

Palliative care

The modern concept

DURING THE LAST TWO DECADES there have been enormous improvements in the standard of care attainable for patients dying of progressive incurable disease.¹ Unfortunately, these improvements have not yet reached the majority of dying patients, especially in Australia. This article is intended to be one step towards rectifying that.

In this field, I think that Dame Cicely Saunders,² Dr Elisabeth Kübler-Ross,³ and Dr Balfour Mount⁴ stand out as pioneers in their respective countries, though they are far from being alone. From their work, and that of many others,⁵⁻⁷ I have extracted those ideas which I believe to be the hallmarks of modern palliative care.

At every stage, care must be "patient-centred", aiming at maintenance of the patient's preferred lifestyle, respect for his or her philosophy of life, and full participation by patient and family in making decisions which will affect them.⁸

The "holistic"⁹ approach is the most appropriate, with its emphasis on the interacting physical, intellectual, emotional, social, and spiritual aspects of the whole person. Holistic care requires skills derived from a number of disciplines, and a multidisciplinary palliative care team often includes a doctor, nurse, social worker and chaplain. In the absence of a full team, the same skills remain important.

When cure or remission is impossible, the only treatments indicated are those which improve the quality of life or prevent its deterioration. The use of chemotherapy or surgery as a placebo is inexcusable. However, changes in a patient's condition may require a return to more active treatment at any stage.¹⁰ The entry to palliative care must be an open door, never a trap.

Associated with (almost) every terminally ill patient are relatives in the process, inexorable and apparently hopeless, of being bereaved. Their distress can be relieved considerably by empathetic support. Skilled help at this stage can also reduce the incidence of pathological grieving,¹¹ which might otherwise continue for the rest of the bereaved person's life. Support for the family must go on after the patient's death, the two most critical periods being the day of death and four to six weeks later.

Care-givers need to care for each other as well as for dying patients and their families, because good palliative care requires considerable emotional investment by all staff members involved.⁸ This is often painful, and it may also stimulate the memory of previous unresolved emotional pain.¹² A team which lacks a friendly and mutually supportive atmosphere is, therefore, likely to be unhappy, to deliver a poor standard of care, and perhaps finally to disintegrate. Specific times for the discussion of problems should be scheduled as a routine, and help from outside the team should be enlisted when necessary.¹²

The patient's home is the ideal base for a continuum of care which may have started in a general hospital, and which can return there, or move to a specialist palliative care unit or terminal care hospital, or continue in the home until

death, according to circumstances. Such continuity of care cannot be achieved unless the staff members move with the patient, and this means spending time in travelling. In the case of home care, this time is especially well invested, as it saves the costs of inpatient care which can be 10 times more expensive.¹³ During home care, it is essential that everyone knows that an inpatient bed is available. Otherwise, the preference of patients for their homes¹⁴ conflicts with the anxiety of patients and relatives over their ability to cope at home.¹⁵

Terminal illness does not keep office hours. Fear and grief often reach their peaks during the night; death frequently occurs after hours; and severe pain which is neglected until 9 a.m. is little different from torture. Thus, whether at home or in hospital, 24-hour availability of care is absolutely essential.⁸ It is certainly hard for the doctor to leave a comfortable bed, but it is harder for a patient to die of cancer or for relatives to lose their loved one. In my experience, unnecessary calls to such patients are very rare.

Until palliative care is accorded by the community the importance that it deserves, there will be a chronic shortage of funds and therefore of paid manpower – and, thus, a constant need for voluntary work. Some of this is done by qualified health care professionals, either free or at reduced rates. On the other hand, a remarkable amount can be done by well motivated lay volunteers who are prepared to undergo suitable training courses and to work under supervision.¹⁶ This has emerged as a major feature of palliative care in England, the United States and Canada, and the current state of health-financing suggests that it will be at least as important in Australia.

