Review

Advance care planning and the older patient

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Summary

Making treatment decisions for older people is difficult, because of the complex interplay of their multiple co-morbidities, but also because of the fine balance of risks vs. benefit in any chosen management plan. This becomes even more difficult when they lose the capacity to tell us what they want, and often in such situations we have to rely on information from others in order to make decisions based on their best interests. Advance care planning should help with making these decisions clearer, based on the documented preferences of what the patient would have wanted while capacity was still present. However, such documents are still very rarely used, and even if they are, health-care professionals are often wary of them for the multitude of ethical and legal problems that can arise.

Introduction

Making treatment decisions with older patients can be extremely difficult. It is often necessary to weigh closely balanced risks and benefits, taking into account high likelihood of significant side effects and unpredictable improvements, while bearing in mind multiple existing co-morbidities and complex treatment regimes. However, these difficulties are greatly compounded when older people lose the ability to make decisions for themselves; doctors may then need to make important decisions in patients’ best interests, often with little knowledge of their previous views or wishes.

Advance care planning (ACP) is a way of addressing this problem by documenting individuals’ preferences about health care while they still retain decision-making capacity. Arguably, enhancing patients’ autonomy by allowing them to retain some control over their care, ACP is also expected to help clinicians arrive at decisions based on individuals’ prior preferences.

ACP may be particularly useful in the context of an ageing population, where progressive chronic conditions such as dementia, as well as acute medical conditions such as delirium, can commonly result in loss of capacity. We therefore look at ACP in older people’s care, discussing the potential benefits as well as examining barriers to its use and highlighting a number of important ethical concerns.

What is ACP?

ACP may describe any activity that involves thinking about preferences for future care. An ACP will
normally be a document held by the patient, with copies given to relevant parties such as carers, GPs and solicitors. In the UK, certain aspects of ACP are now defined in statute. The Mental Capacity Act (MCA) 2005\(^1\) codifies existing common law, providing a number of ways in which people can make decisions about health care, which will take effect when they lose capacity:

- an advance statement of wishes is a record of a person's views or wishes regarding future treatment and may also include a general expression of beliefs and values;
- an advance decision to refuse treatment (ADRT) allows the person to refuse particular treatments in advance and has the same legal weight as a refusal by a person with capacity. Where life-sustaining treatment is refused, this has to be clearly and specifically expressed in writing so that professionals know when, and in what situation, the decision is to be applied; and
- a Lasting Power of Attorney (LPA) enables the patient to nominate someone to make decisions on their behalf. Decisions made by that person have the same legal standing as those of the patients themselves (The MCA 2005 now allows attorneys to be appointed to deal with health-care decisions as well as financial affairs.).

None of these approaches can be used to demand a particular treatment; doctors need only provide treatment they deem to be in the patient's best interests.

### Why carry out ACP with older patients?

Currently, few patients are aware of the existence of ACP as a method of documenting preferences in advance of losing capacity. However, when informed of this option, older patients often express an interest in making a plan.\(^2\) Patients are eager to ensure that their wishes will be documented for future reference and feel that this will reduce the burden of decision making placed on their family. Additional reasons for considering ACP for older patients include the following.

**Acknowledging potential loss of capacity**

Loss of mental capacity is common in older people, and becomes more prevalent with increasing age.\(^3\) Older people are more at risk of an array of conditions that might affect their ability to make or communicate decisions, and the increasing prevalence of dementia, estimated to affect one in six of over 80s\(^4\) also has a significant impact. Guidelines recommend that doctors routinely offer ACP to patients who may die of their current condition, or who have a condition likely to result in impaired capacity.\(^5\)

### Autonomy

Respect for patients' autonomy in decision making is a fundamental ethical requirement. It is no longer accepted that doctors routinely make decisions on behalf of patients; this is just as true in elderly care as in any other area of medicine. Without ACP, it is difficult for clinicians to make best interests decisions for patients who lack capacity. Seeking advice from relatives, carers and other professionals may help in coming to a balanced view, but does not supply a clear answer to every dilemma, and may not always guarantee that autonomy is being respected.\(^1\) ACP provides insight into patients' wishes before they lose capacity, and can be seen as an ethically desirable extension of patient autonomy, giving patients some control over their future treatment.\(^6\) Families and health-care professionals can then feel confident that they are acting on patients' explicitly expressed wishes.\(^7\)

### An aid to decision making

Offering clinicians a guide to patients' wishes, ACP is expected to be of substantial assistance in decision making.\(^8\) Geriatricians in the UK found that it clarified situations that would otherwise have been contentious or complex, and also reduced the use of inappropriately high-intensity treatment, and made decisions regarding the move to palliation and withholding treatment of doubtful benefit easier.\(^9\) It also assists end-of-life discussions, helping physicians to reach a consensus with families.\(^9\)

### Relieving family anxiety

It is known that patients generally want to relieve the burden of decision making on their families towards the end of life, and this strongly influences their actions in making ACPs.\(^6,10,11\) Where families are involved in the process, ACP and appointment of surrogate decision makers such as LPAs, has been associated with reduction in stress, anxiety and depression in surviving relatives.\(^12\)

### Resources and justice

ACP also has ethical value in avoiding burdensome, futile and unwelcome interventions. Modern medicine offers a variety of means to prolong life, all of which have associated drawbacks and significant cost. The default position where patient wishes are not known may be to prolong life and embark on costly and invasive procedures.
When, where and how should ACP be carried out?

