Short-stay, specialist beds in a UK teaching hospital as a model to integrate palliative care into the acute hospital culture

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ABSTRACT Hospital patients should have access to effective palliative care. In our study, three short-stay beds were re-allocated to specialist palliative care as part of a pilot programme. This paper describes the first 100 admissions of patients with inadequately controlled symptoms or distress. Median pain and distress scores were both seven out of a maximum of 10 (interquartile ranges [IQR] 4–10 and 1–10 respectively), reducing to 3.5 (IQR 1–5) and 0 (0–5) after 48 hours. Median length of stay was five days (IQR 3–10); 77% of patients were discharged: 32% to home, 26% to a hospice or community hospital, 19% to their original ward for treatment and 23% died in the unit. A unit education programme introduced as part of the study attracted 600 staff members. Pain and distress were rapidly improved by brief, intense palliative care in a small onsite facility. The pilot programme also influenced the understanding of palliative care in the hospital, demonstrating what it offered patients, family and staff. It demonstrated effective, concurrent working alongside an active disease-management approach, and encouraged collaborative discussions about the goals of care.

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INTRODUCTION

Palliative care should be available for all those with advanced disease who need it, wherever the place of care. Patients with the most complex needs, for example pain which is difficult to control, should have access to skilled expertise in symptom control. It is (arguably) a patient's right to be referred for specialist advice in such circumstances.^{1,2}

Recognising the problem

Most patients die in hospital and will continue to do so for the foreseeable future.³ National strategies emphasize the need to improve general palliative care and access to specialist palliative care in all settings.⁴⁻⁹ Unfortunately there are continuing reports by patients and their families of unsatisfactory experiences of palliative and end-of-life care in acute hospitals. This is not limited to the UK¹⁰ but also found internationally, in America,¹¹ Europe¹² and Australia¹³ for example.

Most acute hospitals have a specialist palliative care advisory service and some have hospice wards onsite. A few large teaching hospitals and cancer centres have dedicated acute palliative care beds or an acute palliative care unit (APCU),¹⁵ but this is not the tradition in the UK.¹⁸ Provision of palliative care in hospital has been identified as the biggest gap in palliative services¹⁹; the

- They provide inpatient facilities.
- They are usually located on the premises of an acute care hospital.
- They are dedicated to acute, severe, complex and unstable physical or psychosocial problems.
- They provide diagnostic precision, close monitoring and intensive treatment.
- Care is provided by an advanced, highly specialised, multidisciplinary palliative care team.

FIGURE I Conception of an Acute Palliative Care Unit.15

need to improve the quality and level of palliative care or establish acute hospital palliative care services has been identified as a priority in the UK.²⁰

Challenges or 'barriers' to delivering palliative care in hospital persist, including delays in recognising the need for palliative care and in referral for specialist advice. 21.22 In cancer centres there are additional challenges to referrals: 23 it may be perceived as an end to cancer treatment, synonymous with a loss of hope for the patients as well as a concern that they will feel abandoned by oncology services. Only through rigorous evaluation of outcomes and joint research will evidence be provided to support the continuation of palliative care in an era of

Palliative care is specialised medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness — whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

FIGURE 2 Centre to Advance Palliative Care. Public opinion research on palliative care 2011.²⁶

limited financial resources.²⁴ Such barriers are likely to explain, in part, why any policies recommending a structured approach to the transition to a palliative care model are seldom evident in hospitals. Now that the need for palliative care has been established,²⁵ the institutionalisation of the practice has been identified as the next big challenge.

