Specialist Palliative Care within the Acute Hospital Setting

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The hospital-based specialist palliative care service is the latest extension of the hospice movement in the UK, bringing the message of specialist palliative care back into the hospital setting. There are now over 200 palliative care services within the acute setting, including 76 specialist palliative care teams. The composition, advantages and disadvantages of such teams are described, and the challenge and importance of evaluating these services are discussed.

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INTRODUCTION AND EVOLUTION OF HOSPITAL-BASED SPECIALIST PALLIATIVE CARE

The evolution of palliative care as a specialty has clearly had its roots in the hospice movement, influenced by the teaching/research-based hospices first established by Dame Ciceley Saunders in the late 1960s. At that time it was necessary to establish the focus for the care of the dying outside the acute hospital setting. Amidst the explosion of medical science in the early part of the 19th century 'death' was regarded as a failure. The hospice movement was a natural swing of the pendulum to redress the balance towards holistic care in terminal illness.

The building of hospice units in the UK meant that there was a forum for concentrating on patients' pain and symptom control as well as their psycho-emotional needs rather than the disease process itself. Gradually there was a need for specialist home care teams so that patients could return home once their symptoms were under control. Thirty years later this ripple effect has come full circle back into the acute hospital setting, with the establishment of palliative care teams (see Fig. 1). The evolving concept of a consultancy team advising on the care of terminally ill patients within the acute hospital setting has been given a variety of names: symptom control teams, support care teams, or terminal care support teams. Now in the 1990s palliative care teams/services/programmes is the name most commonly used for this type of service (1).

As early as 1973, Cartwright et al. (2), in their nation-wide UK study on the care of the dying, stressed the importance of disseminating hospice expertise more widely into the geriatric and acute ward situation, so that all terminal patients could benefit. St Thomas' Hospital (3, 4) was the first hospital in the UK to consider the concept of a peripatetic palliative care team, based on the experience of a similar team at St Luke's Hospital, New York. Despite being an advisory service, the team was able to facilitate a level of symptom control that enabled many

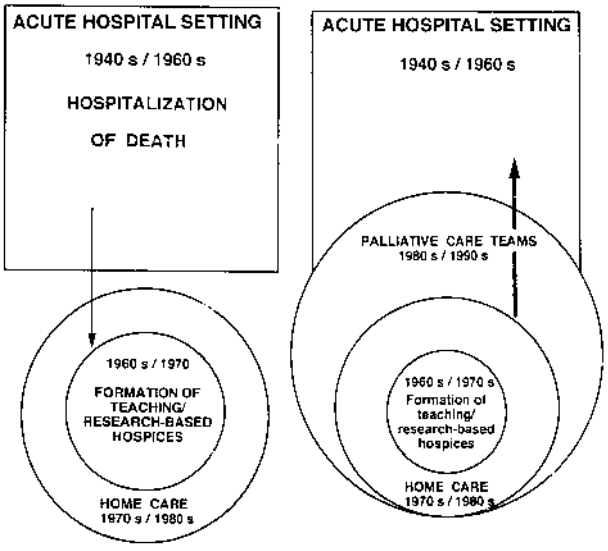

Fig. 1. Evolution of specialist-palliative care in the UK, showing ripple effect of hospice services to home care, back into hospitals via hospital-based palliative care teams.

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Table 1

St Thomas' Hospital terminal care support team statistics

	1st year* 1978	3rd year* 1980	8th year** 1985
Hospital deaths (%)	70	58	58
Home deaths (%)	16	24	17
Hospice deaths (%)	14	18	25

*Lancet (1981) (2).
**Eighth Annual Report (1985) (3)

patients to be discharged home. Within the first three years of the team's existence the percentage of patients referred to the team who died in hospital was reduced from 70 to 58. However, subsequent reduction in hospital deaths was not maintained (see Table 1). The experience of St Bartholomew's Hospital Palliative Care Team is similar—despite a desire to promote hospice home transfer, still 60% of patients referred to the team died in hospital. The reasons given were, unexpected deterioration while undergoing active treatment or investigations, relatives unable to cope with home care, late presentation precluding transfer, and waiting for transfer to hospice (5).

WHY DID SPECIALIST HOSPITAL-BASED PALLIATIVE CARE TEAMS EVOLVE?

