Providing Palliative Day Care for Non-Malignant Conditions

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Background: There is increasing pressure to provide palliative care to patients on the basis of need rather than diagnosis but there is a paucity of practical information on how to provide support to those with non-malignant conditions.

Aim: To examine the feasibility of providing hospice day care to patients with non-malignant conditions.

Method: A year-long pilot project was conducted and then analysed.

Results: Twenty-eight patients out of a possible 52 who fitted referral criteria attended day care during the year, 16 were discharged and four died. Attendance appeared generally acceptable to patients who accepted the invitation but was often sporadic due to acute exacerbations of illness.

Discussion: With appropriate staff education, careful referral criteria, access via clinical nurse specialist (CNS) screening, an overt discharge policy and close collaboration between CNS and specialist palliative care services, we were able to offer palliative day care to a small number of selected patients with non-malignant conditions.

Conclusion: The project did not overwhelm the service, it had negligible impact on the number of inpatient admissions and, at first glance, appeared to be resource neutral.

Keywords: Palliative care; Hospice; Non-malignant disease; Day care

Implications for Practice

- Access to palliative day care services should be based on patients’ needs, rather than on their diagnosis.
- Meeting the needs of a more diverse patient population, including those with non-malignant conditions, may be achieved through service redesign.
- Staff education underpins all changes to service delivery.
- Shared care and collaborative working between staff in palliative care services and clinical nurse specialists qualified in working with non-malignant long-term conditions can improve patient care and experiences.
- Patients with non-malignant conditions must be assessed as suitable for referral to palliative care services by clinical nurse specialists to ensure they are receiving the appropriate medical therapy.
- Accepting patients with non-malignant long-term conditions does not overwhelm palliative care services or significantly increase inpatient admissions.

Background

Historically, specialist palliative care services provide care to patients with cancer but there is an increasing pressure to provide palliative care to patients on the basis of need, not diagnosis (Scottish Partnership for Palliative Care, 2001).

Needs assessments have shown that people with long-term non-malignant conditions have significant physical symptom burdens in addition to unmet psychosocial needs. These conditions include: chronic respiratory disease (Edmonds et al, 2001); heart failure (Murray et al, 2002); end-stage renal disease (Saini et al, 2006); and chronic neurological conditions (Kristjanson et al, 2005).

However, compared with services for people who have cancer and their families and carers, those for people with long-term non-malignant conditions are sparse.

According to the Department of Health’s (2008) End of Life Care Strategy: ‘The challenge for the NHS and social care services now, is to extend this quality of care from the minority of patients (mainly those with cancer) who currently come into contact with hospices and specialist palliative care services, to all people who are approaching the end of life.’

The life expectancy of the Scottish population is increasing but their healthy life expectancy is not increasing at the same pace. This means many Scots are living longer with poor health (Information Services Division Scotland, 2004). It follows that as this ageing population lives longer with morbidity from malignant and also non-malignant conditions, their palliative care needs are likely to increase. The ways in which palliative care services will respond to these changing demographics and the challenge of providing services based on need rather than diagnosis are poorly studied.

Aim

With this in mind, Dundee specialist palliative care services, non-cancer specialists and representatives from the Dundee Community Health Partnership began collaborating on a 12-month pilot project to open Macmillan Day Care at the regional hospice to those with non-malignant conditions. The project aimed to examine the feasibility of providing this new service, as there is a paucity of literature on the actual provision of specialist palliative care for people with non-malignant conditions. This article reports the results of this pilot project, which started in December 2005 and finished in December the following year.
METHOD

Education programme

Non-malignant disease-specific education was highlighted by palliative care providers as a necessity if staff were to provide care to this group of patients (Scottish Partnership for Palliative Care, 2006).

Months before patients began attending day care, the regional Macmillan practice educator and day care team leader developed close working relationships with clinical nurse specialists (CNSs) in non-malignant conditions. These nurses or consultants delivered a series of lunchtime lectures to specialist palliative care staff. The lectures covered advanced cardiac disease, advanced multiple sclerosis, HIV, advanced COPD, advanced renal disease and motor neuron disease. In addition, Macmillan Day Care staff spent work placements with the nurse specialists.