Identifying a solution

Hospitals are orientated to high volume admissions, short lengths of stay and an increasing availability of interventions for conditions which were previously untreatable. If patients are to receive high quality palliative care, often in addition to 'active' medical treatment, the culture in hospitals must change. There appears to be increasing pressure and support for this change from patients, families and clinical professionals.^{26,27}

Practical models of care are therefore needed, not only to deliver high quality palliative care in a treatmentorientated environment, but also to help staff understand how palliative care can support them as they look after patients with serious, advanced illness (Figure 2). In the current financial climate, it is also necessary to continually demonstrate the added value of providing a structured programme of palliative care in hospital. In the UK health service, it is difficult to demonstrate cost avoidance, although it should be possible to generate data showing reduced length of stay, improved symptom management, satisfaction and rational use of resources.24 These data will also provide a source of information for staff, patients, families and management, to help them understand the benefits and implications of having dedicated, high quality palliative care.

OUR PILOT STUDY

This paper describes a new initiative, a one-stop, short-stay unit for patients with complex needs related to advanced disease. The objectives were to embed palliative care within the hospital and show how an intensive, multidisciplinary approach in a focused environment improves symptom burden, shortens length of stay and provides a centre for palliative education. Palliative care specialists and specialists in

other fields were strongly encouraged to work collaboratively, with the intention of dispelling the prevailing view that active treatment and palliation are mutually exclusive.²⁸

Methods

Patient population

The study was carried out in Ninewells Hospital in Dundee, Scotland, an 800-bed University Teaching Hospital and Regional Cancer Centre serving a population of 400,000. There are approximately 4,660 deaths per annum in Tayside, of which 3,500 are likely to have some palliative care requirements.²⁹

Ninewells Palliative Care Service

Ninewells has provided a specialist palliative care advisory service for over 6,000 patients and most of their families since 1998.³⁰ The number, age and frailty of patients referred to the service has increased each year and although complexity was not prospectively recorded, patient management has become more challenging. The palliative care needs of at least one in five patients referred to the hospital advisory service were of sufficient complexity to merit a more intensive approach with an extended range of specialists available to input into care. This concurs with the recommendation of the World Health Organization (WHO) which estimates that 20–30% of all specialist palliative care beds should be in tertiary centres, cancer centres and major acute hospitals.³¹

Acute Palliative Care Unit Pilot (February – December 2009)

In February 2009, three beds (single rooms) on an acute surgical ward were re-allocated to palliative care. Admissions were restricted in the pilot stage to patients in the surgical, oncology and haematology wards. Funding provided the following staffing:

- 7.4 nurses either with some specialist palliative care experience or seconded to train in palliative care;
- 0.6 consultant with extensive experience to provide palliative care teaching;
- one secretary to provide administrative support for the hospital service;
- dedicated sessions from physiotherapy, occupational therapy and pharmacy representatives, ensuring a multidisciplinary approach to medication, home assessments and available facilities.

The chronic and acute pain services, social workers and chaplaincy service committed to support the pilot without additional funding. Nurses were seconded to the unit from a wide variety of wards and shifts were organised so that a palliative care nurse was always available for the unit patients. There was a degree of cross-cover resulting in the sharing of skills and knowledge, helping to spread palliative care skills. This was especially relevant as few nurses in an acute hospital

have training in looking after patients with palliative care needs. A full-time consultant in palliative medicine, already in post, was clinically responsible for the unit and advisory service.

Operational issues

All patients continued to be referred to the hospital palliative care service (HPC) rather than for admission to the unit specifically. The HPC nursing team helped triage potential admissions and provided practical and educational support for the unit nursing staff. Admissions were discussed with the referring consultant and with the patients themselves. Indications for admissions were uncontrolled pain and distress, a likely complex discharge, or an appreciation that the balance of care had shifted to a more palliative approach and that future care needed to be discussed and planned. Communication was important to ensure that the staff's goals of care were in line with those of the patient and family. The referring team continued to review their patient while they were in the unit, and had agreed to accept the patient back to their ward if required. In those cases the HPC service would resume involvement, ensuring continuity of treatment after discharge from the unit.

Data collection

We prospectively collected the following data: Palliative Performance Status (PPS)³² and Palliative Prognostic Index (PPI)³³ on admission; daily Edmonton Symptom Assessment Score (ESAS)^{34–36} and distress score³⁷; documentation of disciplines considered essential for patients to see; date family meeting achieved, likely outcome (on admission) and patient, family and staff satisfaction levels.