Two absolute prerequisites for good palliative care are a high standard of general nursing care, and skilled medical treatment of any pain or other symptoms present. Neither of these can be achieved without satisfactory staffing levels, which must be very much higher than those required for simple custodial care. St Christopher's Hospice, London, does excellent work with approximately one full-time doctor per 12 inpatient beds and 25 full-time nurses per 20 beds, including all shifts (Saunders, C., personal communication, November, 1981). Sadly, almost all the residential facilities I know of in Australia have staffing levels which vary from little better than a third to less than a twentieth of these. I am not saying that palliative care requires extremely high staffing levels – just that they should be comparable with those in "acute" general hospitals, not with those in nursing homes.

The practical aspects of symptom control have been extensively reviewed,^{2,4,17} but two points require special mention. First, chronic symptoms only respond to medication if it is given in a way that maintains therapeutic blood levels around the clock.¹⁸ With chronic pain, for example, "p.r.n." means "pain relief never". Second, "high" doses of powerful opiates are frequently indicated, and can be used effectively (for years if necessary) without unmanageable

tolerance or side effects, and without addiction.¹⁸ In the case of morphine, for example, the dose is not "15 mg, but save it for later" – it is "somewhere between 1 mg and 1,000 mg – usually every four hours, starting as soon as needed, usually taken orally".

The emotional distress caused by terminal illness is of immense significance in the care of patient, family and staff. However, the "knee jerk" prescription of tranquillizers and antidepressants is not the answer to their problems. Their grief, anger, fear, and guilt are normal responses to a real situation, and they will not be helped by being treated for an imaginary psychiatric illness. Instead, emotions should be accepted as natural and appropriate responses to terminal illness, and patients and relatives should be encouraged to express and discuss them.³ They may, of course, choose to deny their emotions, just as some choose to deny the diagnosis. Denial can be a useful temporary defence,³ and must be respected when it is chosen. In other words, patients need permission, rather than coercion, to express feelings, and this is the first essential ingredient for optimal emotional care.

The second is honesty. I have never yet met a patient who was not glad to be treated with carefully timed and gently administered honesty. Indeed, the "conspiracy of silence" is often responsible for more suffering than the disease it pretends to hide.

The third essential in emotional care is effective non-verbal communication, and staff members who are not good at this are not good at palliative care.

Ineffective communication, both verbal and non-verbal, is also the greatest cause of distress in the social sphere. Fortunately, the theory and practice are now well researched;¹⁹⁻²¹ but, unfortunately they are not well understood. I believe every family which includes a dying member needs to be taught the basics of communication and how these basics apply to family interactions. The social worker is often best equipped to do this. Improved communication will allow families to sort out many social issues themselves, although unresolved emotional distress may still require help. Sometimes, also, an important discussion needs to be started and facilitated by the social worker or another team member – perhaps to explore an old family feud, or a dispute over the patient's will. Such unfinished business will otherwise prevent the patient from living fully until the end and dying peacefully when the time comes.

Practical matters such as pensions, allowances, transport and home help must obviously not be neglected. Another important practical issue is the choice of a funeral parlour and decision about the type of funeral. Some families request advice about this well before death occurs.

The spiritual needs of patient, family, and staff must not be neglected either. The prospect of death naturally raises spiritual issues – suddenly the question of the meaning of

life is thrown forcibly into the limelight. To encourage successfully patients who wish to explore this area, and to point out possible avenues for such exploration, requires some study in the fields of philosophy and comparative religion. Although this is traditionally the province of the chaplain, any member of the team may be confronted with the patient's or family's questioning and searching – not to mention his own – and should be as well prepared as possible. The formal religious observances appropriate to a patient's particular creed must also be available as required.

In conclusion, it must be remembered that, though modern palliative care has been developed mainly by multidisciplinary teams in major centres, the principles which have emerged can be applied by any doctor or any other person providing care. Moreover, by tapping the resources of the local community, it is always possible to build an impromptu palliative care team around any individual patient.

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