circumstances, otherwise the default position is frequently to treat actively in the absence of a trustworthy ACD.^{13,14}

Concerns have also been raised about how to maintain an up-to-date ACD, because changing personal circumstances have been shown to result in changing priorities for care.¹⁵ Individuals may have different treatment preferences when they are healthy to those when they are ill and, as a consequence, choices about what treatment is desirable and acceptable may change over the course of their illness.^{16,17} Although GPs are well positioned to initiate ACDs due to their ongoing relationship with their patients, how such information is consistently shared across health care settings remains problematic. Numerous approaches

to sharing ACDs have been investigated both in Australia and internationally, but there has been limited universal uptake due to a lack of systematic processes for embedding them into routine practice at an institutional level and across health jurisdictions.¹⁸ Furthermore, advance care planning needs to be normalised in all health settings. To date, the greatest hope for embedding ACDs across services and jurisdictions is the electronic medical record, which is an important facilitator of advance care planning.¹⁹ However, in Australia, universal E-health records are slow to be implemented and hampered by limited consumer use.²⁰

Participants in the present study identified the importance of communication in advance care planning; indeed, that advance care planning is an iterative process that is predicated on ongoing discussions about the patient’s preferences for treatment. Our findings support the notion that having an ACD in place, as well as the preparation of an ACD, are access points for ongoing conversations about what treatment and care is preferred and is appropriate. Such discourse between health professionals, the patient and, where appropriate, the family is reflective of a patient-centred approach that can be responsive to the changing health and differing decision-making styles of individual patients.²¹ Communication at this level helps build trust between health professionals, patients and their families, as well as an understanding of the care preferences of the patient.¹³ Although palliative care is built on an assumption of open and honest communication, staff in this study reported that they find it difficult to discuss end-of-life issues. Thus, advance care planning and the preparation and use of ACDs provide an opening for the discussion of issues of significant importance to the patient and their loved ones.

The main limitations of the present study relate to the generalisability and representativeness of the data. Although 60 health professionals provided open comments about their experiences, we do not know from which palliative care services these responses came. However, services participating in PCOC are representative of Australian palliative care services generally.²² Furthermore, service managers were asked to distribute the survey to well-informed staff members. Qualitative research aims to include people from a variety of backgrounds who are willing and able to discuss the phenomenon in depth, focusing on their experiences of the issues under discussion. Greater numbers or representativeness of the sample ‘will not necessarily result in a better understanding of the topic’.²³

To increase the reliability of these findings, an investigation of doctors’ perceptions of the clarity and applicability of ACDs when developed in various settings would be helpful. Further research is also warranted to provide insights into patient experiences of advance care planning in palliative care.

Nevertheless, our research has several implications for advance care planning in the clinical setting. First, ACDs must be clear, comprehensive, medically relevant, transportable documents. Second, clear communication channels are necessary for the development and application of ACDs. Because ACDs are individualised, their development and maintenance is highly dependent on an intimate understanding of the patient and his/her desires. Third, having an ACD is not an end in itself. Discussions about preferences for care must be ongoing between health professionals, patients and their families. Any changes in

patients' wishes need to be documented and effectively communicated to the healthcare team and across health jurisdictions.

Competing interests

The authors declare that there are no competing interests.

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