Advance end-of-life healthcare planning in an acute NHS hospital setting; development and evaluation of the Expression of Healthcare Preferences (EHP) document

Rebekah Schiff1, Rory Shaw2, Nadia Raja3, Chakravarti Rajkumar4, Christopher J. Bulpitt5

1Department of Ageing and Health, Consultant Physician, St Thomas’ Hospital, London SE1 7EH, UK
2Medical Director, Hammersmith Hospitals NHS Trust, London W12 ONN, UK
3Specialist Registrar, Hammersmith Hospitals NHS Trust, London W12 ONN, UK
4Professor of Geriatrics and Stroke Medicine, Brighton & Sussex Medical School, Royal Sussex County Hospital, Brighton BN2 5BE, UK
5Emeritus Professor of Geriatric and Cardiovascular Medicine, Care of the Elderly, Imperial College, Hammersmith Hospital, London W12 ONN, UK

Address correspondence to: Dr R. Schiff, Department of Ageing and Health, Consultant Physician, 9th Floor, North Wing, St Thomas’ Hospital, London SE1 7EH, UK. Tel: 020 7188 2086; Fax: 020 7928 2339. Email: rebekah.schiff@gstt.nhs.uk

Abstract

Objective: design and evaluate a document to enable older inpatients in an NHS hospital to discuss and record end-of-life healthcare preferences.

Design: user and professional collaboration to design the Expression of Healthcare Preferences (EHP). Prospective questionnaire survey and outcome evaluation.

Setting and Participants: inpatients on wards for older adults in a London NHS Hospital Trust.

Results: the EHP consists of a form and explanatory booklet. 95 patients (mean age 81, median MMSE 28) received the EHP. 61 (64% (54–74%)) read the EHP and 29 (48% (35–61%)) of these recorded their healthcare preferences in the EHP form. The form prompted end-of-life care discussions between 43% (30–57%) of these patients and medical staff and between 52 (38–65) of these patients and “those close to them”. The EHP was highly rated: on a score of 1 to 10 it was thought to be helpful (median score 8), interesting (8), informative (8) and reassuring (7) but not upsetting (1).

Conclusion: the EHP is an end-of-life advance healthcare planning tool that we have shown can be used to prompt older inpatients to discuss and record their end-of-life healthcare preferences.

Keywords: elderly, advance care planning, Mental Capacity Act, end-of-life care

Introduction

Advanced care planning (ACP) is increasingly accepted as a way of providing patient-centred care particularly at the end-of-life [1–3]. Methods to facilitate this process are underdeveloped in the UK. Here we describe the development and evaluation in terms of utilisation and acceptability to older inpatients of a generic ACP tool in an acute NHS hospital setting.

Method

The study was conducted in two phases.

Phase 1: Development of an ACP tool called the Expression of Healthcare Preferences (EHP)

Using information gathered from the relevant literature [3–10] a first draft of the document was written. This was revised following consultation with two groups of older adults from an older person’s medical out-patients clinic and the local Better Government for Older People (BGOP) reading group and related professionals: geriatricians, a medical director, an oncologist, a palliative care physician and the Patient Advisory Liaison Service. Formal legal advice was provided by a medical lawyer.

A Patient Information Pack (PIP) containing a standard hospital literature and the EHP was created as
Figure 1. Outcome of Expression of Healthcare Preferences (EHP) documents offered to patients.

a vehicle for delivering the EHP to patients on the wards.

A new section was added to the case notes for the filing of completed EHP documents. An electronic tag was added to the Hospital’s computer record system to identify patients with documented preferences.

Phase 2: Evaluation in the hospital setting

A prospective questionnaire survey was conducted. In-patients over 60 years old in elderly care wards (3 acute, 2 rehabilitation) in two acute hospitals with a Mini Mental State Examination score (MMSE) [11] of 23 or above who were medically stable and spoke English were offered the PIP containing the EHP. A research nurse or one of the authors returned prior to the patient’s discharge to ask them to complete a feedback questionnaire (Appendix 1, available as supplementary data at Age and Ageing online) on the pack. Completed EHPs were photocopied to ensure the patient, case notes and research office held copies. A letter was sent to the GP notifying them of the existence of the EHP.

The project was approved by Hammersmith Hospitals NHS Trust Ethics Committee.

Results

The EHP

The EHP consists of a form and an explanatory booklet (Appendix 2, available as supplementary data at Age and Ageing online).

The form has sections entitled ‘About me’, ‘Informing myself and others about my health’, ‘My medical treatment preferences’, ‘Disability and medical treatment preferences’, ‘Other medical preferences’ and a punch-out alert card. The document states that it is not a legally binding advance directive to refuse treatment.

Evaluation

Ninety-nine people were offered the PIP containing the EHP, one person declined and three were excluded from the evaluation due to deterioration of their medical condition (2) and cognitive impairment (1). Data are on the remaining 95 people whose mean age was 81 years (range 62–97) and MMSE 28 (range 23–30).

Of these fifty-one (54%) were females. Figure 1 shows what happened to the PIPs. At least 64 information packs were opened and 61 people (64%, 95% CI 54–74%) read the EHP document.

