

Transitions to palliative care for older people in acute hospitals: a mixed-methods study

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Scientific summary

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Background

Improving the provision of palliative and end-of-life care is a priority for the NHS. Ensuring an appropriately managed 'transition' to a palliative approach for care when patients are likely to be entering the last year of life is central to current policy. Within this context, a transition is defined as a shift from 'curative treatment', with a focus on cure or chronic disease management, to 'palliative care', with a focus on maximising quality of life. Acute hospitals represent a significant site of palliative care delivery and specific guidance has been published regarding the management of palliative care transitions within this setting. In this project we used a mixed-methods case study design to explore current practice regarding palliative care transitions within hospital settings in England.

Aims

Our primary aim was to explore how transitions to a palliative care approach are managed and experienced in acute hospitals and to identify best practice from the perspective of clinicians and service users. A secondary aim was to examine the extent of potentially avoidable hospital admissions amongst hospital inpatients with palliative care needs.

Methods

A mixed-methods study was conducted in two hospitals serving diverse patient populations: Sheffield Northern General Hospital and the Royal Lancaster Infirmary. A service user group was established to support the project and provide guidance at all key research stages. The study was conducted in the following phases:

- *Phase 1: systematic literature reviews.* Two systematic reviews were conducted of the relevant health- and social-care literature using standardised techniques. The reviews identified the research evidence base in the following areas: (1) the transition from curative care to palliative care and (2) the economic impact of avoidable hospitalisations amongst palliative care patients in the UK. Both reviews identified that the evidence base in their respective fields is very limited; findings informed the conduct and interpretation of the subsequent research phases.
- *Phase 2: exploratory focus groups and interviews with medical and nursing staff.* Fifty-eight health-care professionals with experience of palliative care management participated in focus groups and interviews to explore their perceptions of barriers to, and facilitators of, palliative care transitions in hospital.
- *Phase 3: hospital inpatient survey.* This quantitative phase involved a comprehensive survey of inpatients at the two hospitals. Data regarding palliative care needs and key aspects of management were obtained for 654 patients from the following sources: a self-/proxy-completed questionnaire; a survey of key medical and nursing staff; and a case note review.
- *Phase 4: in-depth interviews with patients with palliative care needs.* Fifteen patients who met criteria for palliative care needs and had been present in the hospital at the time of the survey participated in post-discharge in-depth interviews exploring their perspectives on communication with health professionals regarding prognosis and goals of care.
- *Phase 5: retrospective case note review.* Twelve months after the survey a retrospective case note review was undertaken of all inpatients present in the hospital at the time of the survey who had died in the 12 months following their hospital admission ($n = 483$). This examined key aspects of patient management and considered whether the hospital admission was potentially avoidable or not.

- *Phase 6: knowledge transfer events with key decision-makers.* Eighty-three health- and social-care professionals participated in focus groups in Sheffield and Lancaster to explore the implications of the findings for service delivery and policy in their localities.

Results

What proportion of hospital inpatients have palliative care needs?

- Of the 514 patients in the sample, just over one-third ($n = 185$; 36.0%) met one or more of the Gold Standards Framework (GSF) prognostic indicator criteria for palliative care need.
- The majority of these patients (77.8%) were aged ≥ 65 years, with a considerable proportion (23.2%) aged ≥ 85 years.
- The most common GSF prognostic indicator was frailty, with almost one-third of patients (27%) meeting this criterion. Heart disease (20.5%), cancer (19.5%), chronic obstructive pulmonary disease (18.4%) and dementia (17.8%) were the next most common GSF criteria and were roughly equal in prevalence.
- Amongst the 185 patients meeting criteria for palliative care need, a self-completed needs assessment identified that physical symptoms were most troublesome, with 74.6% reporting a symptom that merited 'immediate attention by the attending clinician'. Patients also reported high levels of psychological symptoms, with 43.2% of patients reporting a symptom that merited 'immediate attention by the attending clinician'.
- When medical and nursing staff were asked to identify patients with palliative care needs according to a standardised definition, nursing staff identified 17.4% of patients surveyed whereas medical staff identified 15.5% of patients surveyed. Agreement between medical and nursing staff and the GSF with respect to identifying patients with palliative care needs was poor (Cohen's kappa = 0.22 and 0.25 respectively).

Under what circumstances do transitions to a palliative care approach occur? What is the influence of age and disease type on decision-making? Who is involved in decision-making?

