Transitions to palliative care in the acute hospital setting: reflections on a census at Royal Lancaster Infirmary

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INTRODUCTION

In the UK, around 56% of deaths currently occur in acute hospital settings. The proportion of deaths in institutionalised settings (including acute hospitals, nursing homes and hospices) is predicted to increase by over 20% in the next 20 years.[1] The End of Life Care Strategy for England has highlighted the delivery of high-quality end-of-life care in all locations as a particular area of priority.[2] The strategy acknowledges that the majority of people in the UK die in acute hospitals, despite evidence to suggest that preferred place of death for many patients is not the hospital setting. A review of place of care in advanced cancer suggested well over 50% of patients would choose to die at home, with inpatient hospice care a second preference in the majority of patients.[3] Despite this preference, evidence suggests that the proportion of patients who die at home is decreasing. From 1974 to 2003, the proportion of home deaths fell from 31% to 18% overall; even higher rates of decline were observed for people aged over 65 years, women, and people dying from non-cancer conditions.[1] Even in cancer patients, home deaths fell by 5% between 1994 and 2003 in the UK.[4]

Within this context of increasing institutionalised deaths and decreasing home deaths, care for patients reaching the end of life in acute hospitals is becoming a particular area of research and policy priority. Whilst many patients cite a preference to die at home, acute hospitals may also be the preferred setting for end-of-life care and death for a proportion of patients. Many (particularly older) patients recognise problems with home care and feel reassured by the presence of medical expertise and technologies in hospitals.[5] Research has also shown that preferences for home care may decrease in those who have had personal experience of death or dying; one study reported that whilst 63% of the general population cited a preference to die at home, this decreased to 56% in those with 'close personal experience of death or dying'.[6]

In the last two decades, there has been a steady expansion of palliative care services in the UK. The development of specialist palliative care teams in acute hospitals has been, in part, a response to concerns about the quality of care for the dying in hospitals. These services comprise professionals with specialist training in palliative care whose remit is to care for patients who require continuous or high levels of support.[7] Hospital specialist palliative care teams now work alongside 'generalist' palliative care providers (with no specific expertise in palliative medicine) from ward-based medical and nursing teams.[8] The role of these services is to provide physical, psychological and spiritual support for patients with advanced disease, broadly applying the same principles as hospice-based palliative care. The End of Life Care Strategy has acknowledged an expanded role for 'generalist' palliative care providers as the backbone of the palliative care workforce, and has highlighted palliative care provision as core to the role of all health professionals.[2]

A National Institute for Health Research (SDO Programme) funded study, based at the University of Sheffield from 2009-2012, aims to explore issues relating to palliative care provision in the acute hospital setting. The study aims to examine the potential for improving care for people at the end of life by exploring need for, and provision of, palliative care at two hospitals in England – Royal Lancaster Infirmary (RLI), and Sheffield Northern General Hospital (SNGH). The study addresses the identified need to improve palliative care management within acute hospitals through a study focusing on 'transitions'. Within this context, a transition is defined as a change in the approach to a patient's care from 'active treatment' (where the focus is on cure or chronic disease management) to 'palliative care' (where the focus is on maximising quality of life). Facilitating a transition to palliative care remains a key clinical challenge; however, little is known about this potentially complicated period and in particular how this process is managed within the acute hospital setting. A recent review of the literature identified a lack of empirical evidence relating to the transition, and reported complexity and lack of concurrence regarding the management of a transition to a palliative care approach.[9] The review identified the transition as a confusing and distressing time for patients and families, and acknowledged a need for further research and discussion.

TRANSITIONS TO PALLIATIVE CARE STUDY

The University of Sheffield study, consisting of two phases, was developed in order to explore these issues and address gaps in the existing literature. Phase one, a preliminary qualitative phase, was designed to gain exploratory data and inform the methodology for phase two, a census of palliative care need at the two participating hospitals.

Phase one: qualitative enquiry

Phase one of the study was completed between September 2009 and March 2010. A total of 58 health professionals from Lancaster and Sheffield participated in eight focus groups and four individual interviews. Participants were selected from a range of disciplinary backgrounds and care settings (general

practice, specialist palliative care, and the acute hospital setting) in order to achieve the maximum possible variation of experience and opinion. This qualitative phase of the study aimed to explore health professionals' perspectives and experiences of palliative care management within the acute hospital setting. Data were fully transcribed and analysed using a modified thematic approach.