Quality outcome measures of process, clinical outcome and satisfaction were recorded (Figure 3). Targets included:

Process

- availability of appropriate specialists within two working days
- family meeting achieved within two working days

Outcome

- improvement in pain and symptom scores within two working days
- place of discharge achieved as planned

Satisfaction

simple questionnaire for patient and/or family

Measurement tools

Prognostic and performance status

A PPI was used (a level of six or more predicts a survival time of less than three weeks).³³

Symptom assessment

The ESAS measures nine items on a visual analogue scale with an additional patient-identified problem. It is simple, validated, reliable and applicable for patients in the last

I. Intensive symptom/ distress control	Yes	No	%
Admission ESAS			
48-hour ESAS			
2. Intensive assessment	Appro- priate?	Date referred	Date seen
Palliative Medicine			
Palliative Care Nurse			
Consultant			
Allied healthcare professionals (AHP)			
Occupational therapy			
Physiotherapist			
Community/social			
GP			
District nurse			
Macmillan nurse			
Social work			
Pain			
Anaesthetists			
Neurosurgeons			
Oncology			
Emotional support			
Psychology/psychiatry			
Minister/spiritual leader			
3. Family meeting in two working days			
4. Future planning	Date	Date	Date
Home			
Ward			
Hospice			
Other			
Plans made			
Discharge plan achieved in seven days			
5. Satisfaction			
Patient			
Family			
			

FIGURE 3 Acute Palliative Care Unit improvement measures.

few weeks of their life.³⁴⁻³⁶ It has been recommended as an appropriate tool for the assessment of patients who have been identified as having palliative care needs in all settings including the acute.

A patient's ESAS was measured using a questionnaire on admission to the unit and daily thereafter. Admission ESAS was completed by the patient with or without help from the doctor and subsequently by the patient, either by themselves or with the help of nursing staff. Shortly after the pilot started, we added distress to the original scale.³⁷

Palliative care education

Palliative care education delivered during the pilot will be reported in detail in a subsequent paper. Briefly it consisted of:

- A total of 48 multidisciplinary seminars: 600 staff attended (409 nurses and nursing students, 93 doctors, 20 medical students and 78 allied healthcare professionals [AHP]).
- Six ethics teaching ward rounds were held, considering issues such as resuscitation, feeding and hydration, sedation, informed consent and rationing.
- 3. A 'training the trainers' one-day workshop was offered for specialist registrars in palliative medicine.
- Two three-day advanced communication skills courses were also held.

Limitations of the study

A prospective comparative study with matched patients who could not get access to the APCU but were treated with specialist palliative support on general wards would have made this study more powerful and would have allowed comparison of patient benefit, overall length of stay and re-admission data. We will consider doing this in future and would encourage others setting up a similar service to do so. Given the current financial climate such data would be useful when trying to access funding.

RESULTS

Between 5 February 2009 and 31 December 2009, 574 patients were referred to the Ninewells Hospital Palliative Care Service. Details of the 100 patients admitted to the unit during the pilot period (17%; 100/574 of all referrals) are reported here. As the results report on 100 patients the actual number of patients and the percentage of patients are the same number therefore only percentages are reported. The Wilcoxon matched-pairs signed-ranks test was used to determine statistical significance unless otherwise stated.

Demographics

The median age of patients admitted to the unit was 68 (range 30–89). Patients referred to the advisory service had a median age of 72 (range 18–103). A total of 11% had conditions other than cancer such as severe ischaemic limb pain, end-stage pulmonary fibrosis and renal failure.

Reasons for admission to unit

Pain control accounted for 73% of admissions; 51% of patients required close specialist supervision of drug usage such as alfentanyl, ketamine, methadone or epidural analgesia. In 22% of cases, patients' pain necessitated a consultation with an anaesthetic pain specialist or neurosurgeon.