- Of the 183 patients who met GSF criteria for palliative care need and for whom complete data were available, 61 (33.3%) showed evidence of a transition to a palliative care approach by meeting one or more indicator of adoption of a palliative care approach [do not attempt resuscitation order (29%), referral to specialist palliative care (8.2%), prescription of long-term opiates/syringe driver (4.9%), on Liverpool Care Pathway (1.1%), documented advance care plan (0%)].
- The significant predictors of a transition to palliative care were the GSF indicators for cancer, heart disease and stroke, together with age and living in a residential or nursing care home.
- The retrospective case note review identified that 255 out of 483 patients (52.8%) who had died following an admission to hospital showed some evidence of a transition to a palliative care approach before death (do not attempt resuscitation order 47.4%, placed on Liverpool Care Pathway 14.1%, referral to specialist palliative care 9.1%, prescription of long-term opiates 9.9%, use of syringe driver 3.3%, advanced decision to refuse treatment 0.8%).
- Health professionals reported difficulties in recognising that a patient had entered the last 12 months of life and reported that prognosis was not routinely discussed with hospital inpatients, representing a barrier to a structured transition to palliative care being initiated. However, they were comfortable in identifying individuals with palliative care needs.
- An either/or approach to care was identified among health professionals, rather than concurrent palliative and curative treatment, as recommended in contemporary models of palliative care.
- Older age was perceived by health professionals to act as a barrier to accessing specialist palliative care because older people were seen to have less need for specialist input as a consequence of death being more expected and the perception that older people find it easier to come to terms with a terminal diagnosis.

- There was a persistent assumption among health professionals that specialist palliative care services are inextricably linked with cancer.
- No patients who were interviewed mentioned 'palliative care'.
- Patients are not routinely offered the opportunity to make decisions about the care and treatment that they receive at the end of life.

How is information about a transition to a palliative care approach communicated to patients and their families and how are they involved in decision-making?

- Most patients who were interviewed were unaware of their prognosis and showed little insight into what they could expect from the trajectory of their disease. None reported having held discussions about goals of care during their hospital admission; some patients expressed a reluctance to hold such discussions, preferring to live 'day to day'.

What proportion of hospital admissions amongst people with palliative care needs is avoidable given the current local configuration of health- and social-care services?

- Two palliative medicine consultants identified that hospital admission was potentially avoidable for 6.7% ($n = 14$) of patients who might be in need of palliative care according to GSF indicators. In the retrospective case note review, 7.2% ($n = 35$) of admissions were classified as potentially avoidable.

What patient factors predict potentially avoidable admissions?

- The number of potentially avoidable admissions was too small to conduct multivariate analyses to identify predictors, but it is notable that the majority of these patients (33 out of 49) in both the survey and the retrospective case note review were elderly and resident in nursing or residential care.

What is the cost of potentially avoidable acute hospital admissions amongst patients with palliative care needs?

- An exploratory analysis estimated that the cost of these admissions for the period of the survey was £36,334, but the cost of alternative places of care, based on the same length of stay, was estimated to be £34,807. The estimated economic impact was therefore a potential cost saving of £1527 across both hospitals for the period of the survey. The potential annual cost saving for the two hospitals was estimated at just under £180,000. Restricting the cost perspective to NHS and personal social services costs increased the cost saving to £2.5M per annum as the costs of self-funded care home places and non-NHS contributions to hospice funding are excluded.
- The retrospective case note review examined the appropriateness of admission for 483 patients who had been present in the hospital at the time of the survey but who had died (excluding sudden deaths) in the 12 months subsequently. Thirty-five (7.2%) admissions were classified by our two palliative medicine consultants as potentially avoidable. Taking into account the avoided hospital costs and the cost of providing support in alternative locations, the estimated economic impact is a potential cost saving of £45,287 across both hospitals for the inpatients with palliative care needs on the first day of the survey. The potential annual cost saving of preventing admissions amongst these patients for the two hospitals was estimated to be approximately £5.3M.
- The mean per-day long-stay payment for the 35 avoidable admissions from the retrospective case note review was £191. If it is assumed that this is a reasonable estimate of the cost per day of all palliative care admissions, then reducing the length of stay for all of the 483 patients in this current analysis by 2 days or 3 days would result in an estimated saving in hospital costs of £184,865 or £277,297 respectively. Annual cost savings for both hospitals per annum would be £21.6M for a 2-day reduction and £32.4M for a 3-day reduction.

Conclusions

This study confirms that patients with palliative care needs represent a significant proportion of the hospital inpatient population. However, we have identified a significant gap between NHS policy regarding palliative and end-of-life care management in acute hospitals in England and current practice. In particular, we found limited evidence that a managed transition to a palliative care approach is initiated within hospital settings. A failure to discuss prognosis and goals of care with patients and their families severely limits their ability to be involved in making decisions about their care and treatment. Our findings suggest capacity building amongst non-specialist palliative care clinicians working in the acute hospital setting, particularly in relation to initiating and effectively communicating transitions to a palliative care approach amongst patients likely to be in the last 12 months of life, may improve palliative care management. Further research is needed to (1) inform the development of comprehensive education and training in palliative care management specific to the acute hospital setting and (2) identify strategies to more effectively involve patients in decision-making about care and treatment in their last 12 months of life.

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