

Advance care planning in palliative care: a national survey of health professionals and service managers

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Abstract

Objective. To identify the attitudes, knowledge and practices regarding advance care planning (ACP) in palliative care.

Methods. A nationwide online survey was distributed to Australian palliative care services associated with the Palliative Care Outcomes Collaboration ($n = 105$). Seventy-three health professionals (HPs) and 59 service managers completed the survey.

Results. Regarding ACP, 51% of service managers reported relevant policies and procedures were in place in their service and 44% included ACP in job descriptions. Most HPs were confident in undertaking ACP, including initiating discussions with patients and complying with documents; however, only 44% reported receiving ACP specific training. Although 58% of HPs reported having conversations about ACP with more than 11 patients in the past 6 months, only 44% of managers report that it is offered to most patients. Thirty per cent of HPs were aware of others not adhering to patient wishes in the past 6 months and only 43% of HPs (and 37% of managers) believed ACP is done well within their service.

Conclusions. This first national survey examining ACP in palliative care services demonstrates there is a need to improve systems to support ACP and to understand circumstances in which ACP wishes are not followed.

What is known about the topic? ACP is increasingly recognised as an important part of care of people in hospital and community settings. However, currently there is no empirical evidence about the national uptake and quality of ACP in palliative care settings specifically.

What does this paper add? This nationwide survey shows improvements on past small-scale research showing that ACP is supported by palliative care health professionals; however, the organisational ACP processes and systems did not support best practice in this regard.

What are the implications for practitioners? Palliative care organisations should incorporate ACP systems (including greater access to ACP policies and guidelines) that support health professionals to complete ACP with clients who want to. Greater access to support, such as ACP training and resources, would assist with development of ACP documentation and adherence.

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Introduction

Advance care planning (ACP) refers to an ongoing process completed by people, in consultation with their healthcare providers and significant others, to plan for medical decisions or

treatments in advance.¹ This process documents and describes the patient's preferences, values and aims for future medical treatments and may include completing an advance care directive (ACD) that documents the refusal of specific treatments

in future care and/or the formal appointment of a substitute decision maker should the patient later become unable to consider or communicate their wishes.

ACP has been shown to limit the application of burdensome treatments at the end of life in line with patient preferences,^{2–5} improve patient and family satisfaction with care and reduce indicators of stress, anxiety and depression in surviving relatives.⁴ It also reduces inappropriate hospital transfers for residents of nursing homes.^{6,7}

Since the early 1990s, there has been increasing specialisation in the provision of palliative care in Australia, with palliative care services now available in almost all healthcare settings.⁸ As specialist palliative care becomes more widely accessible earlier in the illness and is made available to patients with less predictable illness trajectories,^{9,10} it is important that ACP is critically examined in this context because it is at this stage of care that end-of-life plans will inevitably be acted upon.¹¹

There is limited empirical research that examines how to effectively incorporate ACP into the palliative care setting. An Australian trial of the Respecting Patient Choices (RPC) model¹² of ACP demonstrated that it was feasible to embed ACP into the organisational structures of three community palliative care services.¹¹ However, there is not yet a clear picture as to how ACP programs impact on end-of-life outcomes in the palliative care setting. Research provides evidence that ACP programs can increase the completion rate of ACDs among palliative care patients,¹³ as well as improve congruence between a patient's preference and place of death¹⁴ and access to palliative care services.^{2,15}

Previous research has shown that ACP is not common in palliative care services and many palliative care patients do not have an ACD in place.^{13,16,17} Potential barriers to ACP include limited confidence with and understanding of ACP among palliative care nurses and a lack of resources within services.¹⁸ A recent systematic review of ACP in specialist and non-specialist palliative care settings further identified that the uptake of ACP may be influenced by health professionals' uncertainty about when and by whom ACP should be initiated;¹⁹ however, most findings were drawn from small convenience sample populations only and did not examine ACP in palliative care services nationwide or look comprehensively at knowledge and attitudes among palliative care practitioners regarding ACP. The present study was undertaken to address this knowledge gap by measuring the attitudes, knowledge and practices of palliative care services regarding ACP to help inform capacity building and policy development in this area. We decided to survey palliative care health professionals (HPs) and service managers separately to identify any differences in knowledge, attitudes and practice regarding ACP.

