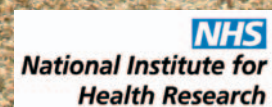


TRANSITIONS TO PALLIATIVE CARE FOR OLDER PEOPLE IN ACUTE HOSPITALS



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Research team and study partners

The study research team were: Prof Merryn Gott (The University of Auckland), Prof Christine Ingleton, Dr Clare Gardiner, Dr Naomi Richards, Dr Bill Noble, Dr Tony Ryan, Sue Ward (The University of Sheffield), Mark Cobb (Sheffield Teaching Hospitals NHS Foundation Trust), Prof Jane Seymour (The University of Nottingham), Prof Mike Bennett (The University of Leeds). The study was undertaken in collaboration with Sheffield Teaching Hospitals NHS Foundation Trust and University Hospitals of Morecambe Bay NHS Foundation Trust.



Foreword

Anita Hayes

Deputy Director,
National End of Life
Care Programme



“The investigators are to be congratulated for this research, which has been conducted so thoroughly and with a practical focus. Their findings will be useful to health professionals and commissioners, who want to provide the best possible end of life care, based on evidence as well as compassion.

Just over half of deaths occur in hospital but we know that seven in ten people nearing the end of life would prefer to die at home. As a result of clinical leadership complemented by nationally designed programmes, there has been considerable improvement in this outcome since the National End of Life Care Strategy was launched in 2008, at which time only 38% of people were able to die in their usual place of residence.

However, we still have more work to do. These studies show that health professionals find it difficult to identify when a person is nearing the end of life, which emphasises the importance of recognising and managing patients whose recovery is uncertain. It also demonstrates that timely conversations about prognosis and choices do not always take place, and therefore we are missing opportunities to support people to live well and die well.

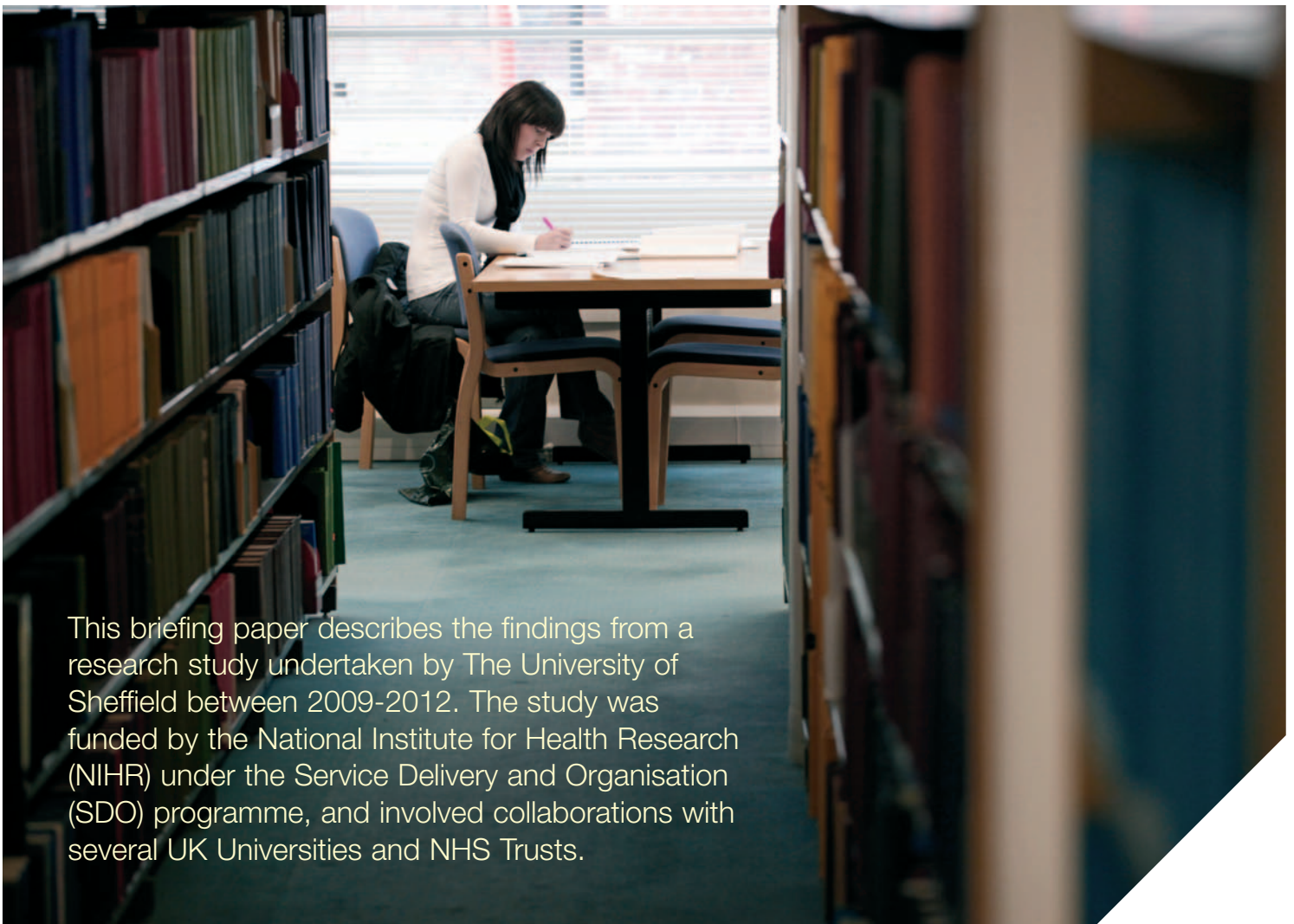
The national *Transforming end of life care in acute hospitals* programme is providing tools and support to help professionals identify these individuals and discuss their preferences and wishes, with the involvement of their loved ones.

