

Advance Care Planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008–2012

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Abstract

Background: Advance Care Planning is an iterative process of discussion, decision-making and documentation about end-of-life care. Advance Care Planning is highly relevant in palliative care due to intersecting clinical needs. To enhance the implementation of Advance Care Planning, the contextual factors influencing its uptake need to be better understood.

Aim: To identify the contextual factors influencing the uptake of Advance Care Planning in palliative care as published between January 2008 and December 2012.

Methods: Databases were systematically searched for studies about Advance Care Planning in palliative care published between January 2008 and December 2012. This yielded 27 eligible studies, which were appraised using National Institute of Health and Care Excellence Quality Appraisal Checklists. Iterative thematic synthesis was used to group results.

Results: Factors associated with greater uptake included older age, a college degree, a diagnosis of cancer, greater functional impairment, being white, greater understanding of poor prognosis and receiving or working in specialist palliative care. Barriers included having non-malignant diagnoses, having dependent children, being African American, and uncertainty about Advance Care Planning and its legal status. Individuals' previous illness experiences, preferences and attitudes also influenced their participation.

Conclusion: Factors influencing the uptake of Advance Care Planning in palliative care are complex and multifaceted reflecting the diverse and often competing needs of patients, health professionals, legislature and health systems. Large population-based studies of palliative care patients are required to develop the sound theoretical and empirical foundation needed to improve uptake of Advance Care Planning in this setting.

Keywords

Advance Care Planning, palliative care, palliative therapy, Advance Directives, Living Wills, terminal care

What is already known about the topic?

- Despite the legal and pragmatic utility of Advance Care Planning (ACP), its uptake has remained limited.
- A range of facilitators and barriers to ACP in palliative care have been identified; however, no systematic review of these factors has been published.

What this paper adds?

- Factors influencing the uptake of ACP in palliative care remain complex and multifaceted, with facilitators and barriers existing at the patient, health professional, health service and legal levels.

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Implications for practice, theory or policy

- The literature shows that contextual factors, as described in this article, are an essential consideration when designing ACP interventions in palliative care.

Background

The formalised concept of Advance Care Planning (ACP) first emerged in the United States in the late 1960s as a legal mechanism to guide the use of potentially life-prolonging medical treatments.^{1,2} Legally binding documents such as Advance Directives (AD) were soon established in several countries, which for the first time allowed individuals to specify their choices regarding medical treatment before incapacity.^{1,3,4} Yet, despite the legal and pragmatic utility of these legal documents, their uptake remained limited.^{5–7} In retrospect, advocates underestimated the complexity of legal health system, individual and socio-cultural factors involved in formulating such documents and achieving their purpose. They also mistakenly assumed that the introduction of new legislation would automatically lead to changes in end-of-life care.⁸ Accordingly, effective implementation of ACP needed to be reconceptualised from mere consideration of legal documentation to an iterative process involving ‘contemplation of one’s values and future treatment wishes, discussions with family and friends, discussions with clinicians, and (legal) documentation’.⁹ ACP thus required input from all relevant stakeholders to produce a consensus view that could be applied to specific contexts.¹⁰

Palliative care has been recognised as an ideal setting to implement ACP because end-of-life discussions are core business for palliative care health professionals.¹¹ The goal of optimising quality of life during incurable illness is also a central tenet of palliative care, and ACP allows the differing preferences of individuals to be identified, documented and enacted.^{12–14} This synergy of purpose has driven interest in embedding ACP as a fundamental aspect of palliative care.^{15,16} Accordingly, ACP in palliative care has been focused upon in international conferences, national health policy in several countries and the popular media.^{4,17–19}

Yet, despite this broad interest, attempts to embed ACP in routine palliative care using relatively simple patient or health professional focused interventions have only had limited impact.^{11,20,21} This was particularly evident in the analysis of the 1995 Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a large well-resourced multi-centre trial that failed to improve AD completion rates and outcomes. It appeared that simply improving patient–doctor communication was insufficient to realise the goals of ACP, and a strategy that could transform systemic processes across a range of institutional settings was needed.²² Subsequently, a number of such ACP programmes were implemented

across several countries; for example, the Respecting Patient Choices Programme that originated in the United States has also been widely promoted in Australia.¹¹ These programmes have provided useful models for system-wide implementation of ACP. Yet, despite these advances, large-scale uptake of ACP in palliative care remains unrealised¹¹ suggesting that the contextual factors that influence its uptake remain only poorly understood.⁸