In discussions about ACP, older people have suggested that the optimum time for ACP is in a period of relative wellness, and that ACP should be part of routine care, perhaps initiated automatically at a certain age threshold. A major concern is to ensure that ACP is carried out while the patient retains capacity; the initial diagnosis of early dementia, for example, may be an appropriate trigger for discussion of ACP. With many patients now cared for at home for as long as possible, addressing ACP on admission to care homes may be too late.

Research suggests that patients prefer specific consultations for ACP, without distraction of other issues. In addition, in order for discussions to be successful and effective, ACP should be a process, occurring over a number of consultations. Professionals who know the patient well, such as general practitioners (GPs) or case managers are likely to be best placed for ACP discussions. However, in some cases, it will be appropriate also to involve the relevant specialist.

Finally, in order for ACP to be most useful, it must be documented and available at the time it is needed; admission to hospital is often an unpredictable event and there is evidence that availability of ACPs in these circumstances is poor. Furthermore, ACPs made in one environment are often not transmitted effectively to others, and there may sometimes be reluctance from health care teams to accept a document that they were not involved in drawing up. A number of proformas exist that may be of help, and some hospitals and hospices have produced their own ACP documents. It has been suggested that a specific proforma for elderly patients might be of additional benefit.

Why do so few older people have ACPs?

Knowledge

When aware of ACP, both patients and doctors are supportive of it, but in practice uptake is low: only 8% of the general public in UK have an ACP. A key problem is lack of knowledge, since neither patients nor clinicians are likely to consider ACP if they are not aware of it. Although patients’ awareness of ACP may be increasing in some areas of USA, the majority of older patients in the UK have still not heard of the concept.

Patients’ assumptions

People in general may have a tendency to think that those close to them know their wishes, and assume that family and carers will follow their preferences, without having carried out ACP or in fact discussed this with anyone. It is possible that these assumptions are a barrier to engagement with ACP.

Clinician discomfort

Even clinicians who know about ACP may struggle to put it into practice. While current teaching and research acknowledge the importance of end of life care, some doctors still feel uneasy discussing ACP. Moreover, many fear that patients will be distressed by such discussions. In fact, older people are generally happy to discuss end of life care, and ACP has been shown to engender hope rather than depression.

Mental capacity assessment

While the MCA 2005 provides a statutory test, assessment of patients’ capacity to participate in ACP may not be straightforward and it has been suggested that this may present a barrier to use of ACP. Patients with whom doctors are considering ACP may be of uncertain capacity, and the significant nature of the decisions involved may make doctors particularly cautious. Nevertheless, patients should be given every chance to participate; capacity is situation specific, so care should be taken to choose the optimal time and environment for assessment.

Can ACP harm patients?

ACP is intended to protect and enhance the autonomy of older people, so clearly it is essential to guard against any possibility that older patients could be persuaded or put under pressure, for whatever reason, to hand over control of their finances, or give another person power to make treatment decisions on their behalf.

ACP should therefore show no evidence of coercion; consent must be voluntary in the same way as in all treatment decisions. However, bearing in mind the fact that consideration of family is a significant factor in making ACPs, the point at which an acceptable degree of influence or persuasion to support an older person’s autonomy becomes unacceptable coercion may be difficult to judge. Clinicians will need to be alert to this issue and assess each situation carefully to ensure
that decisions are made freely and independently by older patients.

In addition, while the purpose of ACP is the discussion of future health-care preferences, there is a risk that professionals will be put under pressure to use ACP as a means of reducing expenditure of health-care resources, particularly by limitation of technologically advanced and expensive life-prolonging treatments. While we acknowledge that health-care costs savings may be a consequence of ACP,25 it is important that this is not the primary motivation.

Some studies have shown that 24–62% of ACPs lack sufficient information to direct care.26–28 In some respects, this can be quite worrying, especially when we are trying our best to follow an ACP in line with a patient's wishes, and correct interpretation of it is variable. If followed incorrectly, we may go against a patient's wishes, contradicting the very purpose of having an ACP in the first place. It is hoped that this will improve as practice of ACP and use of the MCA 2005 becomes more familiar.

**Should an ACP invariably be followed?**

Clearly, the intention of ACP is that the patient's express documented wishes be followed in the event of a loss of capacity, and it should be remembered that an advance decision to refuse treatment is legally binding. However, a number of conflicts may arise.

