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ABSTRACT

Reflection, discussion, documentation, and communication about the types of health care wanted at the end of life are core elements of advance care planning. It is inherently related to palliative care with its focus on quality of life and supporting the person's influence over decision-making at their end of life (EoL). The Australian government's ongoing commitment to a National Framework for Advance Care Directives has been confirmed through the National Palliative Care Strategy 2018.¹ The current National Palliative Care Strategy builds on and is informed by both the National Strategy of 2010 and its subsequent 2016 evaluation. In the following we highlight some of the most recent evidence and its relevance to the Australian context.

Definition

The 2018 National Palliative Care Strategy provides the following definitions:

Advance care plans (ACPs) are defined as statements defining "preferences about health and personal care and preferred health outcomes. They may be made by, with, or on the person's behalf, and are prepared from the person's perspective to guide decisions about care."

Advance care directives (ACD) are defined as "a type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult."

Latest ACP Implementation Evidence

Increasing interest in advance care planning is reflected in the substantial increase in systematic reviews published on the topic over the last five years.^{2,3} This is likely to be a response to population ageing and the accompanying increased number of people dying, and also the increasing prevalence of life-limiting chronic illnesses. Most studies of ACP implementation come from high-income western countries, particularly the US, Canada, Australia, and the UK^{2,3} but the quality of evidence remains of concern.^{3,5}

Recent review of 80 systematic reviews noted five main categories of ACP implementation; interventions providing information or educational content; use of decision aids or

communication strategies; interventions specific to a subtype of ACP; specific or specialised forms of ACP; and interventions seeking to improve palliative or EOL care.³ There is evidence supporting many of these approaches to promote increased AD completion, ACP discussions, and documentation of EOL preferences.

However, outcomes were found to vary depending on context and intervention format.³ For example, ACP education and provision of information is associated with increased AD completion but is more effective when combining computer, video, and discussion, and when simultaneously targeting patients and providers.³ Palliative care-based interventions are associated with improved ACP and ACD completion, greater EOL satisfaction with care, and higher proportions of Do Not Resuscitate Orders.³ Across all approaches, ongoing opportunity for patients and family to discuss with care providers is a key element of success.³

Factors that have been identified as barriers to ACP implementation include:^{2,3,4,5}

- complexity of legislation (with consumer confusion raising questions about utility and finality of decisions),
- cultural factors (reluctance to engage with the topic of death, and approaches based on self-determination and autonomy versus familial

decision-making and deference to authority),

- attitudes to death (including death denial and health professional focus on prolonging life), and
- institutional policies (lack of organisational support and access to documents for EoL, insufficient allocation of time, and lack of specific education).

Available high-level evidence emphasises the central importance of applying a “whole-system strategic approach”.³ More specifically, the need for parallel and interconnected emphasis on all elements having influence on ACP implementation: legislation, policy, social and cultural beliefs of people and of organisations and health systems, funding, and availability of a skilled workforce.³ A view supported by recent Australian research.⁵

The Australian Context

Approaches: Many of the approaches to ACP and ACD implementation listed above have been applied in the Australian setting and reported in the published literature.

Prevalence: Based on a 2017 audit of records corresponding to 2,285 Australians aged 65 years and older approximately 30% of health records contained at least one Advance Care Directive.⁶ Completion rates were highest in residential aged care facilities compared to hospitals and general practice, 48%, 16% and 3% of people, respectively. Recent community-based survey of three Australian states found that six per cent had completed an instructional ACD and 12% had appointed a decision-maker (DM).⁷ Strongest predictors of instructional ACD completion were female gender, and personal experience of a major health scare (three times more likely), and for appointing DM this was age over 55 years.⁷

Legislation: This varies across Australia as does the terminology, scope, and specific incorporation of palliative care.⁸ However, in all states and territories legislation relevant to ACD documentation by a competent adult is in place. Not all have a prescribed form for completing this and it is variably referred to as: health direction, advance personal plan, advance health directive, or advance care directive. ACD legislation in some but not all states and territories allows for palliative care.

Conclusion: Variable and complex state and territory legislation and processes across Australia maybe a source of confusion for consumers and health professionals alike.⁵ Australia is a culturally diverse population and the available evidence suggests that a diversity of culturally sensitive approaches to promoting ACP may be more successful. Similarly, a broad approach targeting systems and direct care elements in parallel is likely to achieve greater impact, and a focus on older people and those with experience of a major health event may be useful.

References

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