There have, however, been some attempts to understand social, professional and clinical contextual factors that influence the uptake of ACP more broadly. For example, patients are unlikely to complete an AD if physicians fail to initiate ACP discussions.²³ Yet, physicians have reported time, emotional and knowledge barriers to having ACP discussions.^{24,25} Concerns about the legal implications of ACP documentation and interpretation have also been cited.^{25,26} There have also been organisational barriers, such as ACP documents not being available at the appropriate time.²⁷ While these studies highlight important issues limiting the uptake of ACP, they are not necessarily specific to palliative care. Hence the question that guided this review was ‘What are the contextual factors that have influenced the uptake of ACP in ‘real-world’ palliative care settings?’ As this review sought to identify factors relevant to the contemporary palliative care environment, literature was limited to studies published from 2008 to 2012.

Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist and subheadings were used to conduct this review.

Eligibility criteria

Only primary research reporting on ACP within palliative care was included. In this review, ‘palliative care’ included both specialist palliative care and other non-specialist settings where a palliative approach was provided. Studies of non-palliative care community members were included when study populations were considered sufficiently similar to palliative care populations. Studies on the views of organisations involved in aged and end-of-life care were also included.

Since this review sought to identify contextual factors in ‘real-world’ palliative care settings, studies that evaluated a novel intervention, tool or model of ACP were

Table 1. Database search strategy.

Database	Search terms (within the title or abstract)	Keywords	Search strategy syntax	Limiters
Medline via EBSCOhost	'advance* care plan*' 'palliative*'	Advance Care Planning; Palliative Care	((TI 'advance* care plan*' OR AB 'advance* care plan*') OR (MH 'Advance Care Planning')) AND ((TI palliative* OR AB palliative*) OR (MH 'Palliative Care'))	English language (Published between January 2008 and December 2012)
CINAHL via EBSCOhost	'advance* care plan*' 'palliative*'	Advance Care Planning; Palliative Care	((TI 'advance* care plan*' OR AB 'advance* care plan*') OR (MH 'Advance Care Planning')) AND ((TI palliative* OR AB palliative*) OR (MH 'Palliative Care'))	
Embase.com	Advance Care Planning; Advance Care Plan; Advanced Care Planning; Advanced Care Plan; Palliative Care	Palliative Therapy	'advanced care plan':ab,ti OR 'advanced care planning':ab,ti OR 'advance care plan':ab,ti OR 'advance care planning':ab,ti AND ('palliative care':ab,ti OR 'palliative therapy'/exp) AND [english]/lim AND [embase]/lim AND [2008-2012]/py	

excluded as they tended to focus on specific illness trajectories within controlled populations.

Information sources and search

Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Embase were searched for studies relevant to ACP published between January 2008 and December 2012 (see Table 1 for search terms). Results and reference lists were then hand searched for further studies of interest. Authors were contacted regarding potentially overlooked studies of interest.

Data collection process and data items

A single researcher (A.L.) undertook thematic synthesis that included identifying relevant data and manually extracting it using a template approach to group common results under main headings. Data were only extracted from text labelled as 'results' or 'findings'. Subheadings were added as data were collated and themes emerged. A second researcher (P.Y.) reviewed the data and further identified themes and subheadings in an iterative process. Since the majority of studies did not specifically report their findings as factors influencing the uptake of ACP, the researchers necessarily inferred barriers and facilitators to ACP from the views and experiences of the study populations.

Risk of bias

The trustworthiness of included studies was graded using the National Institute for Health and Care Excellence (NICE) Quality Appraisal Checklists.²⁸ Each study received an overall grade depending on the number of criteria fulfilled, and the likelihood of unfulfilled criteria altering the study's conclusions. Qualifying studies were

assessed for bias by considering methods of data collection, record keeping, data analysis, the role of the researcher, study context and whether their findings were internally coherent and relevant to the aims of the study.

Results

Study selection

For inclusion and exclusion numbers, see Figure 1. No studies were excluded following quality appraisal. Included studies are detailed in Table 2 (supplementary material available online).