Setting referral criteria

Strict referral criteria were agreed on. They were deliberately the same as referral criteria for patients with cancer accessing day care services (see nursingtimes.net for Appendix 1). Reasons for referral were similar to those for people with cancer, for example psychological support, symptom control, rehabilitation and accessing complementary therapies.

Referrals were to come from nurse specialists in specific non-malignant conditions to ensure patients were also receiving appropriate medical therapy.

Setting a discharge policy

As is standard for our service, patients’ attendance at Macmillan Day Care was reviewed after three months. They were made aware that their ongoing attendance would be discussed with them at this point. Discussions with patients about their aims in attending day care were undertaken and goals agreed at the outset to inform discharge discussions.

Delivering the project

The Macmillan Day Care Unit in Dundee offers places for 16 patients per day. They attend on the same day each week, enabling them to build relationships with other patients.

We decided against having a specific day for people with non-malignant conditions. Instead, patients mixed together on any given day, irrespective of diagnosis.

Potential patients were offered an introductory first visit to be shown around, meet staff, establish the programme’s aims and inform them of the unit discharge policy.

During the project, the Macmillan practice educator, day care team leader and relevant nurse specialists provided ongoing support for day care staff.

Evaluation

Quantitative data was retroactively audited on patients who declined to attend, those who did attend, the number of sessions attended, patients discharged, those admitted to an inpatient unit and the number who died during the project.

RESULTS

CNSs identified 52 patients who fitted criteria and were considered for referral (Fig 1).

Referral criteria met, declined to attend:

Sixteen patients were offered referral to the day care service by their CNS but either declined, were too unwell or died before agreeing to the referral. Patients’ reasons...
for not wishing to attend day care varied but can be broadly categorised as:
- Too ill/died before agreeing to referral (3);
- Not wishing to leave spouse at home (3);
- Fear of hospice or cancer (3);
- Uncomfortable or anxious in new social surroundings (2);
- Content to manage with current services (2);
- Refused all offers of assistance (1);
- Uncertain of reason (1);
- Condition improved, not ready to attend (1).

Referral criteria met and agreed to attend: Thirty-six patients with non-malignant conditions were referred during the year of the pilot project, compared with 171 patients with cancer. Nineteen patients were male. The majority referred were aged 25–64 years (Fig 2), reflecting the younger age of patients with multiple sclerosis.

Of the 36 patients referred, 28 attended for at least one session. Sixteen patients had COPD, eight had multiple sclerosis and four others had either cardiac disease, Parkinson’s disease, end-stage renal disease or HIV infection.

Eight patients either declined to attend day care after having introductory telephone contact with day care staff (3), were readmitted to hospital with acute exacerbations of illness (2), were too ill to attend (1), or had died before being able to visit the service (2).

Patient attendance varied depending on individuals’ needs. The majority (13/28) attended for fewer than five sessions in total (Fig 3). The longest attendance was for 41 sessions as the patient’s discharge was delayed due to hospital admission. Some patients’ attendance was sporadic because of ongoing exacerbations of symptoms or repeated admissions to acute care.

Discharging patients from day care:
Sixteen patients were discharged from day care during the pilot. This included two with multiple sclerosis and one with HIV infection who decided that day care was not suitable for them.

One patient was admitted to the inpatient hospice for complex symptom management and was subsequently discharged home again, continuing to attend day care as an outpatient.

At the end of the pilot, eight patients continued to attend for ongoing symptom management, goal-setting or because their 12-week review date had not yet arrived.

Deaths during the project: Four patients died during the pilot project. Two of these had COPD, one had cardiac failure and one had renal failure. All except the patient with congestive cardiac failure died in an acute hospital.

DISCUSSION
There is growing literature on the palliative care needs of people with non-malignant conditions but a paucity of information regarding how services for these patients can work in practice.