Methods

Study design and participants

The Palliative Care Outcomes Collaboration (PCOC) is an Australian national voluntary program to enable all Australian in-patient and out-patient palliative care services to measure and

benchmark outcomes in their service.²⁰ An initial email was sent to the directors of all 105 palliative care services participating in PCOC advising them of the proposed study.

A cross-sectional design was adopted in this descriptive study and comprised two online surveys that were sent to the PCOC services. The data were collected over a 2-month period commencing in February 2013. The director of each service was invited to nominate two HPs who worked as clinicians within the palliative care service (the HP survey) and nominate one person best placed to provide a managerial response on behalf of the palliative care service (service manager survey) to complete the surveys by forwarding the email to those they had nominated. The email contained the relevant links to the online surveys. Consent was implied by completion of the surveys. Ethics approval for the study was obtained from the University of Wollongong/Illawarra Shoalhaven Local Health District Human Research Ethics Committee (Approval no. HE12/471).

Survey tools

The surveys were designed to ascertain palliative care managers' and HPs' perceptions of ACP in palliative care services. The questions on knowledge, attitudes and practice were modelled on past ACP HP surveys.²¹ The content of the survey items were reviewed by ACP facilitators from the RPC program and quality improvement facilitators from the PCOC program to ensure they were understandable and applicable to palliative care services.

Both surveys covered service practice characteristics and demographic and professional information. The HP survey addressed additional domains such as attitudes, values and beliefs about ACP and ACP practices. The manager survey considered organisational ACP practices and service policy and procedures and attitudes, values and beliefs about ACP. Most questions were closed multiple-choice questions.

Analysis

Data were analysed using descriptive statistics. Descriptive analyses were undertaken using SPSS for Windows, Version 20.0 (IBM, Armonk, NY, USA). Frequencies and corresponding percentages are reported for categorical data.

Results

Demographic and professional information

From the 105 services, completed questionnaires were received from 73 out of a potential 210 HPs (35%) and from 59 out of a potential 105 managers (56%).* Responses were not linked to specific services and we are therefore unable to determine how many services are represented across each group. Most participants were female and aged 45 years or over (Table 1). All Australian states were represented, apart from the Australian Capital Territory and Northern Territory. Most HPs (70%) and managers (80%) had a nursing background, with medicine the second most commonly reported profession (16% of HPs and 7% of managers).

*The response rates are based on the assumption that each service followed the study protocol by passing on the request to participate to two HPs and one manager.

Table 1. Respondent and services profiles

Data show the number of respondents in each group, with percentages in parentheses

Variable	Health professional (<i>n</i> = 73)	Service manager (<i>n</i> = 59)
Gender		
Female	66 (90%)	55 (93.2%)
Age (years)		
<40	15 (20.6%)	8 (13.5%)
40–49	19 (26%)	19 (32.2%)
50–59	34 (46.6%)	26 (44.1%)
>60	5 (6.8%)	6 (10.2%)
State or territory		
NSW	17 (23.3%)	11 (18.6%)
Qld	17 (23.3%)	16 (27.1%)
SA	11 (15.1%)	12 (20.3%)
Tasmania	2 (2.7%)	4 (6.8%)
Victoria	18 (24.7%)	9 (15.3%)
WA	9 (12.3%)	7 (11.9%)
Training classification		
Nursing	51 (69.9%)	52 (88.1%)
Medicine	12 (16.4%)	4 (6.8%)
Social work	5 (6.8%)	—
Occupational therapy	3 (4.1%)	—
Other	2 (2.8%)	1 (1.7%)
Service funding		
State funded	59 (80.8%)	48 (81.4%)
Commonwealth	31 (42.5%)	25 (42.4%)
Not for profit	20 (27.4%)	14 (23.7%)
Private	11 (15.1%)	8 (13.6%)
Local government	1 (1.4%)	1 (1.7%)
Service type		
In-patient palliative care unit	40 (54.8%)	37 (62.7%)
Specialist palliative care provider (community)	33 (45.2%)	25 (42.4%)
In-patient consultative service	18 (24.7%)	22 (37.3%)
Community health consultative service	7 (9.6%)	14 (23.7%)
Aged care service providing palliative care	6 (8.2%)	5 (8.5%)
Other	10 (13.7%)	5 (8.5%)

