

How should end-of-life Advance Care Planning discussions be conducted according to patients and informal carers? A systematic narrative review of reviews

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Introduction

- Advance Care Planning (ACP) is intended to ensure that the care people receive during periods of serious and chronic illness is consistent with their preferences and values, at a time when they may be unable to communicate their wishes.¹
- Benefits include improved communication and increased treatment compliance with people's wishes, but findings and quality of research are mixed.²
- Implementation is difficult: ACP represents decision-making procedures and human experiences of dying and death; and occurs in diverse medico-legal and cultural contexts
- **For effective implementation, there is a need for greater understanding of how patients and carers feel ACP discussions should be conducted.**

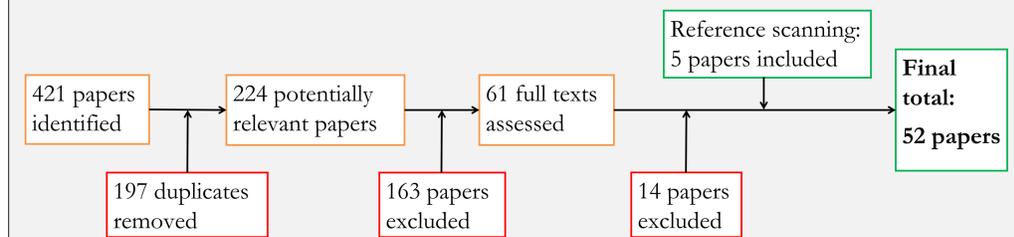
Aim

- To synthesise what is known in the research literature about patients' and informal carers' perspectives on ACP discussions

Methods

- Informed by CLAHRC GM priority-setting work with carers and professionals³
- Search: Cochrane Database of Systematic Reviews; Web of Science; PubMed; CINAHL; PsycINFO (December 2017)* + reference list scanning
- Limits: Peer-reviewed literature reviews published in English since 2007
- Include: literature review of primary research; adopted a systematic search strategy
- Exclude: not possible to identify patient & carer perspectives; ACP with children

Flow of papers through review



Findings so far...

How?   Discussion is difficult and people are often reluctant to start - ACP is emotive, and has legal uncertainties.

 There is a **wide variety of formats**, e.g. documents and computer programmes; supported or self-administered. There is some limited evidence in favour of multimodal approaches delivered with support from health care professionals, but **robust evidence is lacking about patient and carer preferences.**

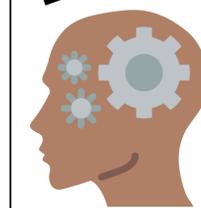
For some groups, such as people with intellectual disabilities, or cancer survivors, **ACP discussions do not seem to take place at all.**

Patients and carers prefer **health care professionals to initiate** ACP discussions. **Good relationships** with health care professionals **are important** – patients and carers want someone who knows their history and who understands ACP.



When?  **Timing may be influenced by the patient's illness.** For people with **dementia**, patients and carers may prefer **earlier** discussions. For **other conditions**, they may prefer to wait until **life-changing events** in the illness trajectory, or when they have a **better understanding** of the seriousness of the illness.

What?



Patients and carers generally **want honesty** about prognosis and options. People may prefer to make practical arrangements for after-death events than think about end-of-life care.

Understandings are influenced by culture e.g. African American and Latino/Hispanic cultures emphasise duty to families, and religious or spiritual beliefs. They are less likely to have had ACP discussions than those who define themselves as white.

Understandings of ACP are influenced by knowledge and experience of illness e.g.:

- Heart failure and chronic obstructive pulmonary disease are not closely linked with dying
- Dementia and chronic obstructive pulmonary disease have unpredictable trajectories
- People with dementia may struggle to imagine the future
- People with chronic kidney disease may fluctuate sharply between desiring survival or not wishing to prolong life.

Patients and carers generally welcome ACP – they report that it gives them **peace of mind**, **decreases worry** about death, and helps them to **feel more in control**. However, patient acceptance partly depends on their values, their understanding of their illness, and the amount of information they can handle. For people with dementia, carers' perceptions in the moment may be more influential than patients' past attitudes and wishes.



Take-home message

Patients and carers generally welcome ACP, but their understandings are influenced by their knowledge and experiences of illness, and their cultural values. Health care professionals should be given the appropriate time and skills to initiate discussions about ACP which are sensitive to individuals' preferences and circumstances, and include strategies for increasing their readiness to engage. This may require a range of methods to help facilitate ACP discussions and enhance patients' and carers' understanding of ACP.

* Keywords included advance care planning, advance directives, living wills, end of life decision, do not resuscitate, review, synthesis