Number and content of completed EHPs

Twenty-nine patients (48% (CI 35–61%) of those we know read the EHP) completed the form recording their healthcare preferences. Their median MMSE was 28 (range 25–30). Eleven completed the form after discussion with medical
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staff, nine after discussion with those close to them and seven without consulting either. Only one person discussed the form with both those close to them and medical staff before completing it.

Four completed forms demonstrated some inconsistency in preferences favouring clinically unworkable combinations of active and palliative care options. Three of these nominated a relative who knew their preferences potentially enabling resolution of this inconsistency should the EHP form become relevant to future care. The third form was only partially completed and not signed rendering it invalid. Hence, 28 patients (46% of those who read the EHP and 30% of those who received the PIP) completed valid EHP documents.

The section on treatment preferences at the end stage of a terminal disease was completed by all (p. 6, Appendix 2, available as supplementary data at Age and Ageing online). Twenty-six people completed the table concerning treatment choices in the context of increasing disability (pp. 9–10, Appendix 2). Twelve chose the least active option ‘if I have this disability I do not have a strong wish to be kept alive at all costs, my priority would be to be kept comfortable’ for all levels of disability. Five chose ‘if I have this disability I would welcome all reasonable treatments to keep me alive’ for all options. Eight people progressively changed from the active to the less active option as the disabilities increased in number and/or chose the least active option for the dementia scenarios. One patient answered inconsistently (see above). Twenty-three patients recorded the name and contact details of a person who knew their healthcare preferences.

Patient feedback

Fifty-six people completed at least part of the feedback questionnaire. As a result of the EHP, 24 patients (43%, CI 30–57%) had discussed their future healthcare with members of the medical staff and 29 (52%, CI 38–65%) with ‘those close to them’. Forty-seven (84%) patients felt the EHP addressed an area of healthcare that was important. Supporting comments included ‘Everyone should be able to say what they want before they lose their marbles’ and ‘You have to make plans so that you can die peacefully’.

Seven (13%) of those who did not complete the form said that they were taking it home to consider it further. Twenty-eight people (50%) not wishing to complete the form reasoned that the content was not relevant to their care or that they did not wish to address end-of-life issues.

Patients rated the EHP on a scale of 1–10 where 1 was ‘not’ and ‘10’ was extremely. Median scores (inter-quartile range) were for helpful 8 (6–9), interesting 8 (6–10), informative 8 (7–9.25), reassuring 7 (4–8) and upsetting 1 (1–4) (Figure 2). Four patients commented that the form was quite long and involved a lot of reading.

Discussion

To our knowledge this is the first project to design and evaluate a document to aid advance end-of-life healthcare planning for older adult in-patients in an acute NHS hospital trust. Our data demonstrate that patients read the EHP and found the information helpful, interesting and informative without it causing distress. It prompted many to discuss end-of-life issues with those close to them and medical staff and one-third choose to record their preferences using the document.

Our ACP system was designed to ensure that patients were free to choose if, when and with whom they read the EHP and hence whether or not they wished to address these issues. This approach was effective with two-thirds of patients reading the EHP and one-third completing it. This compares favourably with ACP systems reported elsewhere, which often involve more complex and labour-intensive methods [12–15]. Factors that may have
influenced this include a population with little experience of ACP, endorsement by the NHS Hospital Trust, the setting where patients had witnessed others in situations described in the EHP with patients recovering from a recent illness possibly being more receptive to considering their end-of-life healthcare and the involvement of older people in the development of the EHP.

Inherent in such a system is the risk that patients who lack capacity or have depression might complete the EHP form. We only offered the PIP to patients with a MMSE above 22. The likelihood of a patient having capacity to make healthcare decisions decreases with decreasing MMSE, particularly once the MMSE score is 20 or less. [16]. This was therefore used as a surrogate capacity marker as it was available in the case records.

Despite relatively little medical advice almost all completed EHPs recorded consistent preferences for treatment options, and many people recorded details of a person to represent their views. Completed EHPs therefore provided much information to aid potential future best interests decisions as described in the Mental Capacity Act [2].

Since this was not a randomised controlled trial we cannot be sure that the EHP was the reason why so many of the patients discussed and recorded their end-of-life healthcare preferences. However, previous data in the same healthcare setting found that none of the in-patients had recorded their healthcare preferences or a person who could represent his or her views [10].

We have little knowledge of the views of those who did not complete the feedback questionnaire. These patients may have felt negatively about the EHP. However, two patients discharged prior to completing the feedback questionnaire felt positively about the EHP since they returned completed EHP documents to the hospital after discharge.

Further research is now required with the EHP to determine its utility and economic implications in other healthcare settings and populations and whether completed EHPs influence subsequent best interests decisions for those who lose capacity.

Conclusion

The EHP is an end-of-life advance healthcare-planning tool that is acceptable to and can be successfully used by older inpatients.

Key points

- Few older people in the UK record their end-of-life healthcare preferences or nominate a person that could speak on their behalf.
- The Mental Capacity Act 2005 enforces the need to seek written evidence of a person’s preferences when making decisions under the principle of ‘best interests’.
- This study describes a document called the Expression of Healthcare Preferences (EHP) that has prompted almost half the inpatients that read it, to record their end-of-life healthcare preferences and nominate others to represent them.
- This document could be used in other NHS hospital trusts to aid implementation of the Mental Capacity Act.

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Conflicts of Interest

None.

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Supplementary data

Supplementary data are available at Age and Ageing online.

References

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