Phase One: the perspective of health professionals
September 2009 to March 2010

Participants: 58 health professionals, Lancaster and Sheffield – from general practice, specialist palliative care and acute hospitals

Method: eight focus groups and four individual interviews to explore experiences of palliative care in hospital

Findings from this phase of the study revealed that various barriers exist to the provision and management of palliative care in acute hospitals. Whilst UK policy advocates a structured transition to a palliative care approach, in practice this is seldom evident in hospital settings. Discussions with patients regarding a transition to a palliative care approach, and discussions regarding prognosis, are not routinely held in the acute hospital setting; patients with palliative care needs are also often ill-prepared for discharge from hospital to the community.[10] Older people are particularly disadvantaged when it comes to equitable access to palliative care services. Evidence suggests that a range of factors including attitudinal differences to older people, a lack of resources, and a focus on active or interventionist care are key barriers to access to palliative care for older people.[11] Health professionals also report a lack of consensus regarding whose responsibility it is to provide palliative care for older people, and uncertainty exists over the roles of specialist and generalist palliative care providers in acute hospitals.[11,12] Patients with non-cancer diagnoses, and particularly those with dementia, are also less likely to receive palliative care in the acute hospital setting. Significant barriers exist to patients with dementia achieving a transition to palliative care. The traditional focus on cancer within palliative care, combined with a lack of recognition of the needs of patients with dementia, mean that many patients with dementia do not receive care appropriate to their needs.[13]

Phase two: census of palliative care need at two acute hospitals

Findings from phase one were used to inform the methodology for phase two, a census of palliative care within the hospital setting. The aim of the census was to examine how transitions to a palliative care approach are managed and experienced in acute hospitals and to identify best practice from the perspective of patients and key service providers. The case study census methodology was selected as an appropriate design for examining processes and outcomes in dynamic healthcare organisations. The collection of data from multiple perspectives is also appropriate for exploring practically and ethically complex situations where flexibility is desirable.

The first census was undertaken in May 2010 at SNGH; this was followed by a second census in November 2010 at RLI. During a two-week census period, every inpatient ward in both of the participating hospitals was visited by a team of researchers. Every inpatient over the age of 18 was included in the census and invited to participate in the study. The following data were collected from consenting patients during the census period:

Phase Two: a census of palliative care needs
May 2010 at SNGH and November 2010 at RLI

Participants: 572 patients and 46 relatives speaking on behalf of patients from a possible sample of over 1,350 adult inpatients; 36 researchers undertook data collection

Methods: Questionnaires completed by patients/relatives; standardised questions to medical and nursing staff about models of care and identification, if appropriate, of palliative care needs; a casenote review of patients' hospital notes

- A questionnaire relating to their care needs, and health and social care use.
- For patients lacking capacity, a 'consultee' (relative or close friend) was invited to complete a questionnaire on the patient's behalf.
- A doctor and a nurse were asked to complete a questionnaire relating to reason for admission and current approach to care (see appendix). For patients with identified palliative care needs, further questions were asked regarding appropriateness of admission, whether prognosis and care approach had been discussed with the patient, and staff training needs.
- Hospital casenotes were examined in order to assess evidence of palliative care needs (according to standardised criteria), reason for admission, and evidence of a palliative care approach.

The census at SNGH targeted over 1,000 inpatients over a two-week period, and recruited 406 patients and 38 consultees to the study (response rate 44%). The census at RLI was similarly successful; 350 inpatients were present in the hospital at the time of the census and of these 166 patients and eight consultees agreed to participate in the study, achieving a response rate of 50%. Whilst the data from the two censuses have yet to be formally analysed, it is worth reflecting on some of the issues that were encountered prior to and during the censuses.

Research of this kind requires careful planning and adherence to stringent ethical and governance requirements. A lengthy process of ethical and governance approvals was required prior to the census. The ethical application process was complex due to the involvement of potentially vulnerable patients with palliative care needs, and the inclusion of patients with cognitive impairment and limited capacity. After discussion with the ethics committee and with our dedicated group of user representatives, specific processes were put in place in order to minimise any distress to patients. These included:

> *Older people are particularly disadvantaged when it comes to equitable access to palliative care services*

- The removal of the word 'palliative' from all patient materials.
- Provision of sources of support for both patients and hospital staff, if required.
- A pre-specified approach for patients with limited capacity (informed by Mental Capacity Act guidance) in order to facilitate inclusion of these patients and their families.
- Dedicated and reflexive training sessions for all researchers involved in data collection.

