Palliative care in the community: setting practice guidelines for primary care teams

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SUMMARY

Background. Previous studies have demonstrated deficiencies in palliative care in the community. One method of translating the results of research into clinical practice, in order to produce more effective health care, is the development of clinical guidelines. Setting standards for such care has been performed by care teams in both hospital and hospice settings but not in primary care.

Aim. This study set out to develop guidelines for primary care teams to follow in the provision of palliative care in the community using facilitated case discussions with the members of such teams, as a form of internal audit.

Method. Five practices were randomly chosen from the family health services authority medical list. Meetings between the facilitators and primary care teams were held over a period of one year. The teams were asked to describe good aspects of care, areas of concern and suggestions to improve these, in recent cases of patient deaths.

Results. In total 56 cases were discussed. All practices felt that cohesive teamwork, coordinated management, early involvement of nursing staff and the identification of a key worker were essential for good terminal care. Concerns arose in clinical and administrative areas but the majority were linked to poor communication, either between patient and professionals within the primary care team or between primary and secondary care. All the positive aspects of care, concerns and suggestions were collated by the facilitators into guidelines for teams to refer to from the initial diagnosis of a terminal illness through to the patient’s death and care of the relatives afterwards.

Conclusion. Developing multidisciplinary as opposed to medical guidelines for palliative care allows primary health care teams to create standards that are acceptable to them and stimulates individuals within the teams to accept responsibility for initiating the change necessary for more effective care. The process of facilitating teams to discuss their work allows for recognition and respect of individuals’ roles and more importantly provides shared ownership, an important contributory factor in the implementation of guidelines.

Keywords: palliative care; primary health care team; multidisciplinary care; recommendations and guidelines.

Introduction

Most people with a terminal illness would prefer to die at home1-3 but despite the fact that the greater part of their final year is spent in the community,4-5 the great majority of all deaths currently occur in institutions.6 Palliative care can be rewarding for both the relatives and professionals involved7 but previous studies have demonstrated a need for continuing audit and improvement in this area. Wilkes found that although 24% of relatives were grateful to their practitioner, 37% were critical of the care provided,8 while Blyth discovered the major reason for this dissatisfaction was poor communication, with doctors failing to provide anticipatory care and adequate bereavement counselling.9

One method of translating the results of research into clinical practice in order to produce more effective health care is the development of clinical guidelines.10 A review of 40 evaluations of clinical guidelines revealed improvements in the process of care in 37 studies11 but uncertainty regarding their introduction12 and effectiveness13 remains. Care of the dying in the community often involves joint assessment and decision making by the primary care team and therefore all members should be involved in its evaluation. Encouraging primary health care teams to develop their own guidelines appears to be more effective than having them imposed.14 Setting standards for palliative care has been performed in both a hospital setting15 and by a palliative care team.16 Although recommendations have been made by individual general practitioners,9,17,18 primary care teams do not yet appear to have developed their own guidelines.

The aim of this study was to develop a set of guidelines for primary care teams to follow in the provision of palliative care in the community using facilitated case discussions with the members of such teams.

Method

Five practices in Newcastle upon Tyne were randomly chosen from the family health services authority medical list, after they had been stratified for size and whether or not they were teaching and/or training practices.

Monthly meetings between each primary care team (as defined by the practice) and the facilitators (L R and R S) were held over one year. Two recent cases in which patients had died were discussed at each meeting. Half of the cases were chosen by the practice and half randomly selected from the Newcastle death database register.19 The critical incident technique,20 which has been shown to be acceptable to primary care teams,21 was used to structure the case discussions. The team were asked to describe good aspects of care and areas of concern related to the care provided during the patient’s final illness and death.

The case discussions were audiotape recorded, the transcript made anonymous and the tape then erased. From the transcript a feedback sheet was produced and sent to the practices within two weeks of the discussion.

Review sessions were held after discussing 10 cases (first review) and at the end of the year (final review). The aim of these sessions was to reconsider the areas of concern and see if suggestions made during the original case discussion had been acted upon. If not, the facilitator encouraged the team to identify individuals to accept responsibility to initiate change. The issues arising in both the first and final review were collated by L R and a protocol for the management of the dying and bereaved in primary care developed.

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Results
All five practices agreed to participate in the study. However, the single-handed general practitioner withdrew from the project and the four cases from his practice were therefore not included in the results. Three practices completed up to the final review and one to the first review. In total, 56 cases were discussed.

Between three and seven general practitioners worked in each of the four participating practices; list size varied from 5000 patients to 14 000. They all employed receptionists, practice managers and practice nurses, and had at least one attached health visitor and two district nurses. Two of the practices were teaching practices and two were training practices.

Aspects of good care and areas of concern identified by the practices were collated. All practices felt a good service could be achieved by effective teamwork, for example involving nurses at an early stage, agreeing joint management decisions, providing adequate day and night time care and ensuring carer/family support. Two practices stated that to ensure continuing quality of care the team should be prepared to accept responsibility for concerns identified in the audit and to act upon them. The identified areas of concern could be divided into three areas: communication, clinical care and administration.