Study characteristics

Over half (13) of the included studies used qualitative methodology such as interviews and focus groups. Three studies employed mixed methodology such as surveys combined with interviews or open-ended questions. The remaining studies (11) used observational quantitative methodology such as surveys and chart reviews to report descriptive data. Eight of these studies performed multivariate data analysis, and one study was prospective. The majority of studies were conducted in the United States (10), followed by the United Kingdom (8), Australia (4), Belgium (2), Netherlands (1), China (1) and Taiwan (1).

Patient factors influencing the uptake of ACP

Demographic characteristics. Two studies reported a positive association between age and ACP. Reynolds et al.³⁰ undertook a retrospective review of 1133 charts in American nursing homes and found that the uptake of Advanced Directives was positively correlated with older age ($p < 0.001$). Dow et al.'s³¹ analysis of interviews with 75 cancer patients also found that those who had completed an

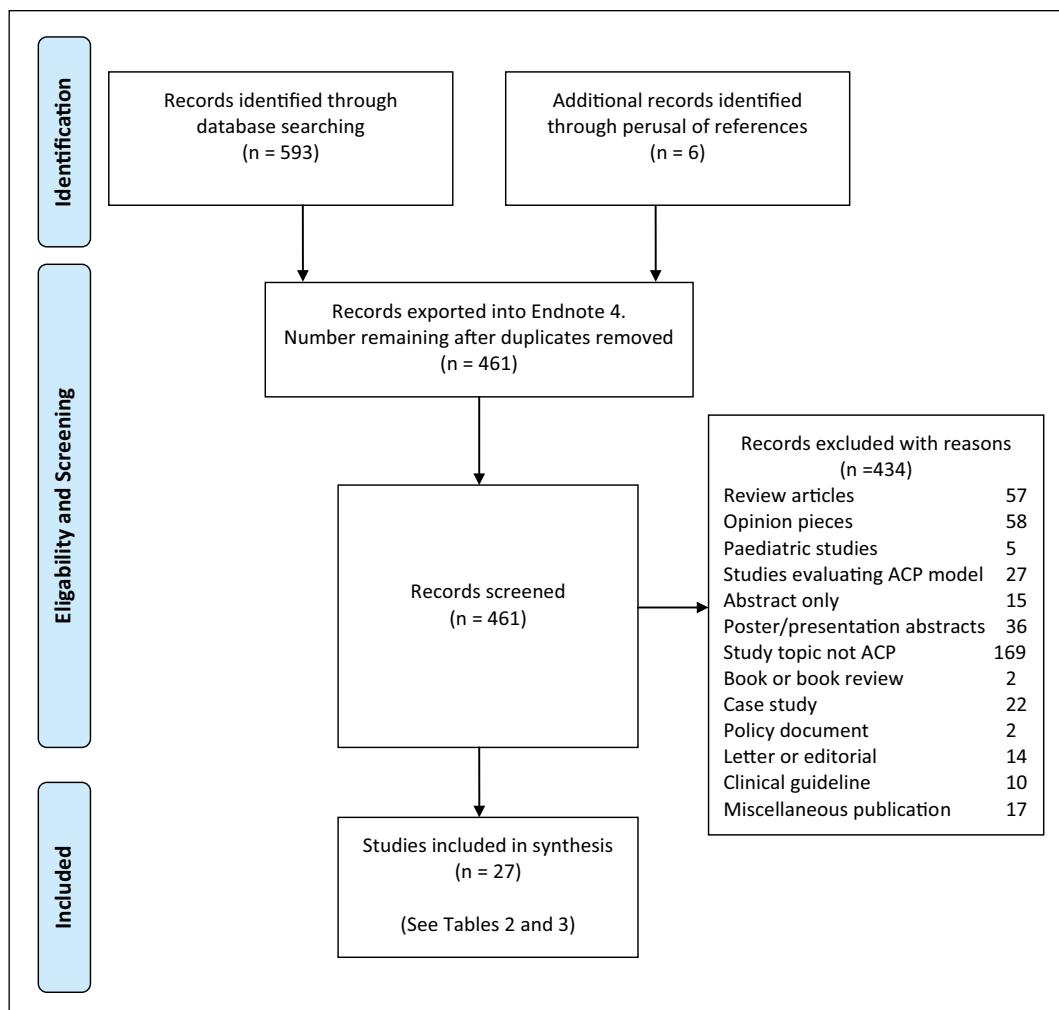


Figure 1. Study selection.