This project has shown that patients with advanced non-malignant conditions can be offered specialist palliative care review with simple service redesign and close collaboration with relevant nurse specialists, without overwhelming our service. Importantly, we do not have data to show how patients, their families or staff evaluated the project and therefore no benefits can be inferred, despite positive informal feedback we have received. This requires further qualitative study.

The idea of attendance at Macmillan Day Care was acceptable to just over half the patients (28/52) who were identified as potential patients by nurse specialists. Some potential patients declined initial attendance because of fear of hospice or cancer, while others declined because of social factors. These included feeling uncomfortable in new surroundings and mixing in groups, or concerns about leaving partners. Eight out of 52 (15%) patients were unable to attend or consider attending because they had acute exacerbations of illness, were too unwell or had died. This highlights the vulnerability of these patient groups.

Once they had begun attending, ongoing attendance appeared generally acceptable to patients, with only 11% (3/28) of patients deciding not to continue after one or two
sessions. Referred patients were screened by a CNS before being invited to attend, so this sample is likely to be skewed in favour of those who were more likely to accept. Also, how their CNS ‘sold’ the idea of attendance and how the offer was framed has not been studied. These figures and the predominance of COPD and MS patients may not share generalities with other regions.

It became clear that a flexible approach to providing day care to people with advanced non-malignant conditions was necessary as their disease trajectories are different (Murray et al, 2005) and their attendance was sporadic due to acute exacerbations of their illness. In practice, most patients attended for fewer than five sessions.

Concerns about overstretching services were unfounded. Only one patient was admitted to the hospice inpatient unit during the pilot. The majority who required admission continued to be cared for in the acute sector. Whether this changes in the future is an issue for ongoing audit.

It is accepted at governmental level that good palliative care should be available to all, regardless of diagnosis (Scottish Executive Health Department, 2000). It is a matter of debate where people with advanced non-malignant long-term conditions access palliative care and who should provide it (Field and Addington-Hall, 1999). It has been proposed that specialist palliative care staff should be involved in training other clinicians in the provision of generic palliative care (Scottish Partnership for Palliative Care, 2006; Traue and Ross, 2005), but this alone cannot guarantee good care for the minority of people who have complex needs best met by specialist palliative care.

Acting as a resource and working in partnership with other clinicians as a pragmatic way to provide input (Wallwork, 2000) has also been proposed. However, this does not enhance or encourage the building of relationships between specialist palliative care and non-cancer services as there is no permanently open line of communication. A collaborative nursing model with nurse specialists coordinating disease-specific care and liaison with community and palliative care services has already been proposed (Loftus, 2000). A recent Scottish report also recommended that the provision of palliative care for those without cancer is the responsibility of the patient’s usual healthcare team, with specialist palliative care services accessed when necessary for complex needs (Scottish Partnership for Palliative Care, 2006).

In this small pilot project we have demonstrated that a shared-care approach with good links with disease-specific nurse specialists worked in practice. We did not remove responsibility for providing generic palliative care from the patient’s usual team and avoided causing anxiety in specialist palliative care staff about their lack of knowledge of non-malignant disease by accepting referrals from nurse specialists who had maximised medical management.

It has been suggested that the provision of palliative care to those with non-malignant conditions may have minimal resource implications and that improvements could be achieved through service redesign and delivery (Scottish Partnership for Palliative Care, 2006). This pilot project did not receive extra funding and at first glance was resource neutral. The time commitment from staff was, however, considerable.

CONCLUSION
This project has made a small, local impact on the inequalities in care for people with advanced non-malignant conditions. More importantly, it has shown this model of care is a practical option for the future, at least in Dundee. With appropriate staff education, careful referral criteria, access via CNS screening, an overt discharge policy and close collaboration between nurse specialists and specialist palliative care services, we were able to offer care to a small number of selected patients. The project did not overwhelm the service, had negligible impact on inpatient admissions and was at first glance resource neutral. In future, robust evaluation is required. More needs to be known about how patients, their families and staff feel about the service and whether or not it is beneficial.

REFERENCES


Scottish Partnership for Palliative Care (2001) Palliative Care for All: Responding to Need Not Diagnosis. Edinburgh: SPPC.
