Terminal Care: How can we do Better?

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In any major organisation it is likely that a majority perform their duties satisfactorily yet without distinction, and a minority at each end of the spectrum perform exceptionally well or exceptionally badly. This also applies to terminal care, and a recent survey[1] has attempted to quantify this quality of performance by interviewing recently bereaved relatives. These may not be conspicuously reliable or accurate as witnesses, but their opinions will at least be of interest in their comparative ratings of doctor and nurse.

The design of the survey mimicked the national pattern by analysing a sample of two deaths in hospital for each death at home.

The relatives in a quarter of cases praised with respect and affection the care given by their GP, although the hospital nurse, closely followed by the hospital doctor, were slightly more often praised, in nearly a third of cases.

But the relatives found fault—sometimes with bitter criticism and great resentment—with both GP and hospital too often for our comfort.

The GP in 16 per cent of cases did not seem interested, did not explain, did not examine, did not visit except on demand, and the visits were grudging, brief, inadequate and revolved excessively and improperly around the repeat prescription that is so often the symbol and token of second-rate care. Symptom control was often unsatisfactory despite this eagerness to prescribe and move on.

When the GP was praised, it was because the doctor seemed to care, to be interested, to respect patient and relative, to visit regularly and also (when they lived in the area) to give them their home telephone number in case of urgent need, to explain things, and to check how well drugs were working before repeating the prescription.

The hospitals were criticised for their uncaring approach in a quarter of cases. Doctors or ward sisters were evasive, information had to be pursued too often by the relative, it was not often efficiently conveyed, and too rarely shared adequately among members of the firm so that different doctors were saying rather different things.

There was also disquiet, not at elderly relatives dying but becoming, near the end, confused or drowsy strangers as a result of what the relatives saw as pointless or degrading overtreatment.

Such complaints point towards the specific problems that need tackling and, since the hospices look after only 5–10 per cent of deaths, despite their expansion to nearly 100 units, this demands training on a large scale for both hospital and community.

Training

Fortunately, training is well under way. Various approaches are being tried. Edinburgh preclinical students talking with advanced cancer cases, Sheffield students visiting them in their own homes, and the education of Belfast students in this fascinating and important subject[2] are all examples of a general trend. Indeed, the majority of medical schools not only take more interest in the care of the dying than 25 years ago, but have a nearby hospice as a reservoir of patients and teachers who help to set the local standards of terminal care.

At postgraduate level the situation is less satisfactory. The demand for a module of hospice training far exceeds the supply. There are comparatively few registrar posts in the hospices and only very few general practice vocational schemes include a hospice module, for all the relevance and value of such an experience. This will need correcting over the next decade and it is good, but not good enough, that some national charities are concerned enough to consider helping with the funding of some such posts.

The ritualistic lectures held for family doctors at so many postgraduate centres are usually attended only by those who do not need to be there. A better idea is to invite whole practices, receptionists, doctors and attached nurses, to meetings, perhaps in the local hospice, together with several neighbouring practices, to discuss their management of terminal cases at local level, with videos and a problem-solving approach. This provides some access at least to the doctors in greatest need.

Meetings of hospital firms or primary health care teams should discuss regularly the deaths of those under their care, to see how lessons can be learned and standards raised.

Postgraduate centres and medical schools should hold occasional clinico-pathological conferences which start with the GP describing the patient before the illness, continue with the hospital doctors describing steps in diagnosis and the acute treatment, then on to the terminal hospice care to end with a discussion on the management of the bereaved relatives’ problems. This will accelerate the integration of hospice expertise with traditional resources that we must achieve.

With ageing relatives, marital breakdown, and loser family ties generally, it is reassuring to see how hard families try to cope with a dying relative. This has been well recognised by the geriatricians[3] but not necessarily by the system; too often an expensive hospital bed is more quickly available to a dying patient than incontinence...
pads, a commode or other simple essentials for home care. Yet home is not always suitable for terminal care and we know that the needs of the relatives require admission of the dying patient more often than the needs of the patient. This makes it clear that the management and support of the family are as central in terminal care as the efficient control of symptoms. There needs to be a more family-centred approach that is not yet well taught in our medical schools nor easily practised in busy hospitals. Basic techniques of family therapy need to be marketed more aggressively to both doctors and nurses, and to be developed among hospices personnel.