Source: Moher et al.²⁹

Advanced Directive were, on average, 14.5 years older than those who had not ($p < 0.001$).

Wagner et al.’s³² survey of 400 inpatient veterans correlated ACP with education, showing, via multivariate analysis, that having a college degree was independently associated with veterans having completed a Living Will ($p < 0.001$).

Diagnosis and health status. Specific patient diagnoses have been associated with different rates of ACP uptake. In their retrospective chart review of 839 public hospital deaths in China, Lau et al.³³ showed slightly higher rates of ACP in cancer (94%) versus non-cancer (89.2%) deaths ($p < 0.053$). Two additional Belgian studies of 1303 nursing home deaths and 1072 general practitioner (GP)-reported deaths by De Gendt et al.³⁴ and Meeussen et al.,¹³ respectively, similarly reported that patients with cancer had the highest rates of ACP compared to other diagnoses. Meeussen et al.¹³ may not, however, have captured ACP done in hospitals as the study relied on GPs to report rates of ACP.

Using multivariate logistic regression, De Gendt et al.³⁴ reported that nursing home residents with severe dementia were six times less likely to have an Advanced Directive than those without dementia (adjusted odds ratio (AOR): 0.182, 95% confidence interval (CI): 0.088–0.377). Dementia was also identified as a barrier to ACP by English nursing home staff in both Froggatt et al.’s³⁵ and Stewart et al.’s³⁶ survey and interview-based studies.

Three studies reported patients with chronic obstructive pulmonary disease (COPD) appear to be disadvantaged in relation to ACP.^{33,37,38} Lau et al.³³ showed a higher proportion of COPD patients (26.9%) only had their first ACP discussions in the last 3 days of life compared to cancer (11.6%) and renal failure (9.5%) patients ($p < 0.001$). The finding of a relative disadvantage in COPD patients was supported by Gott et al.’s³⁸ focus group study of 39 health professionals and MacPherson et al.’s³⁷ study of 10 COPD patients. The latter two studies were, however, limited by their small sample sizes.

The studies by De Gendt et al.,³⁴ Wagner et al.³² and Meeussen et al.¹³ all found an association between patients’

health status and ACP. Specifically, patients whose deaths were expected, were classified as 'more dependent',³⁴ had greater levels of functional impairment³² and retained capacity for decision-making in the last 3 days of life¹³ were all more likely to have participated in ACP. Wagner et al.³² provided the best evidence of this association by formally assessing the physical function of 400 veterans in relation to rates of ACP; however, participants' self-reporting on provider communication allowed potential recall bias. Wagner et al.³² also concluded that patients who reported higher quality of life were more likely to have ACP discussions with their families.

Ethnicity and culture. Reynolds et al.,³⁰ Dow et al.³¹ and Guo et al.³⁹ identified that white populations in the United States were more likely to have engaged in ACP than minorities. This finding was supported by Hirschman et al.'s⁴⁰ survey of 165 family members of deceased patients though the result may have been subject to recall bias. In Wagner et al.'s³² study, multivariate analysis revealed that being African American was independently associated with lower rates of Living Wills ($p < 0.01$). Guo et al.'s³⁹ retrospective chart review of 88 adults with metastatic spinal cord compression identified similar disparities with Hispanic and Latino populations. This study did not, however, identify or control potential confounding factors such as income and literacy.

Previous illness experiences. Factors influencing the uptake of ACP related to previous illness experiences were identified by Clarke and Seymour⁴¹ and Fried et al.⁴² via focus groups with older community members and caregivers. In Clarke and Seymour's⁴¹ study, the 'few participants' who had completed a Living Will did so following personal illness or after seeing friends undertake the process and realising it was not difficult. Community members and caregivers in Fried et al.'s⁴² study, and some of the 38 elderly patients with limited prognosis in Piers et al.'s⁴³ study, said that a fear of bad experiences during death and dying increased their participation in ACP. Interestingly, while good experiences of death and dying motivated some community members to participate in ACP,⁴² it was also a reason some elderly patients chose not to participate.⁴³ These studies were limited by having small sample sizes and culturally homogeneous populations. Furthermore, both Clarke and Seymour's⁴¹ and Piers et al.'s⁴³ studies were at risk of selection bias towards individuals who may have been positively inclined towards ACP.