Communication
All practices felt that intra-practice communication concerning terminally ill patients needed to be improved. For example, other partners and trainees needed to be aware of the patient’s knowledge of his or her illness and prognosis, the proposed management and medication plan and any deterioration in the patient’s condition for on-call cover. It was suggested that an individual general practitioner take responsibility for each patient and document the information fully in the patient’s medical notes. This general practitioner should also inform the duty doctor of the changes in the patient’s condition but, where possible, provide a home telephone number for emergency use to ensure continuity of care. The possibility of discussing such patients in team meetings to update all concerned was raised.

One practice was concerned that the knowledge of a patient’s death had not been disseminated to all members of the primary care team and other health care professionals involved. The suggestions from all practices to ensure good communication of a patient’s death included: a practice information board to record patients’ deaths and possibly other information, for example, hospital admissions/referrals, discussion at team meetings of recent deaths and creation of a standard computerized letter to be sent to the hospital consultant(s) concerned.

For patients dying in hospital one practice felt there was an unacceptable delay in both informing the primary care team of the death and in receiving more detailed information such as the hospital inpatient summary and post mortem information. The general practitioners felt they should be informed within 24–48 hours of a patient’s death in order to provide immediate bereavement care to relatives, and they initiated an internal audit to collect the above information and feed back the results to the hospital.

Clinical care
In all practices the district nurses routinely documented the carer’s/next of kin’s name and contact address in their nursing notes. The doctors in one practice considered this information sufficiently important to be also recorded on the front of the medical notes. District nurses were concerned that the special attendance allowance for terminally ill patients was completed at too late a stage by the general practitioners. In future, it was suggested that the application for this could be jointly completed.

The inconvenient discharge of terminally ill patients from hospital into the community, for example on Friday afternoons and during bank holiday weekends, could be avoided by prior liaison with the hospital. Bereavement visits had not occurred in two cases in one practice. The general practitioners involved felt this service should automatically be provided and an internal mechanism, for example an additional column on the practice death board or an appropriate space in the visiting book, should be developed to ensure this omission was not repeated.

Effective symptom control, especially pain relief, was considered important. In one practice, a general practitioner had discovered an essential drug missing from the emergency bag while on call. A member of the team suggested that the responsibility for keeping the drug supply up to date should be allocated to an individual and the practice nurse agreed to take on this task.

Administration
In all practices, general practitioners did not record every visit to a terminally ill patient in the notes and one practice raised this as a concern. The practices thought that a patient’s death should be recorded in the medical notes and/or on computer. It was also considered important to note the patient’s death in the spouse’s and first degree relatives’ notes (if they were patients of the practice), as this would increase other team members’ awareness of their recent bereavement and may improve early detection of consequent physical and psychological morbidity. This could also provide a mechanism for identifying patients requiring preventive care, for example the offspring of a patient dying from coronary heart disease at an early age.

Development of guidelines
All the positive aspects of care, concerns and suggestions were collated and a protocol for providing good care to the dying and bereaved was developed (Table 1). This was constructed as guidelines for primary care team members to refer to, from the initial diagnosis of a terminal illness through to the patient’s death and the care of relatives afterwards.

Discussion
The critical analysis of cases2 and the opinions of the primary care team members have individually been demonstrated as a means of identifying changes to improve palliative care in the community.17,23,24 This study combined both approaches within facilitated case discussions to provide an internal form of audit by which the primary care team could set their own standards of care. By collating the criteria defined in a number of practices, a set of guidelines was constructed for use as a basis for future audit in general practice. Multidisciplinary guidelines are much more likely to be accepted by the primary care team than medical guidelines.25,26 The process of facilitating teams to discuss their work allows for recognition and respect of individual roles and more importantly, produces shared ownership, an important contributory factor in the implementation of guidelines.27,28 The success of facilitated case discussions depends on the facilitator encouraging the team to provide their own standards rather than imposing his or her own; two practices independently stated that an important part of the audit was not only to recognize areas of concern but to formulate actions constructively to prevent such problems occurring in the future. This echoes existing concerns that the implementation of guidelines requires more thought than their development.29 Initial findings suggest that individual practices implemented a proportion of the guidelines but the final evaluation, to determine whether the audit cycle was completed and the guidelines produced improvements in care, is still in progress. The argument as to whether the application of
guidelines should remain voluntary or became a compulsory part of clinical care remains.10 At a recent workshop on clinical guidelines sponsored by the Department of Health, a suggestion for the use of contracting as a means of encouraging service providers to follow clinical guidelines was made.29 This would obviously contravene clinical freedom and potentially shift responsibility for clinical standards from the medical to the managerial profession.29