This research reminds us that it is imperative to act now, making the experience of care the best we possibly can for older people. We must keep returning to the core principles of dignity, respect and compassion, in our practice and in supporting choice and control regardless of age.

We need to develop and maintain a workforce that understands the particular needs of older people and cares well for them. There are many immediately available resources to support education and professional development, on relevant issues including co-morbidities and frailty.

This research also discusses the potential cost savings from avoiding inappropriate admissions, a secondary benefit that arises from high quality care provided nearer to home. Delivering this kind of care requires an integrated approach across the entire local system.

Continuity of care, provided in the right environment, also matters deeply to people nearing the end of life and to those who love them. With planning, co-ordination and good communication, we can meet their wishes.”



This briefing paper describes the findings from a research study undertaken by The University of Sheffield between 2009-2012. The study was funded by the National Institute for Health Research (NIHR) under the Service Delivery and Organisation (SDO) programme, and involved collaborations with several UK Universities and NHS Trusts.

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 policyⁱ. 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 settingⁱⁱ. 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

The primary aim of the study 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 in-patients with palliative care needs.

'Transitions' to Palliative Care

A transition to palliative care 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.

i. Department of Health. End of Life Care Strategy for England. DoH, 2008.

ii. Department of Health. The route to success in end of life care - achieving quality in acute hospitals. National End of Life Care Programme, 2010.



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 from a lay perspective at all key research stages¹. 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. The reviews identified the research evidence base in the following areas: 1) the transition from curative care to palliative care;² and 2) the economic impact of avoidable hospitalisations amongst palliative care patients in the UK.³ Both reviews identified that the evidence base in the 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 phase involved a comprehensive survey of inpatients at the two hospitals. Data were obtained for 654 patients and carers. The data included patient/carer completed questionnaires, a survey of key medical and nursing staff, and a review of patients case notes.

Phase 4: In-depth interviews with patients with palliative care needs

Fifteen patients with palliative care needs who had been present in the hospital at the time of the survey participated in post-discharge interviews. The interviews explored patient/carer perspectives on communication with health professionals regarding prognosis, and future treatment and care options.

Phase 5: Knowledge transfer events with key decision-makers

Eighty three health and social care professionals participated in feedback meetings in Sheffield and Lancaster to explore the implications of the findings for service delivery and policy in their localities.

Phase 6: Retrospective case note review.

Twelve months after the survey, a retrospective case note review was undertaken of 483 inpatients present in the hospital at the time of the survey who had died in the 12 months following their hospital admission. This phase examined key aspects of patient management and considered whether or not the survey hospital admission was potentially avoidable.

Results

What proportion of hospital inpatients have palliative care needs?

Of the 514 patients in the sample, just over a third (n=185, 36.2%) met one or more of the Gold Standards Framework (GSF) prognostic indicator criteria for palliative care need⁴.