ACP systems and support

The manager survey revealed limited systems and support for ACP. Half the managers (51%) reported that their services had access to written ACP policies and procedures and 44% of services had ACP included in their staff job descriptions. ACP discussions were most frequently initiated by a patient or family request (59%), were more commonly documented in the patient's case notes (69%) instead of a specific ACP form (36%) and most services did not have a process for reviewing patients' existing ACDs (71%). Although the majority of services reported that they transfer patients' completed ACP documents to the local hospital (if they are not already located on the site), most services were unlikely to transfer completed ACP documents to a patient's GP despite 96% believing that GPs have a role in ACP (Table 2).

When managers were asked why ACP is not offered to patients; 31% cited time and resource limitations, 24% cited limited skills with ACP, 36% cited limited ACP training for staff,

Table 2. Advance care planning (ACP) systems across services as reported by managers

Unless indicated otherwise, data show the number of respondents in each group, with percentages in parentheses. GP, general practitioner

ACP process	Service manager
When are ACP discussions normally initiated? (<i>n</i> = 59)	
On admission (in-patient)	26 (44.1%)
At first client visit (community)	20 (40.7%)
In subsequent visits (community)	28 (47.5%)
At first point of contact	11 (18.6%)
Formal review/assessment	17 (28.8%)
Upon patient's request	35 (59.3%)
Upon relative or carer's request	35 (59.3%)
Upon recommendation from other health professional	22 (37.3%)
How are ACP discussions documented? (<i>n</i> = 59)	
Staff member records discussion in general case notes	41 (69.5%)
Patient completes paper based form	28 (47.5%)
Staff member records discussion in specific ACP document	21 (35.6%)
Relative or carer completes paper-based form	19 (32.2%)
Does the service have guidelines about when to review a patient's ACP documents? ^A (<i>n</i> = 52)	
Yes	15 (28.8%)
No	37 (71.2%)
Are patient's completed ACP documents transferred to the local hospital? ^A (<i>n</i> = 41)	
Yes	9 (22%)
As a routine yes, but only when the patient is transferred/admitted	21 (51.2%)
No	4 (9.8%)
Not applicable – the service is based at the local hospital	7 (17%)
How often are patient's completed ACP documents transferred to the patient's GP? ^A (<i>n</i> = 52)	
Always	1 (1.9%)
Usually	10 (19.2%)
Often	7 (13.5%)
Sometimes	11 (21.2%)
Seldom	12 (23%)
Never	11 (21.2%)

^AQuestion not applicable to the total sample as determined by responses to qualifying question.

25% cited limited confidence with ACP and 49% reported that patients and family did not want to complete ACP.

Most HPs were satisfied or somewhat satisfied with the level of support from their senior staff and peers to complete ACP with patients and/or their families (Fig. 1). For example, although ACP is not in the job description for staff in more than half the services, 55% of HPs were satisfied with the amount of time they had to do ACP and 66% were satisfied with the level of support from senior staff.

HP knowledge and confidence

Although only 44% of HPs had completed any ACP training (53% in-service training, 34% external workshop training and 40% online training), most HPs were confident with most aspects important to ACP, such as initiating ACP discussions

with patients, answering patient and family questions about ACP and complying with patient's ACP documents (Fig. 2). Fewer HPs were confident about mediating with families and patients about disagreements (45%), implementing organisational policy and procedures (48%) and teaching other staff about ACP (50%). Only 30% of HPs were confident about knowing relevant state laws regarding ACP.

