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# Auditing palliative care in one general practice over eight years

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**Objective** – To document the delivery and outcome of palliative care in one practice.

**Design** – All appropriate deaths were documented over the period of the study.

**Setting** – One general practice of four doctors caring for 8000 patients in the North-West of England.

**Subjects** – All patients dying of malignant disease which had included a palliative phase of at least one week.

**Main outcome measures** – Place of death; continuity of care; general practitioners' assessment of symptom relief; follow-up of bereaved relatives.

**Results** – 118 deaths from terminal malignant disease were recorded over eight years in my practice. 75% were being cared for by us (GPs) at the time of death. More detailed information was recorded on 64 of these patients showing generally "satisfactory" care.

**Conclusions** – A simple audit can help maintain high standards of palliative care. General practitioners are encouraged to maintain registers of the care received by terminally-ill patients as an aid to quality assurance in this area.

**Key words:** palliative care, malignant disease, audit, general practice.

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Most patients with cancer in Britain still die in hospital (1). However, the majority could probably do so at home (2), where most would probably wish to be (3), cared for by their general practitioners (GPs).

There is evidence of room for improvement in the quality of care that patients and their families receive (2, 4-7). The challenge for educators is therefore "to stimulate and motivate colleagues to practise patient centred medicine in this difficult and demanding field" (7). Audit is a valuable method of education (8). However, palliative care facilitators in general practice have concluded that there are difficulties in developing audit systems for palliative care, and that audit methods used in secondary care need adaptation before they can be used in primary care (6). Furthermore, the main text on the subject (8) does not

specifically address the contribution that GPs can make to audit in this field.

In common with other GPs (9) we consider that palliative care is an important part of our work, which we seek to provide as effectively as possible. Since 1987 we have collected data on the place of death of all patients who had been terminally ill from malignant disease. I describe our experience in auditing palliative care in our practice, and show how this process has influenced us.

## Method

Our long-established urban practice cares for 8000 patients. The practice population is stable, with a turnover of 4-5% per annum, with 6.2% of patients aged over 75. The four partners have

*Table I.* Initial phase of the audit (June 1991 – February 1992). Doctors were simply asked to score each aspect of care as “satisfactory” or “unsatisfactory”.

Aspect of care	Satisfactory care	Unsatisfactory care	Not applicable
Pain control	10	1	1
Non-pain symptom control	10	1	1
Mental tranquillity	7	5	0
Family satisfaction	10	2	0
Patient's choice of place of death	7	5	0
Nurse liaison	10	0	2
Availability of aids	11	0	1
Continuity of care (medical)	11	1	0
Deputizing service informed	7	3	2

worked together since 1987, and our first trainee joined us in 1994. Most nurses have worked locally throughout the study period. Hospice facilities are available for only a tenth of the patients in our practice.

For ten years the practice has used a deputizing service to cover some out-of-hours calls. In 1991 I discovered, by chance, that I was not always informing the deputizing service of terminally ill patients. At the next practice clinical meeting, we discussed extending our data collection for ter-

minal illness from simply noting where patients die to a more detailed audit of the subject.

We “brain-stormed” criteria that we could examine and agreed upon nine (Table I). We included patients who died of malignant disease with a palliative phase of at least one week, and initially decided upon a simple satisfactory/unsatisfactory classification.

I drew up a questionnaire asking about each aspect of care, and gave it to the responsible partner when a patient had died after a terminal illness. We ran the audit for nine months, and then discussed the results at another clinical meeting.

It was then clear that a simple satisfactory/unsatisfactory classification was unable to provide us with enough information, and we therefore changed to a five point, 0-4 classification (0 is dreadful, 4 is excellent), similar to that devised by Higginson (8). We extended the aspects of care to include bereavement consultation and making a note in the spouse's records.

After a further review 14 months later we continued to use the same recording scheme. Details of individual patients were reviewed approximately annually so that we might consider how care could be improved in the future.

## Results

The place of death of patients over the eight years of the study is shown in Table II. In the 14

*Table II.* Place of death of patients with terminal malignant disease.