The majority of these patients were aged 65 or older (77.8%), with a considerable proportion aged 85 or older (23.2%).⁵

The most common indicator for palliative care need was frailty, with almost a third of patients (27%) who had palliative care needs meeting this criteria. Heart disease (20.5%), cancer (19.5%), chronic obstructive pulmonary disease (COPD) (18.4%), and dementia (17.8%) were the next most common indicators⁴.

Amongst the 185 patients meeting criteria for palliative care need, a self completed questionnaire identified that physical symptoms were most troublesome, with 74.6% reporting problematic physical symptoms. Patients also reported high levels of psychological symptoms with 43.2% of patients reporting problematic psychological symptoms⁶.

Patient: "I've found now I've got this very bad cough and I think that is all to do with my heart, I get very, very breathless, I can only walk so far without getting breathless, I have to have a wheelchair if I go further afield you know."

When medical and nursing staff were asked to use their clinical experience to identify patients with palliative care needs according to a standardised definition, nursing staff identified 17.4% of patients surveyed, while medical staff identified 15.5% of patients surveyed. Agreement between medical and nursing staff and GSF with respect to identifying patients with palliative care needs was poor⁴.





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 patients who met GSF criteria for palliative care need, 33% showed evidence of transition to a palliative care approach by meeting one or more indicator of adoption of a palliative care approach.⁷

The conditions cancer, heart disease and stroke, together with age and living in a residential or nursing care home, were significant predictors of a transition to palliative care.⁷

The retrospective case note review identified that 255 (52.8%) out of 483 patients who had died following an admission to hospital showed some evidence of a transition to a palliative care approach before death.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 need.^{9, 10}

Researcher: “And is prognosis routinely discussed with patients in hospitals?”

Hospital Consultant: “We never do that ... I think for a variety of reasons. We don’t routinely do that. It’s not because we don’t want to provide information but quite often breaking bad news to a patient can be pretty difficult... and we take a very different approach which may not be right but unless the patient asks their prognosis we don’t tell them the prognosis.”

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.⁹

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.¹¹



There was a persistent assumption among health professionals that specialist palliative care services are inextricably linked with cancer.^{11,12}

Health professionals also identified that patients are not routinely offered the opportunity to make decisions about the care and treatment they receive at the end of life.⁹

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

Most patients 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 reluctance about holding such discussions, preferring to live 'day to day'.¹³

The son of a patient with palliative care needs explained his father's preference for open discussions. He said: *"He's told the doctor... he said look... I don't want no shillyshallying, if there's anything wrong I want to know just tell me straight."*

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

Two palliative medicine consultants identified that for 6.7% (n=14) of patients who might be in need of palliative care, their admission to hospital was potentially avoidable (dependent of capacity in other services). In the retrospective case note review, 7.2% (n=35) admissions were classified as potentially avoidable.^{8, 14,15}

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 was estimated to be £34,807. The estimated economic impact was therefore a potential cost saving of £1,527 across both hospitals for the period of the survey. The potential annual cost saving for the two hospitals was estimated at just under £180,000.¹⁴

Restricting the cost perspective to NHS and Personal Social Services (PSS) costs increased the cost saving to £2.5 million per annum, as the costs of self-funded care home places and non-NHS contributions to hospice funding are excluded.¹⁴

The retrospective case note review examined appropriateness of admission for 483 patients who had been present in the hospital at the time of the survey, but had died 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. The potential annual cost saving of preventing admissions amongst these patients for the two hospitals was estimated to be approximately £5.3 million.⁹

Reducing the length of stay (LOS) for all the 483 patients by 2 or 3 days would result in estimated saving in hospital costs of £184,865 or £277,297 respectively. Annual cost savings for both hospitals per annum would be £21.6 m for a 2 day reduction and £32.4 m for a 3 day reduction.⁹ However, these cost savings are contingent upon the capacity of alternative services in the community.



Conclusions

This study confirms that patients with palliative care need 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.

Implications and Recommendations

We have identified an urgent need to build capacity in palliative care management 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.¹⁶

Further research is needed to:

Inform the development of comprehensive education and training in palliative care management specific to the acute hospital setting

Identify strategies to more effectively involve patients in decision-making about care and treatment in their last 12 months of life.





Publications

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Disclaimer

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