Performance status

The median PPS of patients was 50 (IQR 30-50), patients spent 50% of the time in bed as a result of

illness and needed considerable assistance with bathing and other activities of daily living. The median PPI of patients was five (IQR 3.5–8.1).

Symptoms

Pain

The ESAS questionnaire was completed or partly completed on admission by 94% patients; 78% and 69% completed the pain and distress elements respectively 48 hours later. The reasons for incomplete or missing data were early death, confusion or delirium. No patient refused. The median pain score on admission was seven, and one-third of patients had pain levels which they reported as 10 out of 10. A score of greater than 10 was not recordable but it was our experience that many patients described their pain as '20 out of 10'.

Distress

The median distress score on admission was seven (IQR I-I0); 40% had a score of I0 out of I0.

Total symptom burden

Most patients had multiple symptoms (Figure 4). Nonetheless, most were able to score their symptoms with the help of a nurse or doctor. Data were available for 73 patients who scored five or more symptoms. In the remainder, patients were too ill. The score of all 10 symptoms were added to give a total symptom burden. The median total symptom burden on admission was 42 (IQR 27–56).

Results after 48 hours in the Palliative Care Unit

Pain

Pain was reduced from a median of seven (IQR 5–10) to 3.5 (IQR 1–5) within 48 hours. For the 64 patients in whom pain was measured on admission and 48 hours later, this was highly significant (p<0.001).

Distress

The median distress score within 48 hours of admission was 0 (IQR 0–5). Of the 43 patients in whom distress was measured on admission and 48 hours later, this reduction was highly significant (p<0.001).

Other symptoms and total symptom burden

The median symptom burden recorded at 48 hours was 33 (IQR 23–46). For the 75 patients in whom admission and 48-hour measurement was possible, this reduction was highly significant (p<0.001; paired t-test). There were significant reductions in: anxiety (p=0.012), poor appetite (p=0.032), tiredness (p<0.001), nausea (p<0.0001), loss of well-being (p=0.04), and overall symptom burden (p=0.001). There was no significant increase in any symptom (based on appropriate choices of paired t-test and Wilcoxon matched-pairs signed-ranks test).

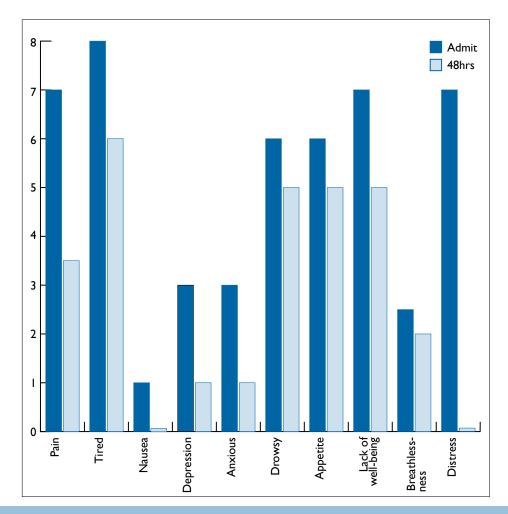


FIGURE 4 Symptoms on admission to the Acute Palliative Care Unit and 48 hours later.

Length of stay

The median length of stay was five days (IQ range 3–10). Almost two-thirds (64%) of patients were in the unit for one week or less. Patients with the longest length of stay had very complex pain, requiring anaesthetic or neurosurgical intervention.

Place of discharge

Seventy-seven per cent of patients were discharged: 58% directly from the unit, 32% went home, 26% to a hospice or community hospital and 19% returned to their original ward for active treatment or further consideration of active treatment. In the unit, 36% of patients were seen by occupational therapy within two working days, showing the benefits of an intensive team approach. Twenty-three patients died in the unit; this number compares with the much higher mortality rate associated with hospice care.