In addition to research ethics applications, cumbersome research governance approvals were required. Unfortunately, delays to these processes in Sheffield resulted in the census being postponed for two months, whilst researchers waited to receive permissions ('research passports') to undertake research in that NHS trust. Research in the area of palliative care clearly necessitates a considered and sensitive approach. Researchers in this field require particular skills and expertise in order that data collection can be undertaken whilst minimising any inconvenience or potential distress to patients and their families. A team of 22 researchers was recruited to undertake the census in Sheffield, with a team of 14 researchers completing the Lancaster census. Researchers were selected from a variety of academic and clinical backgrounds and were able to offer a wide range of expertise in terms of both clinical judgement and research; this level of experience was crucial to the smooth completion of the census.

Once the preliminary administrative and ethical issues had been dealt with, the two hospital censuses were undertaken with relatively few problems. At RLI, prior information provision to medical and nursing staff in the hospital helped ensure staff awareness of the census taking place, and meant the majority of staff were able to participate in the study. Support from senior trust staff and from the Research and Development Department provided additional weight to the study. An emerging research culture was also evident at RLI; this positive attitude to research strikes a marked contrast to other NHS trusts in the UK and was a key facilitator to the smooth running of the study. An unfortunate outbreak of Norovirus during the census period meant that two wards were closed to the research team; however, these two wards were included once re-opened towards the end of the census period.

CONCLUSION

UK policy and research have highlighted the need for increased research into palliative care in the acute hospital setting. However, in order to achieve research of the kind discussed above, many months of careful organisation and planning are required before data collection can commence. A recent report by the Academy of Medical Sciences has highlighted this problem and has recommended the implementation of a new pathway for the regulation and governance of health research.[14] The report states that the current complex and bureaucratic regulatory environment is stifling health research in the UK. An example taken from Cancer Research UK shows a delay of over 600 days between the award of research funding and the recruitment of the first patient. Delays and duplications in obtaining permissions from NHS trusts, and complexities and inconsistencies across the regulation pathway, mean the current system is inefficient and inconsistent.[15] The creation of a new Health Research Agency has been recommended in order to rationalise the regulation and governance of all health research, and embed a culture that fully supports the value and benefits of health research.

Returning to our own study, the data collected during the two censuses are currently undergoing analysis and this article will be followed up with a paper in a future issue of the *Journal* reporting the results and implications of this study. The success of data collection indicates we will be able to generate robust and reliable findings, which in turn may be used to provide recommendations for both policy and future research in the area of acute hospital palliative care.

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The University of Sheffield

Census of care in hospitals
Medical & Nursing staff questionnaire

Job title & grade.....

Staff Gender: *Male / Female* How many years since you qualified:.....

Section A - General

1. Patient Unique Identifier.....
2. Reason for current admission:.....
3. Underlying diagnosis where appropriate:.....
4. Significant co-morbidities:.....
5. Would you be surprised if the patient died:

   during the current admission? *yes / no*

   within the next 12 months? *yes / no*
6. According to the definition on the back page do you believe this patient has palliative care needs? *yes / no*

Section B – only for patients with answer 'yes' to previous question

7. What is the current approach to this patient's care:

   Palliative / Active or curative / Mixture / Don't know
8. Has this approach to care been discussed with the patient or family:

   yes / no / don't know
9. Do you think the patient is aware of their prognosis: *yes / no / don't know*
10. During the current admission, has prognosis been discussed with the patient, or is this intended? *yes / no / don't know*

V2 03/03/10

11. Do you think the current admission was clinically necessary?

    yes / no / don't know

    please give a reason for your answer.....

    .....
12. Do you think there were any safe alternatives to the current admission?

    yes / no / don't know

    if yes please specify.....

    .....

Section C – Training Needs (only to be asked once of each staff member)

13. Do you see providing palliative care as part of your role? *yes / no / don't know*
14. Have you had any specific training in delivering palliative care in the last 5 years?

    yes / no

    If yes, please specify?.....
15. Do you think you require any specific training in palliative care? *yes / no*

    If yes, what kind?.....
16. Would you take up training in palliative care if it were offered? *yes / no*

    If no, why?.....
17. On a scale of 1 to 10 how would you rate the quality of palliative care provided:

    a) On this ward?..... *(N.B. 1=very poor, 10=excellent)*

    b) In this hospital?..... *(tick if doesn't know ☐)*

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Definition of Palliative Care

Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with or dying from a progressive life threatening illness.

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