Individual preferences and attitudes. Participants in Clarke and Seymour's,⁴¹ Fried et al.'s⁴² and Piers et al.'s⁴³ work reported that the desire to maintain control when incapacitated, to relieve the burden of decision-making on family, to prevent family conflict and resuscitation in terminal illness were reasons they engaged in ACP. Conversely, some participant's preference for family, medical staff or God to

be responsible for end-of-life decisions was the reason for not engaging in ACP.⁴¹⁻⁴³

Social relationships. Nilsson et al.'s⁴⁴ multi-centre prospective cohort study of 668 cancer patients identified that participants with dependent children were less likely to have ACP initiatives in place at baseline interview (6 months or less to live) (95% CI). However, the rate of ACP in this group was not evaluated at the time of death and may have changed.

Knowledge and understanding. Bivariate statistical comparisons undertaken by Wagner et al.³² demonstrated that patients who understood the life-limiting nature of their illness were more likely to discuss ACP with their families ($p < 0.001$). Several other studies provide good evidence that poor patient and community knowledge about common end-of-life issues was a barrier to ACP.^{10,38,41-43} Specific knowledge deficits included not knowing the natural history of terminal diseases, artificial feeding, use of morphine, euthanasia, the role of surrogate decision-makers and scope of ACP.^{38,41-43,45} For example, community members in Fried et al.'s⁴² study thought if they were dying, not much could be done and therefore there were no real choices or benefits in ACP.⁴² Interestingly, elderly patients in Piers et al.'s⁴³ study reported not engaging in ACP because they thought they did not have the right to plan their end-of-life care.

Avoidance of acknowledging death and dying. The taboo nature of death and by association the reluctance to discuss end-of-life issues have been identified as barriers to ACP.^{10,36,42,43,45,46} A survey of 23 community palliative care nurses by Seymour et al.⁴⁵ surmised that most people avoided thinking about the consequences of serious illness until it actually happened. Some of the 63 community members and 30 caregivers in Fried et al.'s⁴² study reflected this sentiment by stating that their avoidance of ACP was related to a feeling they would live forever. Elderly patients in Piers et al.'s⁴³ work also refused to acknowledge that they were at the end of their lives despite being aware of their poor prognosis. Some of the patients said that the desire to stay positive prevented them from reflecting on end-of-life care.⁴³ Zhou et al.'s⁴⁶ descriptive survey of 89 oncology nurses reported patients and families being in denial and not wanting to give up as common barriers to ACP. However, using nurses as secondary sources of perceived barriers potentially biased this study.

Concerns about formalising an advance care plan. Concerns about formalising an ACP were voiced by participants in Fried et al.'s,⁴² Clarke and Seymour's⁴¹ and MacPherson et al.'s³⁷ studies; though small sample sizes limited generalisability. Nonetheless, participants in all three studies were worried about formalising an Advance Care Plan because

they thought treatment may be withdrawn too soon or that documenting preferences prevented changes.^{37,41,42}

Sexual orientation. In Cartwright et al.'s⁴⁷ small Australian survey of 19 clinicians and 6 lesbian, gay, bisexual and transgender patients, older gay men were identified as being at increased risk of social isolation and not knowing who to appoint as a surrogate decision-maker.

Health professional factors influencing the uptake of ACP

Uncertainty about when to initiate ACP discussions – timing. Three studies identified health professional uncertainty about when to initiate end-of-life discussions as a barrier to ACP.^{4,38,45} In Robinson et al.'s⁴ study of 14 focus group discussions and 18 interviews with 95 participants, health professionals caring for patients with dementia agreed that initiating ACP at diagnosis was too early; however, at the advanced stage, it was too late. Participants in Gott et al.'s³⁸ and Seymour et al.'s⁴⁵ studies of 39 COPD clinicians and 23 community palliative care nurses, respectively, were particularly concerned that initiating ACP discussions too early might undermine their patient's coping strategies or deter them from participating in self-management activities designed to optimise their condition. COPD clinicians were also unsure when to begin ACP due to difficulties in accurately determining a patient's prognosis.³⁸ Finally health professionals in Robinson et al.'s⁴ work questioned how relevant ACP completed years before death would be in the context of unpredictable illness trajectories and advances in medical treatment.

Uncertainty about who should initiate ACP discussions. Three studies reported difference in opinion about which health professionals were best suited to initiate ACP discussions. This uncertainty led to delays and missed opportunities to initiate ACP. Participants in Gott et al.'s³⁸ and Rhee et al.'s⁴⁸ studies identified GPs as most appropriate to initiate ACP discussions due to their having known the patient the longest. Paradoxically, specialist physicians were also identified as highly appropriate because of their detachment from the patient.³⁸ In Robinson et al.'s⁴ study, a range of clinicians including palliative care specialists, GPs and community nurses self-reported that it was their responsibility to discuss ACP. However, irrespective of whether they had received training, all participants, with the exception of palliative care specialists, felt they lacked the necessary skills.⁴ A lack of confidence, experience, time, training and resources was additional reasons that health professionals felt ACP was outside their role.^{4,10,35,36,38}

Uncertainty about where ACP discussions should be initiated. There was a lack of consensus about the ideal setting for ACP discussion to occur. Although Gott et al.³⁸ and

Rhee et al.⁴⁸ identified the community as the preferred setting, GPs in Gott et al.'s³⁸ study argued that time constraints and patients being acutely unwell restricted their ability to initiate sensitive discussions. This sentiment was endorsed by a small group of patients who described consultations with GPs as being focused only on their acute problems and not their future treatment preferences.³⁷

Setting of care may also be an influencing factor. In hospital settings, noise, lack of privacy and a curative culture were all considered barriers to ACP discussions.³⁸ In contrast, Hu et al.'s⁴⁹ multi-centre questionnaire-based study of 413 health professionals in Taiwan found that working in specialist palliative care compared to oncology was positively correlated with their participation in ACP ($p < 0.001$, 95% CI).

Health professional discomfort with the process of ACP. Minto and Strickland⁵⁰ interviewed six primary care professionals in Scotland and found that the emotive nature of the topic made it difficult for them to facilitate ACP for their patients. Similarly, 55% of the 213 nursing home managers in Froggatt et al.'s³⁵ work reported discomfort with ACP. Oncology nurses in Zhou et al.'s⁴⁶ study also perceived that physicians were reluctant to discuss ACP and delayed the process by focusing on alternative treatment options. Having to navigate dysfunctional family dynamics also discouraged health professionals from discussing ACP.^{35,46}

Communication factors influencing ACP. Palliative care specialists and community nurses in Robinson et al.⁴ and Seymour et al.'s⁴⁵ studies, respectively, reported using patient cues to gauge whether a patient was interested in ACP before initiating discussions. Nurses in Seymour et al.'s⁴⁵ work also identified staff attributes that helped ACP discussions including empathy and awareness of the components of ACP.⁴⁵ However, they also perceived that the traditional power differential between nursing and medical staff impeded the teamwork necessary to implement ACP.

Practical. Four studies reported that health professionals lacked the time and appropriate environments to implement ACP.^{10,35,45,46} Participants in Robinson et al.'s⁴ study said that for many dementia patients, financial and time costs were significant barriers to them legally appointing a surrogate decision-maker.

Health professional attitudes. Staff attitudes to ACP have adversely affected uptake. For example, health professionals in Robinson et al.'s⁴ study questioned its value since they perceived that it duplicated existing patient-centred care. This was echoed by some of the community palliative care nurses in Seymour et al.'s⁴⁵ study who perceived no difference between day-to-day care planning and ACP, and that ACP was simply a set of forms required by legislature. Rhee et al.¹⁰ also highlighted how different

conceptualisations of ACP may have adversely affected its uptake into health systems.