ACP discussions

Most HPs reported initiating ACP conversations with their patients and caring for people who had an existing ACD in place. When asked to specify the total number of ACP conversations with patients, 58% of HPs reported having 11 or more ACP conversations in the past 6 months, with 42% reporting between

none and 10 ACP discussions. Fifty-five per cent of HPs had been a witness for an ACP discussion and 89% had cared for a patient who had an ACD in the past 6 months. Only 45% of HPs believed that they are very experienced at ACP conversations.

Both HPs and service managers reported that issues important to ACP were routinely discussed with patients (Fig. 3). However, only 61% reported that ACP is formally offered to most (50%–100%) of their patients. Fewer than half the participants (43% of HPs and 37% of managers) reported that ACP is done well within their service (Fig. 4).

ACP adherence

Although the majority of HPs had cared for a patient with an existing ACD, only 34% of HPs and 44% of managers reported

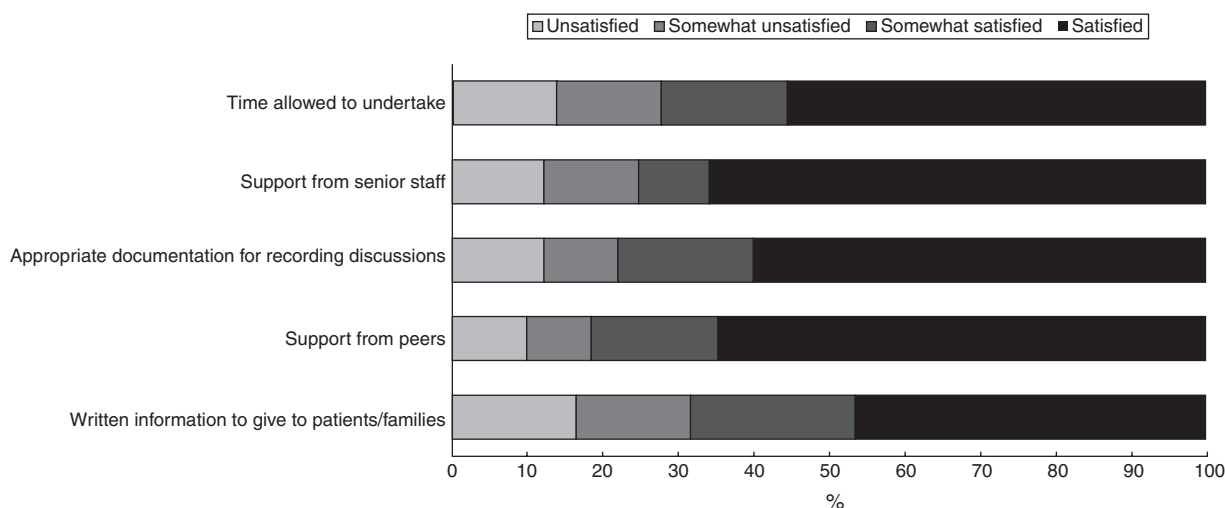


Fig. 1. Health professionals' satisfaction with support to do advance care planning (ACP).

