

Advance care planning

- Advance care planning decisions are becoming increasingly important and advocated as the UK experiences a rapidly ageing population. This briefing examines the evidence for the uptake and delivery of advance care planning in primary care.
- The available evidence for the effectiveness and cost-effectiveness of advance care planning is limited. No direct evidence relating to the delivery and impact of advance care planning on a general population in a primary care setting has been subject to synthesis.
- Limited evidence for care home residents with dementia suggests some potential benefits in terms of reduced hospital admissions and unnecessary use of treatment.
- Imminent Cochrane reviews and updates may shed more light on effectiveness, though disappointingly it appears that these will include only randomised evidence.
- Evidence on interventions to promote uptake and use suggests that verbal information is given over a number of sessions is the best way to enable people to make informed decisions about their preferences for future care before they lose capacity.

This evidence briefing has been produced for Avon Primary Care Research Collaborative by the Centre for Reviews and Dissemination (CRD). Full details of methods are available on request (paul.wilson@york.ac.uk). The content of this briefing was judged to be up to date as of November 2013.

The briefing has been produced as part of CRD core contract funded via the National Institute for Health Research (NIHR). The views expressed in this publication are those of the authors alone and do not necessarily reflect those of the NIHR or the Department of Health.

Background

Advance care planning decisions are becoming increasingly important as the UK experiences a rapidly ageing population, together with increases in the number of people with multiple long-term conditions. NHS spending on end-of-life care is expected to rise by £5bn to £25bn by 2030.¹

The NICE end-of-life care quality standard (QS13; November 2011) defines end-of-life care for adults (18 years and older) with advanced, progressive, or incurable conditions who are approaching the end of their life and are expected to die within the next 12 months. The definition also includes adults with existing conditions who are at risk of dying from a sudden acute crisis in their conditions, or those with life-threatening acute conditions caused by sudden catastrophic events.

Advance care planning is a specific component of end of life care. This being a process of discussion between a patient and professional carer, which may include family and friends, leading to a statement of preferences for future treatment and care, and/or advance decisions (sometimes referred to as an advance directive or living will, which can be legally binding). Advance decisions provide informed consent for refusal of specific treatment if the person is not competent to take this decision in the future.²

A recent study conducted in the south west of England showed that advance care planning in the hospice setting helped patients achieve their preferred place of death, resulting in associated reductions in number of hospital days and hospital costs in the last year of life.³

The Bristol CCGs have requested an evidence briefing to support decisions in relation to the delivery of advance care planning and the potential effect of this intervention in reducing hospital admissions; costs associated with unnecessary treatment; and the chance of the elderly dying in hospital against their wishes.

Methods

This briefing is a rapid appraisal and summary based mainly on existing sources of synthesised and quality-assessed evidence, primarily systematic reviews, health technology assessments and economic evaluations. It is not a systematic review and we have not carried out exhaustive literature searches for primary studies. The scope of the briefing is as follows:

Population: Elderly people approaching end of life, excluding those receiving palliative care or those involved with assisted dying.

Intervention: The intervention of interest is advance care planning. Other relevant terminology might include advance directive (which is a distinct aspect of advance care planning) or end of life discussions.

Comparator: Standard care or a less structured form of advance care planning.

Outcomes: Unnecessary hospital admissions, unnecessary treatment, and reducing the chance of the elderly dying in hospital against their wishes.

Systematic reviews and economic evaluations have been identified by searching the following sources:

- DARE (quality-assessed systematic reviews of interventions)
- Cochrane Database of Systematic Reviews
- NHS EED
- CRD HTA database.

Selected websites to locate any reports of relevant evaluations in UK settings were searched as follows:

- Kings Fund
- Nuffield Trust
- NICE/NHS Evidence
- NIHR SDO/HSDR Programme
- RCGP
- BMA
- www.endoflifecare.nhs.uk

Effectiveness

A small but reliable systematic review has evaluated advance care planning interventions for elderly people with cognitive impairment and dementia.⁴ Advance care planning was undertaken by medical staff, nursing home staff, and social workers in four studies conducted in North America and Australia. The limited evidence found significant reductions in hospitalisations and increases in use of hospice services for intervention groups; increased documentation of care preferences was also found. The authors appropriately concluded that as fewer than 40% of all participants were judged as having the capacity to make decisions, advance care planning may best be carried out prior to nursing home admission, and before cognitive function is lost.

Three relevant Cochrane protocols exist.⁵⁻⁷ Full systematic reviews are expected from early 2014 onwards. All protocols propose an evaluation of advance care planning interventions (one in the general population, due to be completed early 2014; one in patients with advanced chronic kidney disease and using haemodialysis; and one in patients with end stage kidney disease), with primary outcomes relevant to this briefing including: treatment use, hospital admissions, hospital death and pain. Disappointingly, the only completed Cochrane review⁸ is an 'empty' review focused on the effects of end-of-life care pathways in the general population. Of particular interest to this briefing are the secondary outcomes assessing uptake of advance care planning, cost of care and treatment use. The review is currently being updated and is due for completion by the end of 2013.

A scoping review critically described evidence relating to advance directive decision making among independent community-dwelling older adults.⁹ Among 17 studies in the review that explored barriers to completing advance directives, there were five randomised controlled trials. These focused on the provision of educational materials, with or without clinical and/or legal input, and generally found no differences in advance directive completion rates.