All teams in this study felt that cohesive teamwork, coordinated management and the identification of a key worker were necessary for good terminal care, and central to these is effective communication.1 This study has demonstrated, however, that inadequate communication is still a major problem in palliative care in practice. Concerns were identified in all areas of communication; between patient and professionals, within the primary care team and between primary and secondary care. This can lead to inappropriate management decisions (a trainee admitting a patient to hospital in a crisis instead of mobilising more resources to continue home care), unnecessary distress to patient and family (receiving an outpatient appointment after the patient has died) and embarrassment for health professionals (the district nurse arriving for a routine visit unaware that the patient had died a few hours earlier). The protocol developed in this study has demonstrated a number of mechanisms which could easily be incorporated into practice routine, for example writing both the patient’s and family’s knowledge of the disease and prognosis in the notes, recording the patient’s death on an information board within the practice and sending a letter to the hospital staff concerned after the patient’s death. This could improve communication and ultimately reduce the patient, carer and professional dissatisfaction that has been demonstrated in previous studies.9 Reilly and Patten found that almost half of their terminally ill patients had used secondary care in some way (brief admission, outpatient appointment or domiciliary visit) but in more than one third of these instances, the general practitioners reported inadequate communication from the hospital concerned.3 One practice in the present study audited their notification by the hospital of patients dying in secondary care. The initial results revealed an unacceptable delay, and despite an assurance from the hospital that this would improve, the doctors are continuing their audit. Similar to recommendations in earlier research, one practice suggested that improvements in primary-secondary care communication could be produced by specifying time limits for the initial notification of a patient’s death to the primary care team,32 and where relevant, a copy of the post mortem report should be automatically sent to the general practitioner.33

Blyth suggested that two skills essential for good palliative care were ‘intelligent anticipation of problems and well planned use of the many services available in the community’.9 The guidelines developed in this study recommend early referral of a terminal patient to the district and, if appropriate, MacMillan nurse. This could allow information on nursing aids, financial allowances and respite care to be provided sooner rather than later and promote joint clinical decision making. Blyth’s study

**Table 1. Practice guidelines for the management of the dying and bereaved in primary care.**

**Diagnosis and initial management**
- Discuss fully and honestly with patient and relatives
- Record above in notes, for partners’ and trainees’ information
- Involve district and MacMillan nurses at an early stage
- Complete special attendance allowance form (DS1506) with nurse at appropriate time
- Record principal carer/contact person on front of medical notes plus phone number and/or address

**Throughout illness**
- A named GP and district nurse to assume responsibility for a patient
- Provide effective symptom control, especially pain relief
- Provide effective teamwork — joint discussion of clinical problems; coordinated home visits
- Communicate regularly with other health care professionals
- Discuss patient in team meetings, to update members
- Communicate regularly with other practice GPs
- Arrange in-practice cover if named GP absent
- Inform on-call doctors of changes in patient’s health — GP to consider providing own home phone number for emergencies
- Ensure carer support

**Administration**
- Record all visits in the medical notes, for medico-legal purposes
- Record management plans and medication changes in notes
- Liaise with hospital/hospice if patients admitted, to avoid inconvenient discharge times
- Keep emergency drug supply up to date

**For a patient dying at home**
- Record death in patient’s notes/on computer
- Record death in notes of spouse/offspring, for partners’ and trainees’ information — could utilize team meeting to identify names of relevant family members
- Contact hospital to cancel appointments and inform medical staff (standardized letter on computer to hospital consultants involved in patient’s care)
- Inform other members of primary health team: death board in practice; add to agenda of team meeting
- Develop an internal mechanism to ensure bereavement visits carried out by GP who was involved in terminal care if possible
- If appropriate, use patient’s death as a means of offering preventive care to relatives and develop a mechanism to recall such patients

**For a patient dying in hospital**
- GP should be informed within 24-48 hours of patient’s death in hospital, to provide bereavement care to relatives
- GP should receive written information about a patient dying in hospital within an acceptable time period to allow accurate discussion with relatives

**For all patients’ deaths**
- Be prepared to talk through a difficult case as a team, audit quality of care provided and act upon identified concerns
also showed that although all the relatives were initially visited for bereavement counselling, only half had received a further visit three months later.8 Many families stated that ‘there was no point to bereavement counselling as nothing could be achieved by it’ and the interviews revealed that the initial impetus to discovering bereavement problems may have to be doctor-initiated.9 None of the practices in this study had a formal method for ensuring that both immediate and future bereavement visits were performed. However, they felt that an acceptable system should be created to ensure that such a service was not omitted in the future. It has long been recognized that there is an increase in both physical and psychological morbidity in the surviving spouse following a partner’s death14 and all primary care team members should be aware of a patient’s recent bereavement. Recording this information inside the medical records would increase staff awareness and hopefully allow early detection of physical and mental illness.

It is worrying to discover that some of the concerns elicited in this study reiterate anxieties found in previous research8,9,11 and formal mechanisms have not been subsequently created to improve such an important part of community care. This study has revealed the views of four primary health care teams about providing good, acceptable palliative care, and guidelines which could be used by general practice as a basis for clinical care and future audit have been developed. The process of developing multidisciplinary, as opposed to medical, guidelines allowed the teams to create standards that were acceptable to them and stimulated individuals within the teams to accept responsibility for initiating the change necessary for more effective care.

References

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