

Implementation of a quality improvement programme to support advance care planning in five hospitals across a health region

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Abstract

Objectives

Advance care planning (ACP) can help patients with a terminal illness to prepare for the end of their lives. This report describes a regional service improvement initiative to increase the identification of hospital inpatients at this stage in their illnesses and to increase the number of such patients who are offered the opportunity to start the process of ACP.

Methods

Data were collected prospectively over a 7 month period from four acute hospital trusts and a specialist cancer centre in the South West London region. Each unit identified a specific patient population who were screened for eligibility to engage in the process of ACP. Data were recorded concerning the reasons for eligibility, the suitability for discussion and the various reasons why patients did not complete the process, were recorded.

Results

Over a 7 month period 1980 patients were screened and 559 (28.2%) were found to be potentially eligible for an ACP discussion. Of these 227/559 (40.6%) were deemed suitable for a discussion by medical staff. The majority of these patients (195/227; 86%) were offered the opportunity to undergo ACP discussions and 144/195 (73.8%) agreed to begin the process of ACP.

Conclusions

This report shows that a targeted approach can result in increased uptake in the number of patients who engage in ACP. However, systematic identification of potentially eligible patients requires a significant investment of clinical time and resources.

Background

Advance care planning (ACP) is a voluntary process that enables an individual who has the capacity to anticipate how their condition may affect them make decisions, and choices about their future care, and communicate them so that they may be cared for as they would have wished should they lose capacity as their illness advances(1). ACP has been shown to have benefits in many areas of patient care including symptom control, improving patient autonomy and choice, establishing preferred place of care and “do not attempt resuscitation” decisions (2) (3) (4) (5) (6).

In 2010, in response to the national end-of-life care strategy, the South West London (SWL) Cluster Commissioners for Acute Care proposed a local “Commissioning for Quality and Innovation” (CQUIN) initiative¹ with the purpose of increasing the number of patients who were identified as approaching the end-of-life and offering them the opportunity to engage in ACP discussions. Under the terms of the CQUIN each participating hospital received additional income if they developed clinical services to facilitate patients engaging in ACP. The financial rewards for each hospital were contingent upon producing evidence that the necessary processes had been put in place to increase the number of patients being offered ACP discussions, not on the number of patients who actually agreed to participate in such discussions. This report describes the process of introducing this CQUIN and documents the barriers that were encountered in identifying, approaching and engaging patients in the process of ACP.

Methods

Settings and population

Five hospital trusts (three district general hospitals, a teaching hospital and a specialist cancer unit) participated in the CQUIN. Although the overall objective of the CQUIN was the same across the region, individual trusts adopted different strategies for identifying patients who might be suitable for ACP discussions. The patient groups who were targeted, the screening methods employed and the eligibility criteria at each site are summarised in Table 1. Two of the trusts had previously participated, to varying degrees, in the Gold Standards Framework (GSF) Acute Hospitals programme (7).

Evaluation procedures

After preliminary screening, potentially eligible patients were assessed to determine whether it was appropriate to approach them about ACP. The assessment was made either by specialist palliative care teams or the treating clinical team as decided by local clinical practice. Patients were deemed unsuitable for ACP if they lacked capacity, had insufficient cognitive function or if it was deemed by medical staff that discussion about end-of-life issues would cause undue distress.

¹Commissioning for Quality and Innovation (CQUINs) are NHS Institute for Innovation and Improvement frameworks designed to produce improvements in local healthcare practice. Achievement of certain pre-determined clinical outcomes is related to financial payment or penalty depending on the format of the individual CQUIN project (18).

If patients were deemed approachable they were offered the opportunity to engage in an ACP discussion. These discussions were undertaken by the specialist palliative care teams or the treating clinical teams as decided by local practice. The extent and complexity of the discussions varied with the individual patients. An uniform practice was not adopted across the five trusts. Some patients simply agreed to be included on a locality register (eg a General Practitioner (GP) GSF register), or consented to the creation of a Co-ordinate my Care (CMC) palliative care electronic record (8). Other patients expressed wishes about their preferred place of care and/or death and/or their wishes about being re-admitted to hospital again. Some patients completed specific written ACP documentation, and in other patients all communications were verbal and patients' wishes were subsequently recorded by staff in medical notes and communicated to their GP after discharge from hospital.

