

Palliative care

Guidelines for good practice and audit measures

REPORT OF A WORKING GROUP OF THE RESEARCH UNIT, ROYAL COLLEGE OF PHYSICIANS

Introduction

Palliative care is the active total care of patients whose disease is incurable. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families [1,2].

Palliative care is a multidisciplinary activity taking place in Britain in a variety of settings—hospital wards under the aegis of symptom control teams, palliative care units, or at home with a specialised team advising the general practitioner and the domiciliary nursing service.

Palliative medicine has recently been recognised as a specialty in the United Kingdom. Specialist medical training is available in centres which are approved for the purpose by the Joint Committee on Higher Medical Training. A requirement of such training is that audit measures are in place. This applies also to specialist nurse training. Since palliative care is a multi-professional activity, audit must also be multi-professional [3,4].

In order to develop and test constructive forms of audit, the Research Unit of the Royal College of Physicians in association with the Association for Palliative Medicine invited a multi-professional group to propose guidelines for good practice in palliative care in specialised inpatient units, and to propose audit measures whereby it might be seen whether that good practice was regularly achieved. The Working Group included representatives from medicine, nursing, social work, psychology, sociology, and a quality assurance consultant. Six background papers had been commissioned before the meeting on particular areas of interest and concern, as indicated by the headings in the text.* Circulation of these before the meeting allowed plenty of time for discussion, during which these guidelines were agreed.

Background

The characteristics of palliative care have been identified as attention to the whole needs of the individual, and the relief of symptoms whether physical, mental, spiritual or psychosocial. Care extends beyond patients

to their families. Common features are bereavement support, and the continuing education and training of professionals and those volunteers who are also deployed in meeting the needs of the patient and his or her family. Emphasis on the quality of life remaining for the individual, good communication between and among patients, families and staff, and strong multi-professional teamwork are also features of palliative care.

Some of the endpoints of palliative care may be difficult to assess in the context of audit. A peaceful or dignified death may mean one thing to patients and families, and yet another to staff. The way in which bad news is conveyed may have a crucial effect not only on the feelings of patients and families, but also on how they cope with dying and death. The Research Unit of the Royal College of Physicians has previously tried to ensure that published guidelines for good practice (eg [5]) are supported by published scientific evidence of effectiveness. In the case of palliative care, such scientific evidence is harder to find. The guidelines are the product of the experience of a number of colleagues coming from different disciplines concerned with the care of the dying, and reflect the emotional, ethical and practical needs of the patients, their family and of those who work in palliative care units.

These guidelines are to help doctors by providing an analytical framework for the evaluation and treatment of some common clinical problems. They are not intended to replace a doctor's clinical judgement, and are not necessarily the only way in which a particular condition can be managed. They do, however, provide a framework within which audit and review of clinical practice can take place. The guidelines reflect the views of the individual clinicians who attended the workshops.

Guidelines

Admission to a palliative care unit: the first 24 hours

Before admission

- Whenever possible, contact should be made with the patient and/or relatives before admission to reduce fears. The reason for admission should be clearly stated in the case notes. The admission procedure should be documented in a nursing

* See end of article.

standard and should be explained to new team members.

On admission

- The patient should be examined by a doctor within two hours of arrival.
- After a brief initial assessment of symptoms [6], a medical, nursing and other care plan should be completed, preferably with a doctor and nurse working together for some of the admission procedure. The plan should be recorded in the case records.

After admission

- It is essential that the patient and family have opportunities to express their feelings and needs, and to seek information. The family should be offered a meeting with one or two of the team members.
- The patient will need to be orientated to his or her new environment. He or she should be introduced to the other patients, shown the facilities, and have the routines of the palliative care unit explained.
- The first meal is an opportunity to demonstrate individualised care, and the patient should be asked about his or her special dietary requirements.
- On the first evening he or she should be introduced personally to the night staff.
- The patient's symptoms and problems should be reassessed the day after admission. He or she may need to be introduced to other team members.

Quality of the environment in a palliative care unit

The Working Group did not consider basic administrative aspects such as the security with which drugs are stored and dispensed, and precautions against fire.

The physical environment needs regular assessment by a small group of lay people with a special interest in hospice care, as well as by senior staff working in the hospice. The assessment should include:

- cleanliness, decor, comfort and privacy;
- the facilities for bathing and toileting, and for hairdressing, crafts and other diversional activities.

Assessment should also include:

- the quality of the catering,
- control of noise and of smoking,
- practical aspects such as the promptness with which the telephone is answered.

The staff establishment should be adequate to fulfil the care outlined in these guidelines. A Delphi exercise was conducted between 1986 and 1988 and some standards and guidelines for inpatient units were produced [7].

The psychosocial environment is also important. Staff should be friendly and efficient and accessible to

patients and relatives. They should respond quickly to questions that worry patients or relatives.

Expectations of the patients receiving care

The clinical and ethical value of including the expectations of patients and caring relatives in auditing palliative care outweighs the disadvantages of imprecise assessment. Recording patients' expectations encourages and indicates clinical perceptiveness. The expectations of patients and their relatives may be inconsistent and affected by emotions and inexperience, but they are often rational and pertinent.

The clinical records relating to identified problems should include the expectations of patients and their relatives and the proposed professional action. Realistic expectations may reinforce or modify management. Expectations causing or threatening distress merit the record of a plan to help the patient or relative to adjust. Unfounded expectations that comfort the patient or his carer should be noted, with proposed actions or inaction. Subsequent records should state if the plans were enacted, and if not, why not. They should also record subsequent changes in expectations.