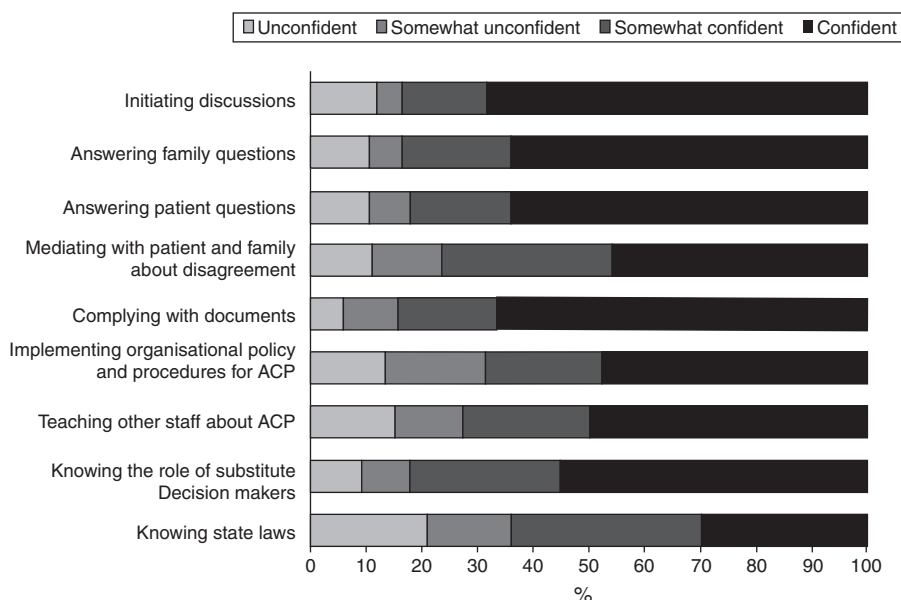


Fig. 2. Staff confidence levels with the advance care planning (ACP) processes.

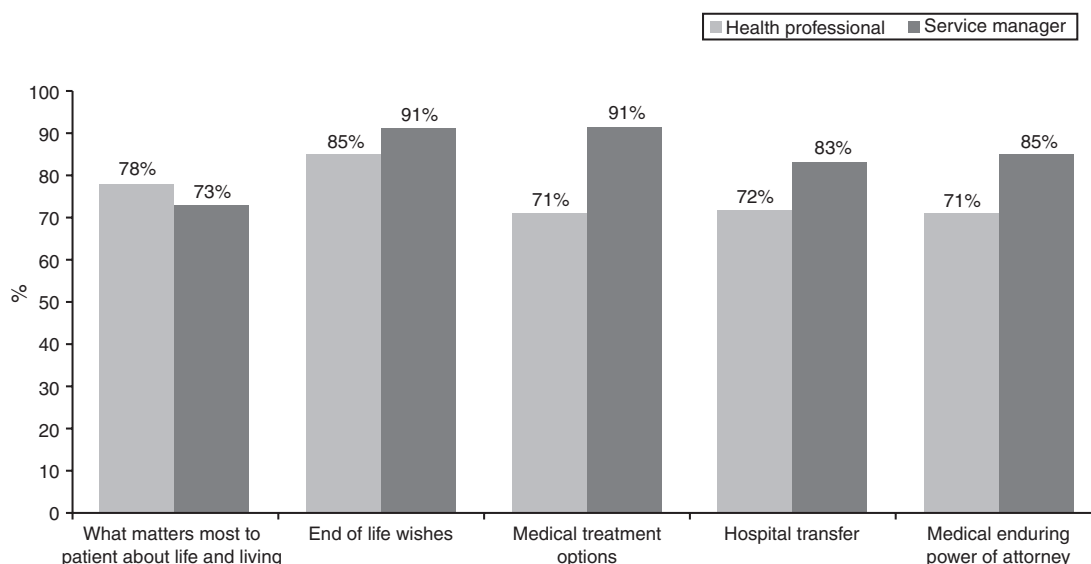


Fig. 3. Percentage of services that routinely discuss issues important to advance care planning (ACP).

