Palliative care at home: an audit of cancer deaths in Grampian region

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SUMMARY

Background. *Ninety per cent of the last year of life of cancer patients is spent at home. Some studies have suggested that care in this setting is often suboptimal. Information on the standard of palliative care delivered at home by general practitioners (GPs) and their teams is limited, and clarification of the problems faced is needed.*

Aim. *To audit the home-based palliative care of patients dying of cancer.*

Method. *Matched postal questionnaires were sent to the GPs and nurses of 1086 successive patients dying of cancer in whatever setting in the Grampian region of Scotland some six weeks after the death to establish the professionals' perception of symptom control, communication problems, use of services, and information given to patients and relatives.*

Results. *Response rates were 88.8% for GPs (964 out of 1086) and 87.1% for nurses (325 out of 375 that were passed on to nurses). Two-thirds of patients received palliative care at home. Pain was poorly controlled in 15.7%, and poor control of other symptoms ranged from 13.8% (nausea and vomiting) to 21% (depression and dyspnoea). Communication difficulties were present in 93.7% of cases, although only 5.2% of these were of a major nature. District nurses were involved in 76.7% of cases and Macmillan nurses in 28.0%. Twenty-six per cent of referrals to district nurses were assessed as being late in the course of the illness. Patients were fully informed about the diagnosis in 66.3% of cases and about the prognosis in 55.4%. General practitioners were more likely to report the presence of communication problems between themselves and the patient (when compared with nurses: 43.9% versus 28.0%), more likely to report that patients were 'not at all informed' about self-help groups (57.5% versus 36.3%), and were less likely to report the involvement of occupational therapists (21.8% versus 39.7%).*

Conclusions. *Levels of reporting of poor symptom control by professionals was much lower than levels reported by relatives in other studies, but there was no difference between the reporting of GPs and nurses. However, a number of areas were identified where care could be enhanced by improved teamwork and further education and training in symptom control, as well as in communication, use of services, and information provision.*

Keywords: palliative care; Grampian region; audit; questionnaire survey; cancer.

Introduction

ONE in three people develop cancer and one in four will die from it.[1] With an ageing population and longer survival because of earlier detection and improved treatment, there will be a steady increase in the number of people living with cancer. Primary care must be able to deal with this increase, as such patients spend 90% of the last year of life at home,[2] with most care being delivered by general practitioners (GPs) and primary care teams.

Although there have been a number of studies auditing care at home,[3–6] more information is needed about the range and severity of problems encountered by primary care professionals and the barriers that prevent optimal care in order to identify the educational and training needs of primary care teams. We conducted a study of primary care based palliative care in the Grampian region of Scotland. This paper presents the results of the first stage of a larger study to audit palliative care in practice.

Method

During the study, patients dying from cancer in the region were identified from the list of deaths provided routinely every week by the Scottish Cancer Registry, and their registered GP was identified by the Information Services Department of Grampian Health Board. Practice managers agreed to retain the records of patients dying from cancer in order to assist data collection.

Before the study, a number of GPs and district nurses were interviewed about the care delivered to recently deceased patients in their practice to identify the more important aspects of palliative care. After these interviews, a questionnaire was developed, which covered four key areas of care, namely 'symptom control', 'communication', 'use of services', and 'information' made available to patients and carers. 'Symptom control' questions asked about the presence or absence of common symptoms and the professional's assessment concerning the level of control of the symptom on a scale of 1 to 5, where 1 represented 'well controlled' and 5 represented 'poorly controlled'. Responders were also asked to rate their perception of the overall control of symptoms. Additional data were collected on the presence or absence of four major clinical problems, for which the concept of 'control' was less applicable (urinary and faecal incontinence, pressure sores, and oral infections) and the drug control of pain. 'Communication' questions asked if communication difficulties existed between patients, health professionals, and carers. Responders were then asked to rate the severity of perceived communication difficulties on a scale of 1 to 5, where 1 represented 'minor' and 5 represented 'major'. Responders were asked to rate their overall perceptions of communication problems. 'Use of services' questions asked if any common services were involved in the provision of palliative care and how early during the course of the terminal illness the services were involved on a scale of 1 to 5, where 1 represented 'early — soon after diagnosis' and 5 represented 'late — terminal phase'.

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'Information' questions asked responders to rate information given to patients and carers about self-help groups, specialist nursing services, financial benefits, diagnosis, and prognosis on a 1 to 5 scale, where 1 represented 'fully informed' and 5 represented 'not at all informed'. Similar questionnaires were developed for GPs and district nurses.

A pair of 'GP' and 'nurse' questionnaires was sent to the registered GP of every patient dying from cancer over a nine-month period from November 1992. A covering letter asked that the questionnaires should be passed on to the GP most involved in the care of the patient to establish whether a significant degree of palliative care, defined as 'at least three contacts over at least 14 days', had taken place in primary care. If a significant degree of palliative care had taken place in general practice, the doctor was asked to identify a nurse or other team member who was most involved with the care of the patient and to hand over the nurse questionnaire to that person. If no significant degree of palliative care in primary care had taken place, the doctor was asked to return the questionnaires uncompleted. There was a delay of approximately six weeks from the time of death to the mailing of the questionnaires. Practice managers were asked to ensure that the medical records were available for the GP to facilitate recall.