Communication to the patient and his or her relatives [8]

A palliative care unit should have a policy for communicating facts and opinions between professionals.

Traditional measures of successful communication in health care have been concerned with outcomes following information given to the patient, and with patient compliance. Neither of these is appropriate in palliative care as not all patients wish for information. Denial is one mechanism for coping. Informed choice is more important than compliance.

Research concerned with measuring the communication skills of health professionals suggests that much work is needed in this area to improve health care. Effective assessment of the problems of patients and their relatives will lead to care being based on their actual needs rather than those assumed. Patients should be asked whether they feel able to communicate their changing needs.

Successfully addressing the problems identified on admission

A recent study has shown that the most severe problems on admission are control of symptoms and family anxiety. Significant improvements in relief of patient symptoms after intervention by a hospice team can be demonstrated by the Support Team Assessment Schedule [9], but this study showed that family anxiety proved difficult to relieve, and although ratings improved initially, anxiety and other problems recurred at death. The Support Team Assessment

Schedule enables team members to examine their work in more detail and to demonstrate the effectiveness of care.

Are those working in palliative care units able to deliver good care?

A palliative care unit should have written policies and procedures which ensure that access is not inadvertently denied to particular groups, eg those requiring admission within 24 hours of referral, or those of lower socio-economic status. A palliative care unit should use some broad measures of patient dependency. Such measures are being piloted in some areas, and are likely to prove to be a helpful tool.

Each palliative care unit should encourage and record the extent of formal and informal staff support and training, the rate of turnover of staff and sickness absence.

Audit measures

Admission policy

1. Are the different social groups in the catchment area of the hospice or specialised unit reflected proportionately in those admitted?
2. Is there a written policy about admissions, particularly in regard to those requiring urgent admission?
3. Is there a record of the reason for admission?
4. Is there a record of the waiting time before admission?
5. Is there a record of the main problems on admission?

Clinical management

6. Is there a record of previous problems and how they were treated?
7. Is there a record about the patient's pain, or was a pain chart completed at first assessment?
8. Is there a record of the patient's aims, expectations and objectives for each of his or her main problems?
9. Is there a record of an action plan and its outcome for each of the patient's main problems?
10. Is there a record of what happened to the patient in the first 24 hours after admission?
11. Were the action plans carried out or, if not, is there a record of the reasons for change?

Support of patients and relatives

12. Is there in place some system for monitoring the effectiveness of care such as the Support Team Assessment Schedule?
13. Is there a record of the patient's key relatives and

their aims and expectations for each of the patient's main problems?

14. Is there a record of whether and how the expectations of patients and relatives were met or modified?
15. Is there a record of the health and coping strategies of the principal carer or relative?
16. Is there a record of the availability of home resources?

Communication

17. Is communication of facts between professionals carried out according to agreed policies?
18. Are patients asked whether they feel able to communicate their changing needs?
19. Is there a record of these changing needs, and are these needs addressed?
20. Are problems of communication within families recognised and appropriate steps taken?

Documentation and administration

21. Do the records contain a final discharge or death summary?
22. Is there a record of the patient's degree of dependency in the hospice or inpatient unit?
23. Is the staff establishment adequate for the needs of the patients admitted? (See reference [8] and background paper (f))
24. Is there regular appraisal of staff linked to in-service and extramural training opportunities?
25. What support system exists for staff and are individual members aware of it? (Suggested questions to staff are available in background paper (b))
26. Is there a record of and regular review of staff absence and sickness rates?
27. Is there a record of satisfaction of patients and their carers with care? (Suggested questions available in background paper (c))
28. Is there a record of the views of a visiting team about the quality of the environment in the units, from the perspective of patients, carers and staff? (Suggested points to be checked available in background papers (b) and (f))
29. Is there a record of all audit meetings, the names of those attending them, the decisions reached, the name of the person nominated to enable necessary change, and a date for a review of the problems encountered at audit?

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Background papers. *The background papers prepared by some members of the Working Group (listed below) are available from the Publications Department, Royal College of Physicians, 11 St Andrews Place, London NW1 4LE, on payment of £6.00 for the set to cover costs of photocopying and*

postage. The Guidelines are available in soft cover, price £5.00.

- a. What should happen in the first 24 hours after admission to a hospice? By *P. Kaye* and *J. Phillips*
- b. How do we measure the quality of the environment and autonomy of the patient in the hospice environment? By *E. Wilkes*
- c. The expectations of the patients receiving care, and whether these expectations are met. By *J. Hinton*
- d. How do we measure whether the communication to the patient and his relatives has been successful? By *Ann Faulkner*
- e. How do we measure whether we have successfully addressed the problems identified on admission? By *Irene Higginson*
- f. Are those working in palliative medicine able to deliver good care? By *Anne Naysmith*

References

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- 6 Hockley JM, Dunlop R, Davis RJ. Survey of distressing symptoms in dying patients and their families in hospital and the response to a symptom control team. *Br Med J* 1988; 296:1715-7.
- 7 Harper R, Ward A, Westlake L, Williams BT. *Good practice in terminal care*. Department of Community Medicine, University of Sheffield Medical School, 1988.
- 8 Maguire P, Faulkner A. How to do it: improve the counselling skills of doctors and nurses in cancer care. *Br Med J* 1988;297: 847-8 and 972-4.
- 9 McCarthy M, Higginson IJ. Clinical Audit by a palliative care team. *Palliative Medicine* 91:5,3;215-21.
- 10 Higginson IJ, Wade IM, McCarthy M. Effectiveness of two palliative support teams. *J Public Health Med* (In Press-Feb 92).