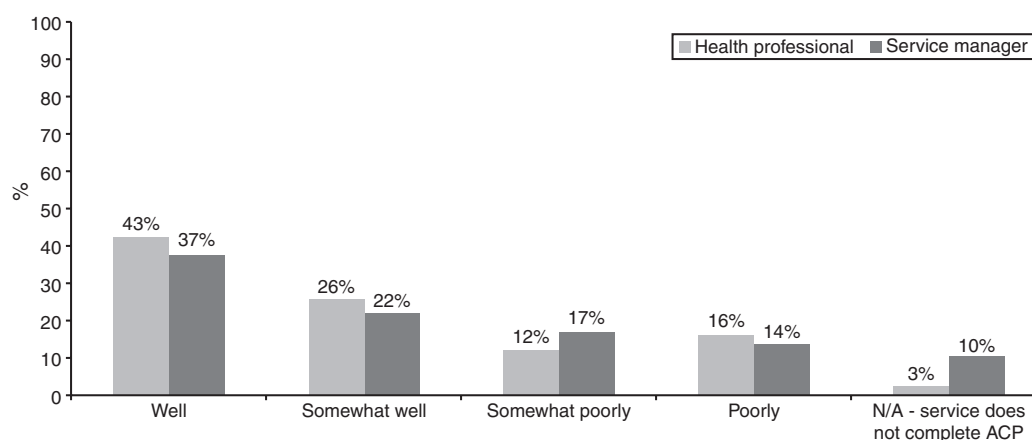


Fig. 4. How well respondents believe advance care planning (ACP) is done within their service.

that their service always follow ACDs. Fewer than half of the HPs (49%) and managers (48%) reported that ACDs are often followed and 17% of HPs and 9% of managers indicated that ACDs are only followed occasionally or rarely. Eleven per cent of HPs had provided treatment to a patient who had previously indicated that they did not want treatment and 30% were aware of others providing treatment to a patient who previously indicated that they did not want that treatment.

Opinions about ACP

On a six-point scale (strongly agree to strongly disagree), 93% of HPs agree or strongly agree that ACP is a valuable and worthwhile activity for their clients, 80% disagree or strongly disagree that discussing death is a barrier to ACP and 57% disagree or strongly disagree that they have had a negative experience with ACP. Seventy-six per cent of HPs and 96% of managers agree or strongly agree palliative care staff have a role in ACP.

Discussion

This is the first published nationwide survey conducted in Australia or internationally of ACP practices among palliative care services. It emphasises findings from past small-scale studies^{11,18,22} that HPs are under-supported by the systems within their organisations to optimise the delivery of ACP to all patients.

PCOC participating organisations are a very good representation of Australian palliative care service providers.²³ The demographic data confirm that the survey is representative of those organisations and those staff who provide palliative care for patients. For example, based on full-time equivalents, the ratio of nursing staff to medical staff working in palliative care across Australia is approximately 9.5:1.²⁴ Our respondents showed a similarly high ratio of nursing versus medical training.

This survey identified a change in the attitude towards and practice of ACP within palliative care services. Compared with past research in the palliative care setting,^{17,18,22} the majority of services in the present sample identified ACP as part of their

role and reported that they are currently involved in ACP. For example, >70% of HPs discuss topics important to ACP with their patients (e.g. appointing a substitute decision maker and medical treatment options) and most reported that they had initiated more than 11 ACP conversations in the 6 months before the survey. Furthermore, nearly 90% of the sample had cared for a patient with an existing ACP in place and many had counselled a family member or patient about ACP.

However, the survey confirms recent findings in England²² of the need to improve enacting patients' ACDs in palliative care. The HPs in that study described barriers to enacting a patient's wishes, including a lack of resources to meet patient wishes, patient wishes not being applicable to the circumstance and/or the family overriding patient wishes. The present survey showed that palliative HPs in Australia face similar difficulties enacting ACDs. Although most HPs had cared for a patient with an ACD, <50% of HPs and managers reported that ACDs were always followed in their service and three in 10 HPs were aware of others providing treatment to a patient who previously indicated they did not want that treatment. The reasons for non-adherence to ACDs are complex and require further research,²⁵ however they may be due to poor ACP documentation, inadequate communication between the treatment team about existing ACDs, difficulty prognosticating, difficulty applying the written information to a complex situation and/or low uptake of ACP across the treatment team. ACP discussions were more frequently documented in the patient's case notes than on a specific ACP document. Recording ACP information informally within the clinical notes is an impediment to patient-centred care because crucial information becomes 'buried' and lost within the myriad of notes.¹¹