All of the hospitals (except Kingston Hospital) kept a record of the total number of patients screened for potential eligibility for the CQUIN. Each hospital palliative care team kept anonymised records of the number of eligible patients and their progress through the ACP process. At the end of the year the databases were collated by one of the authors (GS). Since the number of screened patients had not been collected prospectively at Kingston Hospital, this information was estimated retrospectively from hospital admission statistics.

Collection of other patient characteristics was not routinely recorded across all sites on the CQUIN databases (as they were not required for reporting purposes), thus data such as age, sex and primary/index diagnosis of the patients is not available.

Ethics Approval

This was a service improvement project and thus research ethics committee approval was not required or sought. All data were anonymous.

Results

Data collection started on each site at slightly different times and complete data for all sites was only available for the 7 months from 1st August 2011 to 31st March 2012. A summary of the patient flows across the five hospitals is shown in Figure 1. Across the five sites 1980 patients were screened for suitability to undergo ACP, (Croydon University Hospital 290, St George's Hospital 431, Epsom and St Helier National Health Service (NHS) Trust 482, Royal Marsden Hospital 173, Kingston Hospital 604). Of those, 559 (28.2%) were potentially eligible for an ACP discussion and 227/559 (40.6%) were deemed approachable by medical staff. The most common reasons why patients were considered "unapproachable" were as follows: cognitive problems (n = 122), clinically inappropriate (n = 89), lacking capacity (n = 78), likely to cause distress (n = 70), impaired consciousness (n = 36) or other reasons (n = 30). More than one reason could be applied to each patient. No further information was available to the authors when 'other' was recorded.

A total of 195 out of 227 approachable patients (86%) were offered the opportunity to undergo ACP discussions. The most common reason for not offering a discussion to suitable patients was that they were discharged from hospital too quickly.

Most patients 144/195 (73.8%) who were approached agreed to begin the process of ACP. Patients who declined to engage in ACP discussions were not obliged to give a reason for their decision and

none was recorded. Only 86/144 (59.7%) of patients who engaged in ACP survived their hospital admission to discharge.

Discussion

Statement of principal findings

Over a 7 month period 1980 patients at five different hospitals were screened, with 559 (28.2%) deemed to be in the last months of life and therefore potentially suitable for ACP under the terms of the CQUIN. Only 144 (7.2% of the total screened) actually started the process of ACP, and of those only 108 (5.4%) survived their hospital admission and were discharged. Many potentially eligible patients were unsuitable for ACP because they were too ill, lacked capacity or clinicians judged that discussion of end-of-life issues would be clinically inappropriate.

Relation to other studies

Previous studies have reported the benefits of ACP to various groups of patients (3) (4) or have evaluated the views of healthcare professionals about ACP and reflected on the suitability of payment for quality improvement in the field of palliative care (9). The GSF Acute Hospital Phase 2 evaluation described the beneficial effects of this programme in terms of improved staff knowledge and confidence and in the numbers of patients undertaking ACP. However, the evaluation did not report on the proportion of patients who were eligible, approachable or agreeable to participate in the process of ACP (10).

A randomised controlled trial by Detering and co-workers (2) reported that ACP can result in significant improvements in end of life care, including patient and carer satisfaction and reduced psychological morbidity in surviving relatives. In Detering's study, which was undertaken at a single large teaching hospital, 35% (309/871) of elderly patients admitted under internal medicine, cardiology or respiratory medicine were potentially eligible to undergo ACP discussions, and 80% (125/154) of those allocated to the intervention were actually able to receive it. This suggests that 28% of elderly patients (ie, 80% of 35%) admitted to an acute hospital ought to be able to engage in advance care planning. In contrast our experience was that only 7% of patients admitted to care of the elderly, respiratory and GI cancer services across five hospitals were able and agreeable to participate in such discussions. A number of factors may explain the discrepancy between these figures including differences in case-mix and recruitment settings. However, it is also important to recognise that recruitment rates in randomised controlled trials may not always reflect take up rates of the same intervention in routine clinical practice. Our data suggests that, outside of the context of a clinical trial, the proportion of patients admitted to acute hospitals who are willing and able to engage in ACP may be relatively low.

