

Advance care planning: the future

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ABSTRACT

Objectives There is increased global focus on advance care planning (ACP) with attention from policymakers, more education programmes, laws and public awareness campaigns.

Methods We provide a summary of the evidence about what ACP is, and how it should be conducted. We also address its barriers and facilitators and discuss current and future models of ACP, including a wider look at how to best integrate those who have diminished decisional capacity.

Results Different models are analysed, including new work in Wales (future care planning which includes best interest decision-making for those without decisional capacity), Asia and in people with dementia.

Conclusions ACP practices are evolving. While ACP is a joint responsibility of patients, relatives and healthcare professionals, more clarity on how to apply best ACP practices to include people with diminished capacity will further improve patient-centred care.

INTRODUCTION

Advance care planning (ACP) enables individuals to plan future healthcare. Previous studies (predominantly from the USA) have shown that ACP potentially increases discussion frequency about future healthcare, improves alignment of care with patients' goals among various patient populations and increases use of palliative care services.^{1,2} In palliative care, sensitive discussions about wishes and preferences for future care are encouraged. They can help improve better clarity on what should (or should not) be done when someone becomes unable to make his/her own decisions. Doctors or nurses who have known patients for many years are often in an advantageous position to seek views on topics including goals of care, future resuscitation attempts, hospital admission for interventions/investigations, anticipatory medications at home or even location(s) where patients may wish to be in their final days.³

There is greater focus on ACP, including policymakers, evidenced by education

programmes, laws and public awareness campaigns. For instance, since 2011, UK National Institute for Health and Care Excellence (NICE) quality standards on end-of-life care for adults state that people at the end of life should have the opportunity to discuss, record and review their needs and preferences, if they wish.⁴ UK NICE guidelines on care of dying adults state that healthcare providers must record individualised care plan discussions and decisions in a person's record and share the plan with the individual, those important to them and all of the multiprofessional care team members.⁵ Examples of this in practice, for instance, individualised shared electronic patient care plans, are now being reported.⁶

WHAT IS IT?

In 2017, a consensus ACP definition was published in *Lancet Oncology*.⁷ This was the result of a five-round Delphi study, designed by an international task force of 15 experts from eight countries. The European Association for Palliative Care (EAPC) Board commissioned this white paper and the ACP definition:

Advance care planning (ACP) enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.

In this consensus definition ACP requires decisional capacity at the outset. Currently, there are several initiatives that apply existing ACP practices to further include people with diminished and no



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State of the science

Table 1 Barriers to ACP

Patient factors	Professional factors	System factors
Insufficient knowledge about health situation ¹⁰	Hesitance to discuss possible future deterioration with patients, ¹⁰ especially when they appear well ¹¹	Focus on treatment and cure ^{10 11}
Unpredictable course of disease and difficult prognostication ¹⁰	Fear to take away hope ^{10 12}	Lack of coordination and structured approach to ACP ¹⁰
Hesitance to consider/discuss treatment preferences, ^{10 12} for example, due to anxiety and denial ¹¹	Lack of communication training ^{10 11} /skills ¹²	Unclear responsibilities for ACP initiation ^{10 12}
Expectation that doctors initiate ACP ¹¹	Time constraints ^{10 11}	Lack of accessibility of documented goals and preferences ¹¹
	Difficulties to find the right moment to initiate ACP ^{11 12}	Limited resources ¹²

ACP, advance care planning.

decisional capacity. One such example is Wales, where a national strategic task force was set up in 2018, to define and plan an innovative national approach towards ACP and best interest decision-making in palliative care.⁸ Furthermore, a national future care planning (FCP) conference in 2019 discussed how this should be advanced. Agreement was reached to introduce the terminology ‘Future Care Planning’ as an umbrella term to capture both ACP *and* best interest decision-making for individuals who lack decisional capacity from the beginning. This definition was endorsed by the Welsh government and operationalised into national workstreams.⁸ A further initiative of applying ACP practice to those without decisional capacity is the recently launched EAPC Task Force on ‘ACP in dementia’.⁹

BARRIERS AND FACILITATORS

Despite positive evidence for the effectiveness of ACP, the frequency of such conversations between patients and healthcare professionals remains low in clinical practice. Research in chronic respiratory disease showed that while many patients and professionals are interested in ACP, less than a third of patients reported having had such interactions.¹⁰ There may be a discrepancy between expressed interest and the extent to which ACP actually occurs in practice. Research has demonstrated significant barriers (table 1).^{10–12} Recent studies also highlight barriers relate to cultural factors. Non-white ethnicity is associated with lower acceptability of formal ACP, at least in the USA.¹³ ‘Western’ autonomy concepts may not be relevant in Asian cultures, where autonomy is often understood to be relational rather than individual.¹⁴

DIFFERENT MODELS

Current ACP models place stress on it being a process. They vary in the extent to which healthcare professionals play a central facilitator role. Several models are designed to support clinicians, using standardised, structured conversation guides. An analysis of 34 such guides showed they usually focus on an exploration of patient perspectives on illness, living well,

end-of-life issues and decision-making.¹⁵ One example is the ‘Serious illness care program’ in the USA.¹⁶ This centres around a freely available conversation guide.¹⁷ In other models, ACP conversations are held by trained facilitators who are not necessarily clinicians. Internet programmes increasingly support the ACP process, especially the early stages. A good example of an interactive, well-studied and freely available online ACP tool designed to support patients’ engagement is Prepare for Your Care.¹⁸

CORE ELEMENTS OF ACP CONVERSATIONS

We have outlined guidance about core elements of ACP in a logical order of topics to be discussed (box 1). It remains most important that ACP discussions are person centred and adapted to the person’s concerns and questions, and the order and number of topics can be changed, depending on circumstances.

CONCLUSIONS

In essence, ACP is a process of excellent communication: within the family, in the clinical encounter and throughout care pathways. While ACP is a joint responsibility of patients, relatives and healthcare professionals, more clarity on who should initiate ACP may facilitate application in practice. We need to know more about how individuals prefer ACP discussions to be framed and initiated, find better ways to support professionals to initiate ACP conversations and raise public awareness to enable early adoption and reduce differentials in access and uptake across societies.

Development of these goals may catalyse ACP’s full potential: the facilitation of care aligned with patients’ preferences and goals, to the benefit of patients and those close to them. The importance of *patients’* preferences (rather than those of the patient and the family) may unnecessarily exclude those without capacity and restrict ACP to a primarily ‘Western’ activity. Patients without decisional capacity should be brought into anticipatory decisional frameworks more, and when this is not possible, to gather what their views are from friends, family and carers. FCP work in Wales¹⁹ which incorporates both ACP *and* planning decisions for

Box 1 Core elements of advance care planning (ACP)

- ▶ Ensure you help maximise individual's ability to engage in ACP, including hearing aids, translators or other means of facilitating discussion without discriminating.
- ▶ Explore individual's current understanding. Explain the aim, content, barriers and facilitators; consider legal regulations.
- ▶ Explore their readiness to engage in ACP and individualise the ACP process.
- ▶ Explore their health-related experiences, knowledge, concerns and personal values in the physical, psychological, social and spiritual domains.
- ▶ Explore personal goals for future treatment and care.
- ▶ Where appropriate, provide medical information (eg, about diagnosis and prognosis) and pros and cons of possible treatment and care options.
- ▶ Where appropriate, clarify goals and preferences for future medical treatment and care, and check whether these are realistic.
- ▶ Discuss the option of appointing a personal representative (written record) and determine their role (per local legal jurisdiction). Clarify the extent to which the personal representative may participate in medical decision-making when the individual cannot express preferences himself or herself.
- ▶ Notify them about the option of indicating values, goals and preferences in a written document. Encourage them to provide family and healthcare professionals with a copy.
- ▶ Explain that documented goals and preferences can be adapted and changed.

individuals without decisional capacity, current work in Asia (replicating ACP consensus in five Asian countries, with more focus on the role of the family) and current efforts in the field of dementia are providing frameworks as to how this work is now evolving internationally. These initiatives will hopefully generate a more inclusive concept of planning care for the future, with ever-increasing evidence on how best to initiate and embed this practice.

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