ACP implementation has been most successful when a whole-systems approach is adopted,^{3,4,11,12} including strategies such as community engagement, HP education and training, documentation processes and organisational policies and procedures. In the context of palliative care, a whole-systems approach to ACP requires effective communication of the patient's wishes across the whole interdisciplinary healthcare team (including social workers, occupational therapists and physiotherapists), not just to the doctors and nurses at the end of life. Contrary to the above recommendations,^{11,12} and in line with past research in other healthcare settings, the majority of the palliative care services' ACP systems in the present study were underequipped to support HPs. Only half the managers reported that they had written policies and procedures available within their services and fewer than half included ACP in the position description of HPs. These findings are consistent with those demonstrated previously in Australian residential aged care facilities where, although most residents were found to have an existing ACP document in place, the services' palliative care policies regarding ACP were inconsistent between services.¹⁶ Similarly, despite the majority of HPs reporting that they had either initiated or cared for a patient with an existing ACP in place, fewer than half had completed any ACP training. In addition, HPs were not confident in their knowledge of state laws regarding ACP, which is consistent with Australian research showing that medical practitioners lack a comprehensive understanding of the law regarding ACP, despite believing that it would assist their medical decision making.²⁶

Although they reported limited ACP-specific training, the HPs in the present study showed high levels of confidence with ACP discussions, including initiating discussions, answering patients' and families' questions about ACP and complying with ACP documentation. These levels of confidence are higher than reported previously. For example, surveys in the UK in 2010¹⁸ and in Australia in 2013¹⁷ found that palliative care nurses had low levels of confidence to initiate ACP discussions with patients and families. Other Australian studies show similar trends across other healthcare settings. Three separate Australian qualitative studies reveal that doctors and nurses^{27,28} and social workers²⁹ believe that they have poor ACP knowledge and training, and that they are confused about ACP documentation and laws. This is thought to contribute to the low uptake of ACP by patients.

Given the important role that ACP training³ and knowledge of relevant laws³⁰ plays in ACP practice, there may be a concern that HPs are potentially overly confident in these aspects of ACP. Understandably, HPs appear to be more confident with patient-centred aspects of ACP discussions and less confident in their knowledge of ACP-specific legislation.

From the patient's perspective, the factors associated with a 'good death' are: managing symptoms, avoiding prolongation of dying, achieving a sense of control, relieving burdens placed on the family and the strengthening of relationships.^{31,32} The delivery of ACP in palliative care would assist the delivery of these factors because it has been shown to lead to improved end-of-life care and greater satisfaction for both patients and family, as well as to reduced stress, anxiety and depression in surviving relatives.⁴ Furthermore, dying patients have identified facilitated ACP as an integral part of palliative care.^{33,34} Although the surveys in the present study identify systematic issues and variability to the implementation of ACP across Australian palliative care services, HPs overall showed a familiarity with and support for ACP in their roles and it is therefore pleasing that palliative care services are normalising ACP processes, such as discussions with patients and family, and embedding them into their practice.

Limitations and considerations

There are several limitations to the generalisability of the findings of the present study to all palliative care services in Australia. First, respondents self-reported on their practices and experiences with ACP and there is therefore the potential for over- or underestimating prevalence of practices. We minimised responder bias by ensuring that participants were aware that the survey was anonymous. Further, we provided a definition for ACP in order to avoid ambiguity and ensured that questionnaire items were phrased to optimise objectivity. Although the HP response rate was relatively low, the manager survey response was reasonable and the gender and occupation characteristics of our respondents is representative of the palliative care workforce in Australia, where the majority are nurses and female.²⁴ Finally, to maintain anonymity, the surveys did not include any means of linking responses to particular services. We are therefore unable to determine whether the 59 responses from service managers represent 59 separate services or how many services are represented by the 73 health professionals who responded.

Conclusion

This is the first national survey of ACP in palliative care services in Australia. It demonstrates an improvement in the implementation of ACP in the palliative care setting compared with previous reports, but highlights the need to build capacity, competence and confidence through training and to improve organisational systems, including policies and guidelines, to support ACP. These results warrant further research focusing on the issues of why and in what circumstances ACP wishes are not followed in the palliative care setting and on the appropriate involvement of general practitioners in the ACP process.

Competing interests

The authors declare that there are no competing interests.

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