But this broadening of the professional role inevitably takes the doctor and the nurse beyond the bedside and the laboratory. Despite the admirable clinical symposia recurrently held at such centres as St Christopher’s, London, Michael Sobell House, Oxford and St Colombus’, Edinburgh, we need the clinician to understand something of leadership, of team-work, of the functioning of small groups and of the other outside assistance available for patients within the system ranging from social services to the voluntary sector. This is partly why management training for newly-appointed NHS consultants has been so rapidly developed. It should also be available to senior colleagues, who may be unhelpfully set in their ways. We need to remember that most patients seeking the comforts of fringe medicine have previously been dissatisfied with conventional medical care of a less than distinguished quality. Terminal care is thus another area requiring management skills.

It is impossible in the care of advanced cancer to ignore the role of the nurse. So far as the patient is concerned, she may well be a more central figure than the physician. Training in the schools of nursing has, as with doctors, greatly improved over the last decade yet is still of variable quality. This may mean that more senior colleagues are less well trained than their juniors, a phenomenon not unknown to medicine.

The English National Board runs in some 15 centres approved full-time six-week courses on the care of the dying and their family. These improve the confidence and background of already interested and experienced nurses. The course explicitly does not claim to produce specialist nurses yet is routinely misused to that end. We need to plan for an advanced course to take such experience further; pilot courses are already being worked out.

Since most major centres now have a hospice within reach, it has been found of the utmost value to arrange temporary exchanges of nursing staff between hospice and acute wards. The hospice staff gets updated, and they learn again to respect their nursing colleagues from the local hospital. This mutual respect is also learned by the visiting hospital nurse and the acute wards become influenced by the detailed nursing care and the regard for the emotional and physical welfare of the patient so characteristic of hospice care.

Case conferences on suitable patients should be held for both doctors and nurses, although the enthusiasm of the nurses often makes the occasional doctor appear as a lonely colleague dedicated more to a sponsored lunch than to an interdisciplinary meeting of minds.

Attitudes

Advanced cancer is a problem that requires teamwork. It involves the needs of the patient, the resources of the family, the therapeutic strategies of the doctor, the bedside and management skills of the nurse, the emotional and spiritual support from social worker and chaplain, and most important of all, the interplay and fusion of these elements to produce a strategy agreeable to the patient. The patient needs to feel actively concerned in his management rather than a helpless prisoner.

This cannot be helped by the fact that nearly a third of dying patients have little idea of their real situation. And basic teamwork is greatly prejudiced when a third of doctors are unwilling to entrust to capable and experienced nursing colleagues honest discussions with the patients about the future. Although lies are rare, evasion is common, but it is not enough to tell the patient the truth and let them get on with it. This is a recent and growing tendency that can be as damaging as uncertainty.

Prognosis should remain uncertain within limits, for that is the truth of it. Patients should be encouraged to ask for information they want, but not have it forced upon them. Someone dying may, early in the illness, feel the need for less information than is required later on. The young usually need more information than the old, but generalisations are to be mistrusted. Relatives are to be listened to courteously but the plea ‘You won’t tell him will you, he couldn’t stand it’ is often to be translated as ‘You won’t tell him will you? I don’t think I can handle it’.

Family members may need more time, information and confidence than their patient. This cannot be delivered if communication between hospital and GP is unsatisfactory, and family doctors still need to keep an eye on the local obituary column to see when their hospitalised patients have died.

Furthermore, a higher priority must be given to improving communication between different hospital colleagues, and who told what and when must be clearly written up in the notes, or juniors will need to play safe, say nothing, and so unwillingly deprive their patients of solace and comfort.