Analysis was undertaken using SPSS for Windows. Poor quality of care (for example poor symptom control, major communication difficulties) was considered to have occurred if responders had answered 4 or 5 to any question. There was a variable response rate to individual questions. In the results, the denominator for percentages is the actual number of responses for each item. Responses from the matched GP and nurse questionnaires were analysed using the McNemar test. To reduce the problems associated with multiple testing, we used a significance level of 1% and report exact P-values for results where $P<0.01$ but $P>0.001$. There were few statistically significant disagreements between the GPs and nurses in either the frequency of symptoms/problems or the perceived quality of care. Therefore, we present the data from the GP questionnaires and report any significant differences.

Results

Response rates

A total of 1086 pairs of questionnaires were sent over nine months, of which 964 were returned from doctors (88.8% response). Of these, 321 (33.3%) had not received a significant degree of palliative care as defined, leaving 643 for analysis. Altogether, 373 nurse questionnaires were passed onto the nurse by GPs, of which 325 were matched (87.1%). These 325 pairs of questionnaires were compared.

Symptom control

Table 1 summarizes responses from the GP questionnaires. There were no significant differences between GP and nurse responses in the matched questionnaires.

Doctors reported that urinary incontinence was present in 21.5% of patients, faecal incontinence in 15.8%, pressure sores in 19.3%, and oral infections in 25.2%. In the paired analysis, 77.4% of patients had received opiates during their terminal illness, and 47.7% had received opiates for longer than four weeks. Oral morphine was prescribed in 64.8% of the cases, diamorphine in 25.6%, and cyclimorph in 3.9%. The oral route was the last route of administration in 69.4% of patients, the subcutaneous route was used in 22.0%, and the intramuscular route in 7.2%.

In the paired analysis, nurses were more likely to report the presence of urinary incontinence than doctors (31.3% versus 23%, McNemar test, $P = 0.002$).

Communication

Table 2 summarizes responses from the GP questionnaires. Some communication problems were identified in 93.7% of patients. However, the prevalence of major problems was only 4.8%. In the paired analysis, doctors were more likely to report the presence of communication problems between the GP and patient (when compared with nurses; 43.9% versus 28.0%, McNemar test, $P<0.001$), and the presence of major communication problems (7.6% versus 2.8%, McNemar exact two-tailed significance, $P = 001$).

Use of services

Table 3 summarizes responses from GP questionnaires. In the paired analysis, doctors were less likely to report the involvement of occupational therapists (compared with nurses; 21.8% versus 39.7%, McNemar test, $P<0.001$).

Information provision

In the paired analysis, doctors were more likely to report that patients were 'not at all informed' about self-help groups and financial benefits (compared with nurses; 57.5% versus 36.3%, McNemar test $P<0.001$; 8.6% versus 2.5%, McNemar exact two-tailed significance $P = 0.002$ respectively).

Discussion

To our knowledge, this study is the largest case series of primary care provided palliative care. Collecting valid data on the quality of care in terminal illness is difficult because of the different perceptions and expectations of the different parties involved. In this study, data were self-reported by doctors and nurses on the management of individual patients. The validity of this approach in palliative care is uncertain. Studies of the quality of care in other areas have suggested that self-reported data tend to overestimate performance.[20] Similarly, in a study of palliative care in Cumbria, Herd[6] observed that health care professionals tended to report better levels of symptom control than carers. However, in another study of palliative care, Higginson and McCarthy[16] observed high correlation between patient's scores and team scores on the support team assessment (STA) schedule. We therefore think that our results should be interpreted cautiously and should be considered conservative, with real performance likely to be worse.

The reported frequency of symptoms is similar to that reported in other studies.[5] However, there were greater differences in the reporting of major problems. For example, in the current study, the reported prevalence of poorly controlled pain was only 16% (reported by doctors), whereas, in the *Regional study of caring for the dying*,[17] 47% of patients were considered to experience pain for which treatment by the GP gave only partial relief or none at all (reported by carers). This difference may relate to differences in data collection, differences in the perceptions of the responders reporting symptoms, or improving quality of pain management in general practice. In this study, the majority of patients who were reported to have pain received opioids by the oral or subcutaneous route for more than four weeks before death. These features are recognized as indicators of good practice in pain control.[18,19]

There was some evidence of suboptimal care. A small number of patients (7.2%) received drugs intramuscularly, which is more painful than the subcutaneous route (the preferred route of administration if oral medication is no longer possible). Sixteen patients (3.9%) had been given cyclimorph, which is generally considered to be inappropriate in palliative care because it has to

Table 1. Patient symptom control reported by GPs (all doctors: $n = 643$).

Symptom	Frequency *n* (%)	Poor control (scores 4 + 5) *n* (% of symptom)
Pain	556 (87.6)	87 (15.7)
Constipation	496 (79.4)	76 (15.3)
Anxiety	486 (77.5)	98 (20.2)
Nausea/vomiting	449 (71.6)	62 (13.8)
Agitation	415 (66.1)	75 (18.1)
Depression	410 (65.4)	86 (21.0)
Dyspnoea	352 (56.1)	74 (21.0)
Overall assessment of symptom control		80 (12.9)

Table 2. Communication difficulties reported by GPs (all doctors: $n = 643$).