Strengths and weaknesses

A strength of our study was the multi-centre nature and ecological validity of the data. The service improvement initiative on which this report is based was locally devised but was in keeping with the national End of Life Care Strategy (11). As such our experiences are directly relevant to other acute hospitals in England and Wales.

One of the limitations of our evaluation was that the service improvements introduced at each centre were slightly different, and data collection processes between sites were not entirely consistent. As a result the number of patients who were screened for eligibility at the Kingston site had to be retrospectively estimated using hospital admission statistics. Although a common coding was adopted for why patients were deemed (for instance) to be unapproachable, no auditing was undertaken to check for consistency of coding across sites, to find missing data or to clarify the meaning of “other” responses.

Meaning of the study

We found that systematic identification of potentially eligible patients required a significant investment in terms of clinical effort. We did not record how many clinician hours were invested in identifying potentially eligible patients or in informing them about ACP. However, our data suggest that for every 100 patients screened for suitability only 7 patients actually proceeded to engage in an ACP discussion.

Unanswered questions and future research

Our results should be regarded as a “pilot evaluation”. In the next 2 years (2012-2014) the South West London (SWL) Cluster Commissioners for Acute Care have supported the roll-out of this ACP CQUIN initiative across an increased range of hospital wards/specialties, with a wider remit to include discussions with proxy decision makers when appropriate, and an emphasis on increasing the numbers of patients with palliative care electronic communication records. This has required a considerable investment in education and training for generalist staff. Further evaluations of the implementation process will be required in order to assess how this service improvement initiative is delivering better patient care in a cost-constrained environment.

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Contributors:

PS, JW, MM, AW, LK and DS contributed to the planning and conduct of the study. GS was responsible for data management and analysis. All authors contributed to the writing and approval of the final manuscript. PS acts as the guarantor of the study.

Competing interests:

Participating trusts received payments under the CQUIN scheme for identifying suitable patients and offering them the opportunity to start the process of advance care planning.

Ethics approval:

This was a service improvement project and thus research ethics committee approval was not required or sought. All data were anonymous .

References

1. Advance Care Planning. National End of Life Care Programme. [Online] [Cited 22nd December 2013] Available from <http://www.endoflifecare.nhs.uk/care-pathway/step-2-assessment,-care-planning-and-review/advance-care-planning.aspx>
2. Detering K, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345
3. Kirchoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a Disease Specific Advance Care Planning Intervention on End-of-Life Care. *J Am Geriatr Soc.* 2012;60:946-950.
4. Kevin P, Janssen DJA, Randall CJ. Advanced Care Planning in COPD. *Respirology.* 2012;17:72-78.
5. Dunlay SM, Swetz KM, Mueller PS, Roger VL. Advance Directives in Community Patients with Heart Failure. *Circ Cardiovasc Qual Outcomes.* 2012;5:283-289.
6. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association Between Advanced Directives and Quality of End-of-Life Care: A National Study. *J Am Geriatr Soc.* 2007;55:89-194.
7. National Gold Standards Framework Centre. Acute Hospitals Training Programme. [Online] [Cited: 14th December 2013] Available From <http://www.goldstandardsframework.org.uk/acute-hospitals-training-programme>
8. Co-ordinate My Care. <http://www.coordinatemycare.co.uk/>
9. Hannon K, Lester H, Campbell S. Recording Patient Preferences For End-of-Life Care as an Incentivized Quality Indicator: What do General Practice Staff Think? *Palliat Med.* 2012;26:336-341.
10. National Gold Standards Framework Centre. Phase 2 GSF Acute Hospital Programme Evaluation – Final Report. [Online] [Cited: 14th December 2013] Available from <http://www.goldstandardsframework.org.uk/library-4#>
11. Department of Health. End of Life Care Strategy. [Online] [Cited: 23 August 2012.] Available from http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf.