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Evidence *summaries*

Advance care planning for adults with a progressive condition approaching end of life or loss of mental capacity: a systematic mapping review of the evidence

- Advance care planning (ACP) is a voluntary process of discussion about future care for individuals and their care providers. It may include an individual's concerns and wishes, important values or goals, preference and wishes for types of care.
- We searched the international literature and mapped the scope and quality of existing review evidence, along with recent primary studies and cost effectiveness evidence.
- Evidence on ACP for adults with a progressive condition approaching end of life or loss of mental capacity is varied and of mixed methodological quality.
- Most reviews did not evaluate specific interventions; some focused on components of the ACP process, such as decision aids, but provided limited detail. Reviews took a broad-brush approach and detail is lacking on the implementation of ACP.
- There was no overall assessment of possible harms related to ACP in the identified reviews.
- Existing evidence does not address issues important to stakeholders, such as initiating conversations, continuity of care and sharing of information, and the need for skilled facilitation.
- Conducting further general 'meta-reviews' of evidence would not be helpful but high-quality research is needed that: addresses a specific and focussed research question of interest to stakeholders; considers ACP as a complex intervention; addresses and measures relevant outcomes; and evaluates the cost-effectiveness of ACP in the UK.

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Why is this evidence needed now?

Advance care planning (ACP) can be defined as “a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline” (NICE guideline NG142, 2019).¹ ACP is typically used in the context of end of life care or in situations where there is an expectation that people may lose mental capacity to engage in decisions about their care. An ACP discussion might include an individual’s concerns and wishes, their important values or personal goals for care, their understanding about their illness and prognosis, preferences and wishes for types of care or treatment in the future and the availability of such treatment.

The NICE guideline on care and support for people growing older with learning disabilities (NG96)² highlighted the lack of studies evaluating the effectiveness and cost-effectiveness of ACP in this population. We were asked to undertake a rapid review of the wider evidence evaluating ACP for end of life care in a broader population, to inform this research gap and assess the scope of the evidence.

Objective

To undertake a systematic mapping review of the evidence; the aim was to assess the methodological rigour and scope of the existing evidence rather than to extract, evaluate and synthesise findings from individual publications. The focus and scope of the work were informed by patient and public involvement (PPI) and stakeholder engagement and consultation.

Identifying the evidence

After initial scoping searches, comprehensive searching of eight databases was undertaken with no geographic, language or date restrictions. The databases searched were: CINAHL; Cochrane Database of Systematic Reviews; Embase; Epistemonikos; Health Systems Evidence; MEDLINE; Prospero; and Social Care Online.

We identified 92 evidence syntheses, of which 16 failed to meet our minimum methodological criteria. A total of 76 evidence syntheses were

therefore included: 28 evaluating effectiveness only, 37 process and implementation only, 10 evaluating both, and one guideline. Twelve cost-effectiveness articles were identified including three reviews and nine primary studies. We also identified two reviews of reviews and 18 systematic reviews that were ongoing.

In estimating recent primary research activity, we identified 406 primary studies published between 2017 and October 2019 (102 studies published in 2017, 134 in 2018, and 170 in 2019). Of the 170 studies published in 2019: 85 evaluated effectiveness; 72 evaluated process and implementation; and 13 evaluated both effectiveness and process and implementation.

Full details of the project are presented in the Web Report³ available online:

<https://doi.org/10.3310/hsdr-tr-130864>

Mapping the evidence

Evidence syntheses

The reviews identified span a number of years with an increase in publications in recent years; the primary studies included in the reviews date from the early 1990s. There is significant overlap between the studies included in the reviews but it has not been possible to systematically assess the extent of this.

Reviews encompassed a range of methodologies (e.g. quantitative, qualitative, mixed methods, realist); there was also diversity of study designs among the studies included in the reviews. Few RCTs or controlled trials were reported and there was varying rigour across all study designs.

Few reviews reported details of the ACP intervention; this was particularly the case in the qualitative reviews. Where details from the primary studies were provided, these might include a broad range of interventions, but all interventions were combined together in the results.

Across the reviews, participants included patients, carers, family members or surrogates, and health care professionals (e.g. nurses, doctors, care workers, social workers).

Most reviews combined studies with different patient groups, although a number of reviews focussed on patients with specific conditions; the most frequently studied condition was dementia, other conditions identified included cancer, heart disease and kidney disease.

Settings were heterogeneous across the reviews. Most included studies from mixed settings, with few separating findings into specific settings e.g. hospital, nursing home, community or primary care.

There was wide variation in the outcomes reported both across and within reviews; outcome measures used were frequently not reported. Reporting of patient-centred outcomes was sporadic, few reviews reported congruence between patient wishes and care received. Some reviews reported outcomes for carers or family members but this was often lacking. Views of patients, carers and staff were similarly sparsely reported.