Parties involved	Frequency *n* (%)	Major problems (scores 4 + 5) *n* (% of group)
GP/patient	285 (45.1)	49 (17.2)
Patient/hospital	208 (40.5)	45 (21.6)
Patient/relative	264 (44.8)	42 (15.9)
Patient/district nurse	132 (26.6)	18 (13.6)
Relatives/district nurse	87 (18.7)	6 (6.9)
District nurse/GP	62 (11.4)	3 (4.8)
Relatives/GP	191 (31.3)	18 (9.4)
Relatives/hospital	156 (33.7)	21 (13.5)
GP/hospital	153 (26.2)	23 (15.0)
District nurse/hospital	35 (9.5)	0 (0)
Other parties	32 (5.0)	5 (15.6)
Overall assessment of communication problems	577 (93.7)	30 (5.2)

Table 3. Involvement of services reported by GPs (all doctors: $n = 643$).

Service	Frequency *n* (%)	Late involvement (scores 4 + 5)
District nurse	458 (71.2)	119 (26.0)
Health visitor	139 (21.6)	20 (14.4)
Social worker	61 (9.5)	10 (16.4)
Occupational therapist	46 (7.2)	12 (26.1)
Physiotherapist	49 (7.6)	20 (40.8)
Macmillan nurse	115 (17.9)	54 (47.0)
Self-help	10 (1.6)	0 (0)
Marie Curie nurse	33 (5.1)	24 (72.7)
Night nurses	131 (20.4)	108 (82.4)
Other	68 (10.6)	11 (16.2)

Table 4. Information giving reported by GPs (all doctors: $n = 643$).

	Fully informed (score 1) *n* (%)	Not at all informed (score 4+5) *n* (%)	Don't know *n* (%)
Self-help groups	35 (5.4)	210 (32.7)	328 (51.0)
Specialist nursing services	166 (25.8)	86 (13.3)	236 (36.7)
Financial benefits	181 (28.1)	60 (9.6)	261 (40.6)
Diagnosis	426 (66.3)	13 (2.0)	111 (17.3)
Prognosis	356 (55.4)	20 (3.1)	117 (18.2)

be given intramuscularly and it is not possible to increase the dose without increasing the bulk of the injection and the concurrent dose of cyclizine.

Reported levels of nausea, vomiting, and constipation are higher than in the *Regional study of caring for the dying*, which might reflect the side-effects of more widespread opioid use.

The communication questions were asked in such a way that the responders might report any form of communication difficulty arising from deafness, confusion, and dysphasia, as well as problems of transmission of information between parties, inability to contact appropriate people, and difficulties with denial, collusion, and withdrawal. A total of 93.7% of patients were reported as having some degree of communication difficulty, although only a small proportion (5.2%) of these were perceived as major problems. Unsurprisingly, doctors appeared to be more aware of communication problems directly affecting them than nurses.

However, this does indicate a lack of sharing of information between health care professionals caring for patients.

The district nursing service is clearly the most frequent provider of supportive care to patients and carers, and nurses were involved in 76.7% of all cases. However, in 26% of cases, the district nurse was only involved at a late stage in the terminal illness, despite the fact that, in many situations, this can be very unsatisfactory for all concerned. Other services tend to be less involved. Macmillan nurses were involved in surprisingly few cases (28%), although there was a limited availability of home care Macmillan nurses at the time of the study. Social work, physiotherapy, occupational therapy, and self-help groups would all seem to be underutilized, although ignorance on the part of the GP about who is actually involved in the care was demonstrated, with nurses reporting far more frequent involvement of occupational therapists and greater awareness of self-help groups.

Two-thirds of patients had been fully informed about the diagnosis of cancer. Fewer (55.4%) were aware of the prognosis. There were, however, a substantial number of cases in which the doctor did not know whether the patient had been fully informed of the diagnosis and prognosis (17.3% and 18.2%). This might be explained in the cases of patients where more of the terminal phase was spent in hospital or the patient had died in hospital or was confused, demented, or in denial. However, it may indicate poor communication between health care professionals or a failure to consider this important aspect of care routinely. Disappointingly, few had been fully informed of the specialist nursing services, financial benefits available, and self-help groups. This probably indicates GPs' ignorance about the aspects of care or their beliefs that other team members might inform patients and carers of these services.

This study has identified a number of features of home-based palliative care in the Grampian region that suggest potential benefits from further education and training of GPs and primary care teams. With better training and appropriate use of current knowledge, the proportion of poorly controlled symptoms could be decreased further, and inappropriate opioid use discouraged. The communication difficulties described are many and varied. Services were frequently involved too late, and the provision of information was often lacking or patchy. There appears to be scope for improved team work to clarify the roles and responsibilities of team members and to enhance the sharing of information about communication difficulties, thus ensuring better coordination of care for patients and their carers.

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