**ACP vs. patient's current ‘wishes’**

The idea that previously documented preferences should override a patient's current interests may be ethically problematic.9 ACP encourages patients with capacity to predict their preferences when seriously ill, but preferences may change, and it is very hard to gauge how one may feel in circumstances that are different from any previous experience.29 Indeed, patients who are seriously ill are often more willing to consider intervention than they might have anticipated while still well.30

Nevertheless, there does seem to be some evidence to suggest that stability of preferences increases with patients' age31 and that those who make ACPs have more stable views than those who choose not to.30 The point of ACP is not to override the wishes of a patient who is able to express preferences, but to give an indication of the wishes of a patient who is unable to voice any opinion. ACP may not always be 100% accurate, and certainly in older people who have multiple co-morbidities, devising an ACP that takes into account all possible clinical scenarios will be extremely difficult and may not lead to a clear descriptive plan of action in a current circumstance. However, it still serves as a tool for use in situations where there is simply no better means of establishing what the patient wants.

**ACP validity and applicability**

In order to be legally binding, advance decisions to refuse treatment must be ‘valid’ and ‘applicable’. The MCA 2005 gives specific criteria for this,1 also summarized in GMC guidance on end of life care.32 On these grounds, it may sometimes be decided that an advance decision need not be followed. However, it may still be the only available evidence of the patient's wishes, and as such may still be a useful pointer in assessment of best interests. This is similarly true for advance ‘requests’ for treatments, though not legally binding.

**ACP vs. clinician’s judgment**

There may be situations where a clinician’s view of what is appropriate may conflict with the documented wishes of a patient in an ACP. In a recent qualitative study, it found that geriatricians, being the people most likely to encounter ACPs in clinical practice, although positive about its use, felt that unless it was absolutely prescriptive in its use in precise situation and treatment context, would have served to have only limited influence in their decision making.33 Where a conflict between autonomy and beneficence occurs, physicians are at risk of breaching the MCA if a non-ACP-compliant decision is made in the patient's best interests. The GMC advises32 that clinicians in these circumstances may withdraw from providing care, once arrangements have been made for a replacement to take over their role. Withdrawing from care may offer little solace to the clinician who feels that the wrong action has been taken. Yet this could be seen as a simple extension of the kind of logic that allows a competent patient to refuse treatment against clinical judgment.

In life-threatening situations where an ACP has not been made known to the clinical team, or when it cannot be fully verified prior to treatment it may be likely that management in the best interests of a patient will take precedence, before which consideration of ACP can occur.

The central issue is to be as sure as possible that patients’ ACPs (if applicable) are presented as early as possible in any clinical scenario, and are carefully considered in the precise context that is
presented, thought through and discussed with all relevant health professionals, so that the most appropriate course of action can be taken.

Conclusions

ACP is supported by both patients and doctors and has documented benefits in extending autonomy and facilitating decision-making. Though currently under-used, partly through widespread lack of knowledge, it could be a valuable asset in end of life care if routinely discussed with patients by health-care professionals who know them well.

ACP is likely to be particularly relevant for older people, who are at greater risk of conditions affecting their capacity to make decisions. However, specific problems associated with ACP in older persons care do exist, ranging from drawing up a plan that incorporates all potential future clinical scenarios, to the complex assessment of capacity to participate and concerns about coercion. In addition, there may be a greater sense of urgency, in ensuring that discussions take place while patients still retain capacity to decide on their future care.

Continued low uptake of ACP suggests that further education of both public and health-care professionals needs to take place regarding the benefits of ACP. However, it is also essential that professionals have a good understanding of the potential barriers to its use and have these in mind when considering ACP with their patients.

Lastly, physicians should always keep an open mind with regards to the existence of such documents when seeing patients admitted acutely to hospital. It is helpful to ask conscious and competent patients if they have an ACP. Otherwise, if that is not possible, asking the patient’s GP or next-of-kin would be the next best option. If there is no evidence of an ACP then the patient should be treated in accordance with their best interests at the outset, until such information becomes available. There is certainly a push for regional ‘do not attempt cardiopulmonary resuscitation’ policies and guidelines, where patients’ wishes regarding this issue are recorded on a patient held record, which crosses health care interfaces. This could be extended to incorporate ACP documents so that a patient’s wishes will always be available to any health care provider.

Search strategy

PubMed was searched using the terms ‘advance care planning’, ‘living wills’, ‘advance decisions’. Reference sections of relevant papers were also screened, and citation searching of key authors was also performed.

Authors contributions and disclaimers

D.A., B.H. and A.S. prepared the manuscript with critical input from L.K.B., S.P.C. and P.K.M. All authors approved the final version. S.P.C. was one of the lead authors of the Royal College of Physicians’ Evidence-based National Guidelines on Advance Care Planning.

Conflict of interest: None declared.

References