Health service factors influencing the uptake of ACP

Three studies reported an association between the types of medical care patients received, the healthcare setting and rates of ACP.^{13,40,51} In Hirschman et al.'s⁴⁰ study, patients who had an Advanced Directive prior to hospice enrolment were more likely to have discussed specific end-of-life issues such as the use of antibiotics ($p < 0.01$). This result remained significant after controlling for race. Meussen et al.¹³ and De Gendt et al.³⁴ found that patients who received specialist palliative care, or treatment aimed at palliation in the last week of life, were more likely to have undertaken some form of ACP. In a retrospective chart review of 175 deaths by Wu et al.,⁵¹ having received geriatric or general medicine input (AOR: 1.6; 95% CI: 1.1–2.3), or treatment as an outpatient (AOR: 1.8; 95% CI: 1.2–2.6) was also strongly associated with patients having completed an Advanced Directive (95% CI). Similarly, Meussen et al.¹³ found that patients who had contact with their GPs in the last weeks of life (odds ratio (OR): 2.71; 95% CI: 1.7–4.1), or who died at home (OR: 2.16; 95% CI: 1.5–3.0) had higher rates of ACP. However, the previous two studies may not have captured all ACP episodes due to a lack of documentation or to GPs not being aware of ACP completed in hospital. Finally, De Gendt et al.³⁴ reported that nursing home residents who were not transferred to hospital during the last 3 months of life, who died in the nursing home and who had longer lengths of stay were more likely to have ACP documented.

Four studies highlighted reluctance by both health professionals and community members to engage in ACP due to there being inadequate resources to facilitate end-of-life care choices.^{35,41,45,50} Participants in Rhee et al.'s¹⁰ and Froggatt et al.'s³⁵ work also said that not having access to appropriate documents, including existing care plans, impeded ACP. Community nurses in England also reported difficulties in documenting, storing and retrieving ACP information when patients had multiple sets of medical records.⁴⁵

Legal factors influencing the uptake of ACP

In both Australia and the United Kingdom, clinicians expressed uncertainty as to the legal validity and transferability of ACP documentation.^{4,10} As a result, end-of-life care decisions tended to be made 'on the spot' by the physician looking after the patient at the time. For example, 275 Australian intensive care doctors surveyed by Corke et al.⁵² believed that end-of-life decisions were exclusively medical decisions and that ACP wishes only needed to be respected when they concurred with medical opinion. This

study was, however, limited by many respondents giving single-word responses that may not have adequately reflected the complex iterative decision-making processes employed in real-life situations.

Health professionals were reluctant to document a patient's mental capacity regarding ACP, even though they routinely made comparable judgements in clinical practice.⁴ In Taiwan, improved clinician knowledge about decision-making capacity legislature positively correlated with ACP participation.⁴⁹

Participants in Rhee et al.'s¹⁰ study also said that fragmented patient care impeded implementation of ACP due to difficulties in interpreting pre-existing documentation. There were also concerns regarding the legal implications of not correctly following documented wishes and implementing such wishes in potentially inappropriate situations.^{4,10,42}

Discussion

This is the first systematic review of the diverse range of patient, health professional, health system and legal factors that influence the uptake of ACP in palliative care. With regard to patient factors, those with cancer diagnoses continue to achieve higher rates of ACP compared to those with non-malignant life-limiting diagnoses. This is possibly due to clinicians' perceptions of increased reliability in predicting cancer patients' deaths compared to those with non-malignant conditions.⁵³ Increased rates of ACP were also demonstrated in patients who had greater levels of functional impairment and who understood their prognosis was poor. While such findings suggest that assessment of functional status could be a useful indicator to initiate ACP discussions,⁵⁴ they also indicate that ACP discussions tend to occur late in the course of a person's illness. In some cases, such discussions may occur too late for the person to be able to actively engage in the ACP process resulting in missed opportunities to make choices about their end-of-life care. Importantly, the available evidence suggests that patients' desire for end-of-life discussions with their physicians is not associated with being in the late stages of illness⁵⁵ and that individuals can be at different stages of readiness for ACP discussions.⁴²

While understanding a poor prognosis did prompt some patients to engage in ACP, the literature also highlighted complex factors that have hindered its adoption. For example, many individuals had not heard of ACP, and there was a general lack of knowledge about end-of-life care, particularly in the community. Some patients even thought there was not any point in completing ACP since they believed nothing could be done if they were dying. Similarly, some elderly patients thought they did not have the right to plan their own end-of-life care. These examples reinforce the need to raise awareness of ACP, particularly if it leads to improved patient-centred care through informed decision-making.^{56,57}