The fact that so many cancer deaths still occur in hospital is probably one reason for the ripple effect of specialist palliative care being drawn into the acute hospital setting in the form of hospital-based palliative care teams. Despite the establishment of hospices and their home care teams the majority of people still die in hospital. First, the unpredictability of the terminal phase of a non-malignant disease will always mean that admission to hospital is likely in case this is not a final event. Secondly, patients with a non-malignant disease are unlikely to be accommodated within a hospice setting precisely because of the unpredictability of prognosis. Thirdly, hospice education needs to be given not only where the majority of people die, but where professionals are exposed to it during training. Too often the people attending hospice education courses are those nurses, doctors, and social workers who are already converts to the practice of palliative care. Hospice education needs to be made available to those who care for the dying as part of their day-to-day surgical/medical practice. The peripatetic palliative care team therefore not only plays an important part in advising on good palliation of symptoms while patients remain in the acute setting, but also takes part in the education of nurses and doctors while in training in the acute hospital setting.

There are now around 76 palliative care teams in the various university hospitals in the UK and 132 other hospitals have nurse specialists advising either solo or as part of a team. The ideal model is that of a multidisciplinary palliative care team. However, some hospitals struggle with the financial outlay of such a service and may rely on a consultant being available from a local hospice unit.

COMPOSITION AND AIMS OF PALLIATIVE CARE TEAMS

The palliative care team usually comprises nurse specialists, a social worker, a doctor and, more occasionally, a psychologist. Many hospitals have started a team with the bare essentials, from which a service has been built up. These positions have often been funded by drug companies or various charities for a 2–3-year period and then taken over by the hospital/health authority. The size of the team is important—not so small that the team becomes overloaded with the amount of work, but not so large that it becomes unwieldy. Little research has been done on the best team size against caseload, but the average team working within a hospital of about 800 beds would probably include two nurse specialists (full-time) to bring 'continuity' to the changing environment of a university hospital, a consultant in palliative medicine (full- or part-time), a secretary/co-ordinator (full-time) who has an interest in the caring work done over the telephone with the relatives and patients before and after a death, and a psychologist (part-time) or social worker with experience in family work and anticipatory/post-death grief (full- or part-time). If the expertise is to be disseminated to other areas of acute hospital care, such as respiratory or care of the elderly, then it is crucial that such a team reflects a multidisciplinary emphasis.

There are six major aims concerning the role of a palliative care team (6); these should be incorporated into the everyday function of a team:

1. To work alongside the ward team caring for terminally ill patients by advising on symptom control and psychosocial/existential issues.
2. To provide extra counselling and support to relatives where there is particular distress/anger, young children, or a previous difficult experience involving the death of a relative.
3. To provide support and advice to the staff caring for these patients and experiencing difficulties with more complex grief situations.
4. To take part in multidisciplinary education relating to issues of palliative care:
   - informally at ward level
   - formal lectures
   - writing of booklets/guidelines
5. To act as a bridge to existing hospices/home care services.

6. To audit and research areas of interest within symptom control and issues surrounding the emotional impact of dying within the acute hospital setting.

Referrals to a palliative care team come either through the doctors or the charge nurses on a ward. It is important that the senior doctor in charge of the patient agrees to the palliative care team's involvement. When there is a doctor in palliative medicine associated with the palliative care team, then referrals will more than likely involve advice on pain and symptom control. More often than not, however, once the patient has been seen, other problems are identified. Having a multidisciplinary emphasis to the palliative care team means that most difficulties can be addressed by a specialist in the care of the terminally ill. The constant flow of referrals can be taxing for the less experienced members of the team. Most team members are unlikely to work effectively if they see more than three new patients each a week as well as the remaining patients and team commitments.

Most palliative care teams set out to apply hospice-care principles to patients and families facing end-stage, non-malignant disease and so disseminate hospice philosophy to other areas of medical care. This is particularly important in aspects of pain and symptom control associated with renal disease, rheumatology, care of the elderly, and so on.

ADVANTAGES OF A SPECIALIST PALLITIVE CARE TEAM

The palliative care team represents a visible standard of care for the dying. It is more difficult for a suboptimal practice of care for the dying to be practised if ward staff are being reminded and supported by a specialist palliative care team. These teams provide continuity of care for patients and their families amidst a changing hospital scene of staff rotation.

The knowledge and skill of symptom control and the psychosocial aspects of care for both patient and the family can be shared and passed on through interaction with the palliative care team. Teaching at ward level both informally via a 'role-model' method as well as through seminars enables the immediacy of communicating psychosocial skills of the dying to be taught. It is difficult to teach these skills didactically.

A further advantage of the palliative care team within the acute hospital setting is that it brings hospice expertise to those patients who do not want a hospice transfer or for whom a non-malignant disease precludes transfer to a hospice facility. Such a team is a resource for other professionals, making the hospice relevant to all terminally ill patients and their families and not just to cancer patients. Good symptom control is by far the most applicable area of hospice care within the acute setting. Symptom control and appropriate care can therefore by maximized at an earlier stage in the disease process.