Year	General hospital	Own home	Nursing <sup>1</sup> home	GP community hospital	Other (incl. hospice)	Total
1987	0	3	0	4	0	7
1988	1	6	1	3	0	11
1989	0	7	4	4	1	16
1990-91 <sup>2</sup>	5	5	4	7	0	21
1991-92	5	5	1	2	0	13
1992-93	6	3	2	1	0	12
1993-94	5	8	2	1	2	18
1994-95	4	12	1	3	0	20
Total	26	49	15	25	3	118

<sup>1</sup> includes residential homes

<sup>2</sup> 15 month period from January 1990 to March 1991, inclusive. Otherwise years refer to 12 month periods.

*Table III.* Second phase of the audit (March 1992 – April 1993). Doctors were asked to score each aspect of care from 4 (completely satisfactory) to 0 (totally unsatisfactory). Scores of 3 or 4 were “satisfactory”; 2, 1 or 0 were “unsatisfactory”.

Aspect of care	Satisfactory	Unsatisfactory	Not applicable or unknown
Pain control	12	2	0
Non-pain symptom control	7	7	0
Mental tranquillity	9	5	0
Family satisfaction	12	1	1
Patient's choice of place of death	8	5	1
Nurse liaison	11	2	1
Availability of aids	11	2	1
Continuity of care (medical)	13	1	0
Deputizing service informed	13 (yes)	1 (no)	
Bereavement consultation	9 (yes)	1 (no)	4*
Note in spouse's records	10 (yes)	0	4*

\*not applicable

*Table IV.* Third phase of the audit (May 1993 – March 1995). Doctors were again asked to score each aspect of care from 4 (completely satisfactory) to 0 (totally unsatisfactory). Scores of 3 or 4 were “satisfactory”; 2, 1 or 0 were “unsatisfactory”.

Aspect of care	Satisfactory	Unsatisfactory	Not applicable or unknown
Pain control	33	4	1
Non-pain symptom control	32	5	1
Mental tranquillity	29	8	1
Family satisfaction	35	3	0
Patient's choice of place of death	33	3	2
Nurse liaison	34	0	4
Availability of aids	31	0	7
Continuity of care (medical)	36	2	0
Deputizing service informed	35 (yes)	3 (no)	
Bereavement consultation	18 (yes)	6 (no)	14*
Note in spouse's records	17 (yes)	0	21*

\*not applicable

months from February 1992 to April 1993, inclusive, we cared for 14 patients through their terminal illness. The results are shown in Table III. The 38 patients during the subsequent 23 months are shown in Table IV. Overall levels of performance in the care of 64 patients in the years 1991-95 are shown in Table V.

For ease of interpretation scores of 4 or 3 have been classified as “satisfactory”, and those of 2, 1 or 0 as “unsatisfactory”.

## Discussion

Only a minority of patients with cancer die at home (1), and the same is generally true in our district (10). However, a study of patients in a semi-rural area (West Cumbria, England) (2) showed that 53% died at home, and a further 9% in GP-run community hospital beds. A recent study in South Devon, England, showed that 33% died at home, 7% in residential care, and 22% in

Table V. Trends in care (June 1991 – March 1995). Patients with “satisfactory care”, as percentages of all those to whom it applied, in each phase of the audit.

Aspect of care	June 1991– February 1992	March 1992– April 1993	May 1993– March 1995
Total patients included	12	14	38
Pain control	89%	86%	89%
Non-pain symptom control	89%	50%	86%
Mental tranquillity	63%	64%	78%
Family satisfaction	83%	92%	92%
Patient's choice of place of death	63%	62%	92%
Nurse liaison	100%	85%	100%
Availability of aids	100%	85%	100%
Continuity of care (medical)	89%	93%	95%
Deputizing service informed	70%	93%	92%
Bereavement consultation	Not assessed	90%	75%
Note in spouse's record	Not assessed	100%	100%

community hospitals (11). Our figures are similar, with 54% dying in their own homes (including residential homes), and 21% dying in our community hospital under our care.