The literature also highlights uncertainty about ACP among health professionals. In particular, there was a lack of consensus about when to introduce ACP. While clinicians caring for patients with dementia agreed ACP needed to be introduced prior to a loss of decision-making capacity, they also said the time of diagnosis was too early. Similarly COPD clinicians were unsure when to introduce ACP due to difficulties in accurately determining a patient's prognosis, and due to fears that early ACP could undermine patients' physical and psychological coping strategies. The authors, however, observed that COPD clinicians tended to associate 'end of life' with 'terminal' or the last weeks of life and postulated that a broader conception of end-of-life care could enhance ACP. This is an important observation because it reduces the burden on health professionals to identify a single 'ideal time' to introduce ACP and is consistent with ACP being an iterative process applicable throughout the illness course.

This review also revealed that health professionals were concerned about initiating ACP discussions when there were insufficient resources to support patient choices for end-of-life care. For example, due to insufficient funding, palliative care units have limited admissions of patients with non-cancer diagnoses.⁴⁵ In contrast, however, referral to specialist palliative care was associated with increased rates of ACP. Patients who received geriatric or general medicine input, or were treated as an outpatient, were also more likely to have their end-of-life care preferences documented. The findings of this review show that barriers to ACP are more complex than deficits in the knowledge of individuals and instead extend to entire health systems. Accordingly, introducing best practice clinical guidelines, in the absence of changes to health systems, is unlikely to lead to changes in clinical practice.⁵⁸⁻⁶¹ Policy reforms, which include financial incentives for clinicians to engage in ACP, may also be needed.¹⁰ Care needs to be taken, however, to acknowledge the complexity and sensitivities surrounding ACP. Concern about government-led ACP programmes has already been raised by health professionals in the United Kingdom who described such programmes as 'a potentially blunt, one size fits all approach where ACP is reduced to a checklist rather than being carried out using expert clinical judgment'.⁴⁵

The literature also highlighted that legal barriers remain to the widespread implementation of ACP. Health professionals, patients and families all report being confused about the legal status of ACP, particularly as to how it might change their rights and responsibilities, and increase vulnerability to litigation. There was also some evidence in the literature of a concerning trend for some health professionals to override ACP at the clinical juncture when it needed to be observed.^{43,45,52}

Limitations

This review is based on the assumption that engagement in ACP has benefits. The review did not attempt to examine

outcomes from the ACP process. While it is acknowledged that this assumption should be the subject of further critique, the amount of literature on the topic of factors influencing uptake was sufficiently large to necessitate some limitation to the scope of this review. There are also a number of methodological limitations of the included studies that may impact the strength of conclusions. Another limitation of the review is that each of the included studies defined and measured ACP differently. This may produce a degree of over-generalisation in the findings; however, the paucity of literature that examined ACP as an iterative process made it impracticable to exclude studies that measured ACP through legal documentation alone. The literature was also distributed among differing health systems and cultures. While this has benefits for understanding local situations, it creates a potential obstacle to generalising the results. The inclusion of ACP intervention studies may also have uncovered specific factors that helped or hindered their interventions, which may have been supportive of our results.

The quality of studies included in this review varied. Many of the studies used small convenience samples and employed instruments of potentially limited validity and reliability. Moreover, few of the studies based their work on explicit theoretical frameworks and most researchers tended to focus on a limited number of variables.

Conclusion

This review confirms that the contextual factors influencing the uptake of ACP are complex and multifaceted. These factors span the social and cultural beliefs of patients, families, health professionals, and health systems, as well as the structural constraints of our health and legal systems. Accordingly, increasing the uptake of ACP in palliative care is likely to require a multimodal strategic approach. The same factors that affect the uptake of ACP in palliative care are likely to be applicable to non-palliative medicine, whenever decision-making capacity is lost. Nonetheless, before findings can be generalised, larger population-based studies of palliative care patients are required to develop a sound theoretical and empirical foundation to develop interventions that improve the uptake of ACP in this setting.

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Declaration of conflicting interests

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