There was significant variation in the methodological quality and clarity of reporting. Many of the high quality and well reported reviews provided a clear commentary on the limitations of the included studies and made recommendations for future research to address these concerns.

Economic evidence

An overarching theme from the reviews of economic evidence was the lack of UK-based studies and cost-effectiveness analyses. Identified studies were highly heterogeneous and had serious methodological limitations and applicability to the decision problem; this limits the ability to draw firm conclusions about the economic outcomes associated with ACP.

Primary studies

Of the 170 primary studies published in 2019, few studies were conducted in the UK and the methods used varied widely. Most of these studies included mixed patient populations, while the remaining studies focussed on patients with specific conditions including cancer, dementia, heart disease, HIV/AIDS, liver disease, kidney disease, neurological/ neuro-degenerative and intellectual disabilities.

Discussion

This mapping review describes a large but somewhat confusing evidence base. Many of the identified reviews report a primary evidence base which mainly consists of small methodologically limited studies with often poorly described interventions; these limitations preclude definitive conclusions being drawn from the synthesised results.

Despite the lack of robust primary studies identified in the reviews, there has been a recent proliferation of primary studies. However, a limited assessment of the primary studies published in 2019 suggests that little has changed in the newer studies.

ACP can be viewed as a complex intervention where it is important to understand how the individual components interact to produce outcomes and how changes in complex processes are inter-related. However, much of the research doesn't examine the processes involved or attempt to unpack the issues around individual components. Details of the interventions were very limited and most reviews did not evaluate specific interventions, although some reviews did focus on specific components of the ACP process, such as decision aids and ACP conversations.

Stakeholder and PPI issues

The available evidence does not address many of the issues identified as important to stakeholders at the start of this project. There is little clear evidence looking at the circumstances under which ACP might work, how it should be implemented and understanding the nuances of its components. Most reviews take a broad-brush approach and detail is lacking.

There was no overall assessment of harms; some primary studies may have assessed harm but the reviews did not focus on this as an outcome.

Patients do not always feel empowered to talk and may be waiting for health care professionals to open up conversations. At the same time health care professionals may be less reticent if questions have been asked by patients or their families. The ACP conversation

was one area which some reviews addressed (both general and condition specific) and might warrant further exploration.

PPI advisors also highlighted the importance of ACP conversations, along with the need for advice and support on practical issues. The need for continuity of care and sharing of information was also considered important, as well as the need for skilled facilitation. Outcomes considered important by the PPI advisors were quality of death, and for a carer not to have to bear the responsibility for all decisions and negotiations.

The process and implementation reviews in dementia did cover many of these issues in the outcomes they included, but again the review authors reported on the paucity of available studies and methodological weaknesses. Quality of death was not identified as an outcome. Outcomes from patients, carers, family members and surrogates were included in the reviews but not the dissonance between them.

Conclusions

This systematic mapping review has identified a large number of existing reviews looking at the effectiveness, cost-effectiveness, process and implementation of ACP. The evidence is heterogeneous and of mixed methodological quality. Many review authors note the limitations of existing primary studies and the lack of information on important outcomes. There appear to be ever increasing numbers of primary studies and reviews, but currently these are not addressing the questions of interest to stakeholders.

References

1. National Institute for Health and Care Excellence. End of life care for adults: service delivery. London: NICE; 2019.
2. National Institute for Health and Care Excellence. Care and support of people growing older with learning disabilities. London: NICE; 2018.
3. Thomas S, Claxton L, Wright K, Eastwood A. Advance care planning for adults with a progressive condition approaching end of life or loss of mental capacity: a systematic mapping review of the evidence. Southampton: NIHR; 2020. <https://doi.org/10.3310/hsdr-tr-130864>

What is most important for future research?

- Further high-quality research, considering ACP as a complex intervention is needed. Research should be disease specific and of direct relevance to the UK setting which will take account of provision and access to available services.
- Choice of outcomes is important. Congruence between care received and expressed preferences was rarely reported but is a key outcome, more research is required to construct reliable and valid tools to measure this.
- Further research is needed to evaluate the cost-effectiveness of ACP in the UK. Economic modelling to reflect the complexity of the interventions may be beneficial.
- The methodological limitations of the existing evidence should be addressed in future research. Reporting of studies should be improved, and ACP interventions should be explicitly defined and described in detail to allow assessments of which elements determine ACP effectiveness.
- Conducting further general 'meta-reviews' of evidence would not be helpful. Further synthesis of primary studies may be helpful to address a specific and focussed research question of interest to stakeholders. However, a rapid assessment of primary studies published in 2019 indicated that, as with earlier studies, methodological limitations may preclude definitive conclusions.

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