But we are at last ceasing to look upon death as our failure. There is more to the art of medicine than the production of a tidal wave of unfilled geriatric need. We are at last beginning to realise that part of the art of medicine is not to prolong life but independence, for as long and as comfortably as possible. Survival at all costs is a false objective: just as a cry for euthanasia is usually a symptom of inadequate support, a brave inclination not to be a nuisance, and inadequate symptom control.

Cost-Effectiveness

Many junior doctors and nurses are most critical of their own achievements in terminal care; their dissatisfaction is indeed an encouraging feature. However, they have little idea of how to improve the situation and tend to want to transfer too many to hospice care, just as their seniors

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transfer the old and confused but keep the young on active treatment to treat their own needs, despite the superior family counselling experience of the hospice.

But it is clear that a massive proliferation of hospices is not the answer. We need hospices for the problem case, to provide extra support in the home, day care, respite care and family support or—since 20 per cent of hospice admissions are social isolates—a new family. Yet most patients will die on the acute ward or at home. The hospices need to be sited near schools of medicine and nursing, in big cities and in retirement areas. They should not be built in market towns where often the best of British medicine is to be found and the community network of support is reasonably intact.

Hospices are expensive. A nurse:patient ratio of 1.5:1 means roughly £500 per patient-week. Home support nurses, each costing £15,000 a year are much more cost-effective so long as they are able to integrate with the local district nurses and GPs without mistrust or paranoia complicating the provision of an additional resource.

Hospice-trained support nurses working similarly in the local hospitals can influence communication and symptom control out of all proportion to their cost: but they need in their turn to be tacful as well as tough, and to be both accepted and supported.

Day hospitals for hospice-type patients are growing. They allow relatives to feel more supported, and an eye to be kept on progress without wasting time on unnecessary home visits by the doctor. They provide a stimulus and companionship often more effective than the drugs, a hairdresser more welcome than the health professional, and a variety and diversion that help to keep them going. Such a Day Hospital could look after about 15 patients each day for five days a week for a cost of less than three hospice beds.

Yet in our enthusiasm we must remember that the most cost-effective of all is a well-briefed and involved family, a well-trained doctor and a caring nurse and, if need be, a trusted local hospital up the road.

*This article is based on a paper read at the Conference on Advanced Cancer held at the Royal College of Physicians in December 1985.*

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**Book Review**

*Genetic Biochemical Disorders* by Philip F. Benson and Anthony H. Fensom. Oxford University Press, 1985. 692 pages. Price £55.

This is a straightforward, very concise compendium on inborn errors of metabolism by two authors who have supervised the Supraregional Laboratory for Genetic Enzyme Defects. I have found it a useful quick reference book, but its limitations should be pointed out. There is no significant overall discussion of the general concepts of inherited disorders and the ways in which the biochemical consequences may be harmful, nor of the interaction between genetic and environmental factors. Neither is it comprehensive. The reader looking for information on the renal tubular acidoses, familial periodic paralysis, pseudohypoparathyroidism, the haemoglobinopathies, diabetes mellitus and cystic fibrosis, to choose six of the conditions I used as test cases, will go away empty-handed. I tried to work out the rationale for what had been included and what had been left out, without much success. However, I obtained rapid and excellent information on variants of phenylketonuria and glutaric aciduria—two of the three relevant conditions which came my way in clinical practice during the time this review was gestating. Not surprisingly, it is quite strong on biochemistry, but it makes no serious attempt to deal with the ‘new genetics’, i.e. knowledge obtained from recombinant DNA techniques. It is exceedingly well referenced for the conditions it deals with—over 25 per cent of the text is occupied by the references. This book is of value as a lead into many rare conditions which the potential readership of paediatricians, neurologists, geneticists, obstetricians, pathologists, medical biochemists and dieticians listed in the preface will occasionally encounter. It makes no attempt to give the very detailed consideration of these disorders to be found in Stanbury et al. (*The Metabolic Basis of Inherited Disease*) in either the background, diagnosis or treatment areas. However, the reader should be able from the reference list to get on to the right sources rapidly if further details are required.

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