Cost-effectiveness

NHS Improving Quality facilitated an economic evaluation (published in May 2013; to be reviewed in May 2014) of early implementer sites relating to the Electronic Palliative Care Co-ordination system (EPaCCS). The system is designed to support the co-ordination of care, including support for conversations about end of life care wishes. Users had to undertake training in advanced care planning before they received their system login details. Data analysed from four early adopter sites revealed health care cost savings arising from increased numbers of people dying in their usual place of residence.

Of particular interest to this briefing is the reported independent data analysis from the south west of England.¹⁰ Hospital deaths in the area (covering 1.9 million people) relating to people transferred to EPaCCS were below 10% (compared to the England average of 54.5% between 2008 and 2010). This equates to cost savings of £47,952 per 200,000 population per annum (using £399 per saved death in usual place of residence), or £177,900 per 200,000 population per annum (using £1,480 as the average cost of a hospital admission ending in death).

A wider review¹¹ contained one economic evaluation relevant to this briefing¹²; a randomised controlled trial comparing usual practice with the *Let Me Decide* advance directive programme. *Let Me Decide* provided various choices relating to life-threatening illness, cardiac arrest and feeding for elderly people in Canadian nursing homes. Although cost data from 1997 are out-of-date, results highlight that it is possible to reduce the number and length of hospitalisations (and therefore health care costs) through the expressed preferences of residents to remain in a nursing home as opposed to inpatient care. Total number of hospitalisations in the intervention homes was 143 compared to 290 in control homes. There were no significant differences between groups on mortality or the residents' satisfaction.

Educational / training interventions

Training programmes relating to end of life care planning have been evaluated in a recent systematic review.¹³ This set out to evaluate the impact of three interventions including the Gold Standards Framework in relation to provision of end of life care in UK nursing homes. Although the review suggests quality the Gold Standards Framework programme has increased the use of advance care planning, this conclusion is based on two before and after studies of limited quality.

An overview of seven systematic reviews containing mixed methods considered interventions specifically to increase the completion rate of advance directives. Among the wide range of interventions evaluated, the authors concluded the most effective method was a combination of informative material and repeated conversations between patients and health care professionals over clinical visits, and with interactive opportunities.¹⁴ Of particular relevance to this briefing are two included systematic reviews contained in the overview. The first review¹⁵ contained 10 RCTs and focused on the elderly, showing that provision of written materials in addition to interactive seminar increased the completion rate of advance directives by at least 45%. Additionally, the review concluded that the best professional to deliver advance directive programmes depended on the mode of delivery, complexity of advance directives, settings, and target populations. The quality of included trials was not assessed.

The second review of 55 studies¹⁶ evaluated the effectiveness of interventions to promote the use of advance directives in older adults. Though not clearly described, the

interventions were delivered by nurses, clinicians, social workers and multidisciplinary teams in the outpatient setting. Advance directive completion rates were increased significantly when verbal information was given to patients over a number of sessions. The quality of included studies was not assessed.

User experience

A systematic review of qualitative studies has investigated attitudes of patients and healthcare professionals to advance care planning discussions with frail and older people. The review highlighted the disparity between patients generally finding timely discussions welcome, and healthcare professionals feeling limited to engage in discussion due to time pressures and the absence of a precipitating event. Other barriers to discussions included the reluctance of family members to engage in the process, passive expectations about decision-making and uncertainties about the trajectory of illness.¹⁷

Communication issues were highlighted in two systematic reviews of mixed methods. The first included 14 studies of satisfactory quality. Facilitators of successful end of life care discussions for patients with non-malignant respiratory disease were style and content of communication, determining patient preferences, balancing realism and hope for the patient and involving the relevant health professional.¹⁸ In the second review the importance of professional training and education and measures to facilitate patient understanding were identified as factors to facilitate care planning across a range of life-limiting illnesses.¹⁹ The quality of included studies was not assessed.

Service user perspectives of advance care planning have been explored in two systematic reviews of mixed methods.^{20,21} The review focussing on children is less relevant to this briefing. In terms of elderly people with dementia, the second review suggested that timing of advance care planning interventions may be critical in this particular population, given the degenerative nature of the disease. However, the quality of the included studies is low.

The only review focusing solely on health professional perspectives on the use of advance directives²² showed that successful implementation was hindered by fears about the purpose of advance directives and conflicting support for legally binding documents. The review combined studies of mixed methods and their quality was not assessed.

Funded by the NIHR HS & DR programme, qualitative research evaluating patient and professional experiences of the initiation of advance care planning in community care settings is ongoing and due for completion in February 2015.²³

Implications

The available evidence base for the effectiveness and cost-effectiveness of advance care planning is limited. No direct evidence relating to the delivery and impact of advance care planning on a general population in a primary care setting has been subject to synthesis. Imminent Cochrane reviews and updates may shed more light on effectiveness, although disappointingly it appears that these will include only randomised evidence.

Limited evidence for advance care planning with care home residents with dementia suggests some potential benefits in terms of reduced hospital admissions and unnecessary use of treatment.

Evidence on interventions to promote uptake and use suggests that verbal information is given over a number of sessions is the best way to enable people to make informed decisions about their preferences for future care before they lose capacity.

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