Although there were annual variations over the eight years (Table II), most patients continued to die at home. Data over this length of time are particularly useful, and I would suggest that the proportion of patients dying at home is an important measure of the quality of a palliative care service. The need for more hospices has been questioned from within the hospice movement (12), and it has been considered that the present state of about 15% of patients with advanced cancer dying in hospices may well be about right.

There is evidence of room for improvement in the quality of care that patients and their families receive (2, 4-7). For example, GPs in West Cumbria, England, reported that 14% of patients had uncontrolled pain (2), and 19% of GPs questioned in another survey considered that at least 20% of patients have unsatisfactorily controlled pain (13). Our figures were similar, showing that 13% of patients had “unsatisfactory” pain control, and thus demonstrating that there was scope for improvement.

Another study suggested that many doctors and nurses did not seem to recognize the importance of controlling symptoms other than pain (7). We found non-pain symptoms harder to control, and the absence of any clear trends in symptom con-

trol over time reflects our experience that these problems are not always open to ready solutions. In retrospect, some symptoms such as pruritus were beyond our ability to alleviate.

Jones et al. (7) considered that “Although care has improved greatly over the past 10 years... many doctors and nurses were unaware of the problems of carers... (for most of these deficits) the remedy lies with the health professionals”. We believe that, with most patients being under our care at death, relatives have the chance to make grievances known to us. Formally including the views of carers in an audit can raise ethical problems (8). In the last three years bereavement consultations have been held with at least one close relative of 79% of patients with such a person available, which gives us the opportunity to include the views of the families in our assessment. In a study of terminal care in a single practice, Blyth (4) concluded that bereavement consultations were useful, and that it was important to record deaths in relatives' case records. We agree: audit ensures that recording occurs, provides a useful aide memoire, and is a prompt to offer a bereavement visit.

Our experience is that almost all patients wish to die at home, and dissatisfaction was strongly associated with death away from home. We were usually able to maintain both nurse and medical liaison, although the simple expedient of informing the deputizing service remains a problem in

some cases. Wilkes (14) highlighted the difficulty in getting trusted, familiar out-of-hours advice in Sheffield. However, a decade later, 91% of carers in Devon had no difficulty in obtaining urgent help from a GP when they needed it (7). If continuity is to be maintained, it probably needs continued monitoring since a fifth of relatives questioned by Cartwright (13) expressed concerns about the absence or infrequency of visits by GPs.

Wilkes (14) also noted that there could be delays of four or even eight weeks in obtaining such basic equipment as incontinence pads or commodes. Aids have rarely caused us a problem: perhaps this aspect of service provision has genuinely improved?

Earlier research found deficiencies in care (4,9), but these have not always been addressed (5), and formal mechanisms for improvement have not been created (5). Practices need information to judge the quality of the services they are providing. Many practices have shown that they are willing and able to use audit to identify their specific weaknesses in palliative care (6). Furthermore the future development of palliative care in primary care requires appropriate audit methods (6). Palliative care is not easy to evaluate (15), and audit has an important part to play in this essential task (15). I believe our series supports the contribution that audit can make to the evaluation of services.

The strength of an audit such as this is as a method of evaluating the processes of care, rather than being a scientifically rigorous method of assessing outcomes such as pain control. It gives the providers of health care information about the nature and quality of the care they are delivering. It reminds them to maintain activities such as bereavement consultations and the recording of deaths in relatives' records. It gives overall proportions of events, such as those dying at home, that allow an over-view of the service. In short it gives primary care providers a reasonably brief means to start evaluating an important aspect of care.

The workload of GPs has received much attention recently. Although there is no reason to believe that GPs do not continue to consider terminal care an important part of their work (9), this must be delivered at a time of increasing pressures. Higginson (8) comments that all the teams who completed her 17-point audit of palli-

ative care would have liked fewer items: i.e. an audit should be simple, tried and tested, and not too time consuming. Our audit took only a few minutes per week to administer and collate.

We have shown that it is possible to audit this difficult but important area of practice in a way that reflects actual care and practice. It is generally an affirmative exercise: we were encouraged that our work was generally satisfactory or better, and had data showing where improvement may be possible. The approach of death emphasizes the uniqueness of each individual and family, but there are enough similarities for us to learn lessons, maintain standards and plan improvements.

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