Education

Over the year, nine Foundation Year I doctors gained practical experience of looking after palliative care patients. During the weekends and at night, trainees in surgery, oncology and palliative medicine had on-call responsibility for unit patients.

DISCUSSION

Referrals

World Health Organization recommendations state that 20% of hospital referrals to specialist palliative care would benefit from admission to a dedicated unit for a more intensive approach.31 Previous research confirms this,30 and 17% (100/574) of all referrals to the Hospital Palliative Care Service were admitted to the dedicated unit. The concept of the unit, although based on hospice principles, was not that of a hospice. It was established to demonstrate the beneficial practice of providing palliative care earlier in a patient's illness through more 'upstream' intensive intervention. Patients who are actually dying should be appropriately managed on their own ward with support, if needed, from specialist palliative care. In fact 61% of patients admitted to the unit had a PPI of six or less and were therefore predicted to survive more than three weeks. Subsequent analysis confirmed PPI to be highly sensitive and specific for shortterm survival in this group of patients.38 Unit mortality was low (23%) compared with hospice mortality. Exceptions included patients who were admitted directly from acute receiving wards, when no single room was available or when the environment was unacceptable.

Referring teams were encouraged to visit their patients in the unit. This ensured the patient did not feel abandoned and allowed the referring teams to see the specific benefits of palliative care. It also ensured that opportunities for appropriate active treatment were not missed. It is important that a palliative care service is not seen solely as an advisory one; roles can be reversed and other specialists can see how we manage patients when having responsibility for their care. The principles of hospice care can therefore be applied alongside and in addition to 'active treatment'.

All patients were considered for discharge home in as short a period of time as was realistic.

Distress

The percentage of admissions for unsatisfactory pain control (73%) was predicted.³⁰ The pilot study clearly demonstrated that distressing symptoms, which had failed to respond easily to specialist advice, could be rapidly controlled by admission to a specialist, more intensive setting.

Collaboration and education

Specialists in palliative care see a minority of hospital patients with palliative care needs, but they can influence hundreds of hospital staff by example. Successful collaborative working is critical; in cases where palliative care input has been helpful to staff, this has influenced willingness to seek specialist advice in other cases. We believe it is helpful for clinicians in specialties other than palliative medicine to see how palliative medicine can complement their care. Consultants and staff for example were able to see that patients who were very ill, or possibly dying, could have their care successfully and speedily arranged in the community. Communication of course goes both ways: a number of surgical or oncological interventions can improve quality of life towards the end of life, immeasurably. Joint discussions and consultations can clarify to professionals, the patient and their family how the goals of care and a good quality of life can be achieved through considering the benefits and consequences of both approaches. Patients and their families should not need to choose between two reasonable options – one interventional and treatment orientated, the other with symptom control as a priority. They should have the opportunity to discuss both.

Culture change

The justification for having a small unit with one palliative care nurse and dedicated medical time for only three beds was initially a challenging one to make. However once the unit was in place, the rapid improvements in levels of patient pain and distress created clinical curiosity, as individual consultants saw the benefits for their own patients. The result of having specialist beds in the hospital meant that surgical trainees in particular became more familiar with managing patients with palliative needs and came to accept this as part of their core responsibilities.

Education alone is unlikely to overcome either individual concerns about managing palliative care patients or the organisational barriers. However education programmes which offer a sense of ownership of skills in association with practical involvement and clinical observation of quality care, should enable a well-informed professional to practice the skills required with confidence and take responsibility for palliative care for their patients. Analysing end-of-life care remains difficult and collaborative working between specialties allows the greatest likelihood of offering balanced, informed care.

CONCLUSION

Our study demonstrated that pain and distress were rapidly improved by providing more intensive, specialised palliative care in a small on-site facility. Palliative care teams in specialist units have an important role to play in the active management of patients alongside other specialties. The pilot study, including the associated palliative care education also influenced the level of understanding of palliative care and is, we believe, contributing to a culture change in the provision of palliative care within the hospital.

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