When there is a specialist palliative care team based in the hospital, it can act as a bridge to hospice home care services and hospice units. This 'bridge' can effect a greater seamlessness of the service to patients and their families facing a terminal illness. These teams are reasonably inexpensive to run, as they operate within the existing hospital structure. Expenses can often be shared throughout a number of specialities, as most areas of care within a hospital are exposed to difficulties associated with terminally ill patients and their families.

DIFFICULTIES ASSOCIATED WITH PALLIATIVE CARE TEAMS IN THE ACUTE SETTING

Bates (3) stresses that the presence of a hospital palliative care team can cause potential confusion over who is responsible for care. It is important to remember that however involved a team member may be with a patient, the responsibility for care rests firmly with the consultant in charge of the patient. Generally there is no problem. Few teams have the right to admit patients and patients are admitted on the referral of their consultant surgeon/physician.

There is always the danger of a palliative care team, that was meant to improve the standard of care, becoming an agent for 'de-skilling' those at ward level. Team members must remember that they should be modelling a palliative care role not 'taking over' the care. When ward staff are busy and appear harassed, it is all too easy to make this the excuse for doing the care work oneself, for example, writing out a prescription if one is the doctor on the team, phoning the general practitioner or community nurse. It is vital to remember that if one takes over this task, then the staff will no longer think this is something they should be doing. One is there to advise, not to take over the care.

Advising on palliative care issues within the context of an acute hospital setting will inevitably sometimes be a compromise compared with the care and time available within the hospice setting. For those members on the team who have come from a hospice background, this compromise can sometimes be difficult. Prescriptions often do not get changed straight away. Sometimes suggestions written in the medical notes will be challenged. The team member then needs to be able to make it perfectly clear why a certain drug or intervention has been suggested. Evidence that has been published can be very useful.

As team members become known and the workload increases requests for new referrals can sometimes be overwhelming. It is important to set boundaries and be able to adhere to them. It may be that if a team comprises only nurse specialists, then the decision not to accept referrals of patients with a non-malignant diagnosis needs to be enforced. This is sometimes difficult, but it can also be used by the team to request for a specialist doctor to join the team.

Palliative care team members run the potential risk of conflict, not only as it interfaces on the ward but also within the team itself. Respecting the fact that ward staff have their own expertise which may not be in palliative care is particularly important in preventing antagonism. The difficult and challenging situation of a hospital often tends to attract strong personalities onto a specialist palliative care team. It is important for team personnel to be able to uphold their ideas, but this should be done through skill and expertise rather than an overly strong ego. Roles within a team are less well defined than the normal roles of healthcare workers within the hospital setting. The nurse specialists' role in particular is blurred. The extension of such a role through knowledge in symptom control and counselling advice needs to be recongized. However, the doctor or social worker on the team needs to be secure enough in their own expertise not to be undermined by the overlap in roles. The physician's role in particular is there to confirm advice regarding pain and symptom control, and to be able to challenge greater emphasis on the education of junior doctors in the care of the dying. Research into various analgesics and anti-emetics within the field of palliative care can only be stimulated by the presence of a specialist in palliative medicine.

EVALUATION OF SPECIALIST HOSPITAL-BASED PALLIATIVE CARE TEAMS

Evaluation of hospital palliative care teams has been the subject of an on-going debate. Four years after the establishment of the palliative care team at St Bartholomew's Hospital, London, indicators showed that complaints from relatives of patients who had died in the hospital had fallen from a consistent 8.6% of all complaints to 1% over a 6-year period (7). Obviously, a full evaluation of such a team relies much more on identified outcome measures than just a complaints indicator, but is none the less a complex task. Colleagues at the Western General Hospital, Edinburgh are just about to undertake a full evaluation into the effectiveness of the hospital-based palliative care team. They will use a quasi-experimental design using the surgical directorate in the hospital as the experimental arm and compare it with two surgical directorates with no on-site specialist palliative care as the control arm. They will not only be measuring patient and family outcome, but will also look to the attitudinal change, knowledge and experience of both medical and nursing staff within the directorates.

CONCLUSION

In conclusion, I believe that patients should be allowed to die where they feel most comfortable. Whether this is at home, in a hospice or within the acute hospital setting, there should be the expertise available to deal with distress. There are definitely some patients who like the hustle and bustle of the acute hospital setting. The on-site specialist palliative care team in the acute hospital makes a cost-effective way of not only providing support and advice for the terminally ill, but also represents an educational resource for those nurses and doctors in training. My philosophy on the care of patients who are terminally ill wherever they choose to die is best summed up in the following quotation: 'Death must simply become the discreet but dignified exit of a peaceful person from a helpful society without pain or suffering, and ultimately without fear' (8)

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