

TERMINAL CARE

by

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INTRODUCTION

AS the Journal of the Royal College of General Practitioners¹ rightly points out, the dead cannot complain, the bereaved seldom do so and where the dying are concerned there is no possibility of trying harder next time. While the patient requiring terminal care is often thought of as one dying with a painful malignancy, it is important not to forget patients in terminal phases of cardiovascular, cerebrovascular, neurological or respiratory illness and to remember children with, for example, spina bifida, cystic fibrosis and muscular dystrophy who now live much longer than formerly. Terminal care, by definition then, refers to the care of a patient whose treatment, following accurate diagnosis of his illness, becomes palliative rather than curative and who is expected to die within a time which is usually less than a year, but may range from a few days to a few years. These patients and their families require very special support which involves not only high quality nursing but also explanation and counselling, help with spiritual and social problems, palliation of physical ailments and the use of other methods of enhancing the quality of life such as physiotherapy and occupational or recreational therapy. Alleviation of the worst miseries of the dying patient and his family is not dependent upon new buildings nor expensive equipment but depends primarily upon enlightened professional attitudes and doctors have a very definite responsibility to endeavour to acquire these.

OBJECTIVE

The objective of a physician involved in terminal care should be to create an environment in which the patient can receive relief from physical and emotional suffering throughout his illness. The patient should have access to professional staff who can help him to meet death in comfort and with dignity by removing or alleviating unpleasant symptoms and preventing him from experiencing fear or loneliness. There are thus three main areas to consider in planning a practical approach towards meeting these objectives. These concern (1) the environment; (2) relief of physical symptoms and (3) relief of emotional suffering.

The Environment

The locations in which terminal care may be provided are the home, hospital and hospice. Social changes over the past years have affected the pattern of dying. Family units have become smaller and more women go to work outside the home. Therefore, as older family members quickly become physically tired and younger people may have other responsibilities, help may not be readily available for the patient in the home. However, should the patient wish to stay at home the practical aspects of assistance from nurses, social services, voluntary services and sources of

financial aid should be considered carefully. Aids to nursing in the home, for example, a fan, commode, bed rest, deodorizer and night sitting and laundry services should quickly be made available.

A study done in Belfast in 1979 revealed that almost 60 per cent of all deaths now occur in hospital.² Twenty five per cent occur suddenly and only 11 per cent of deaths occur at home following a period of terminal care. Many patients are admitted to hospital just a few days before their death. Since so many people feel that the ideal death is to die peacefully in one's own bed, why should this be so? It may result from insufficient help being available at home so that 24 hour nursing care eventually becomes impossible. Relatives may lack or lose confidence in coping as the personal needs of the patient increase. Another reason may be that the disinclination of the patient or family to accept the imminence of death may leave them unprepared for the final deterioration. The family may be unable to cope with anxiety regarding administration of medication, being alone at the time of death, how best to help the patient and what to do after death. They may be anxious that help from a known and trusted doctor or nurse may not be immediately available when needed. Recognizing such possibilities, appropriate action must be taken to minimize these anxieties.

In hospital these patients may feel neglected because of the pressing demands of other acutely ill patients and, indeed, staff may be glad of excuses to avoid spending time with the terminally ill, especially if they feel ill-equipped to cope with the patient's emotional needs. However, in hospitals where staff are concerned and knowledgeable about the treatment of the terminally ill this need not arise. Should patients then need to be readmitted when home management is no longer possible they return to a familiar and caring setting where they may feel quite happily secure.

The third possible environment is that of a hospice or terminal care unit where skills of specialists may help in achieving good control of symptoms. Here patients may be seen on an outpatient or day centre basis or may be short-stay or long-stay inpatients. In some cases the unit may send staff to visit the patient at home or to work in conjunction with the primary care team. However, some regard admission or referral to such a unit with great distress and there are disadvantages in detaching the dying from the rest of the community. The success of such units is based upon the skill and high level of commitment of the staff. There are usually religious services held in these units for those who wish to attend but pressure is never put upon patients to alter their beliefs. A psychiatrist is often available to both patients and staff and may be called upon to help staff members who feel distress, anger or dislike of patients and their illnesses and then undergo feelings of guilt. Close contact with the clergy associated with these units in spiritual counselling is also of great practical value.

In deciding upon the environment in which terminal care should be provided many factors must be considered. There are benefits in involving the family in the care of the patient. Helping with routine tasks can increase and improve family communication and mutual support. It is often a comfort after death for them to know that they have helped the patient as much as possible during the illness. Obviously it is easier for them to help in their own home and adequate nursing resources should be provided to assist them. Day care centres may be a useful means of allowing the family a break from an intense situation and hospital sources can

provide expert advice on pain relief and control of other symptoms. The best environment for terminal care must thus depend upon individual needs, wishes and the facilities available. Every circumstance has its own problem to be solved and it is important that staff involved should have an understanding of the problems, an adequate level of knowledge, reasonable resources to work with and a positive attitude towards achieving the best results for each individual. To do so to the best advantage needs good and clear communication between all members of staff.

For the future, an integrated system with co-ordination between primary care, hospital and hospice sectors should be the goal. Hospices, with their specialist experience, should continue to be initiators of new approaches to symptom relief and centres for research rather than merely providing beds for dying patients. Local needs should be considered in the planning of care. More special unit or hospital care is likely to be needed in larger towns and cities where transport is relatively easy but homes and families tend to be smaller. In rural areas with stronger family ties and greater difficulties in travelling a stronger emphasis will be placed on care at home.

Relief of Physical Symptoms

Of all factors in terminal illness pain is one of the major problems requiring relief. The intensity of pain is closely related to its cause and the interpretation placed upon it by the patient. For example, pain experienced in a short-term illness and readily understood differs considerably from chronic pain which often lacks obvious meaning for the patient but which may invoke the possible threat of admission to hospital, the need of surgery, permanent disablement or death itself. Pain, such as that of metastases in bone or affecting a nerve root, alters the patient's social and interpersonal relationships and his ability to live a normal life. It may isolate him from the world around. It may also affect his finances for it may be the factor which prevents him from continuing in paid employment. Pain is potentiated by fear and tension and these are great antagonists to analgesia.

Physical pain will be alleviated most effectively in an atmosphere which provides some security for the patient and family. With regard to pharmacological measures, the physician may use simple analgesia initially, such as paracetamol, dextro-propoxyphene or dihydrocodeine, before progressing to the opiates to which the maxim "too little, too late" is often applied. These drugs should be introduced at a time which is not too late for them to be valuable and in a dosage which is sufficient to make the patient comfortable. Useful opiates are phenazocine, dipipanone, pethidine and Brompton Cocktail, which contains cocaine and diamorphine in an alcohol base. A useful adjunct to these analgesics is chlorpromazine which sedates, helps nausea and potentiates analgesia. Non-steroid anti-inflammatory drugs, such as indomethacin, are also useful, especially in controlling nerve pain.

Principles applying to the use of analgesics are that they should be administered on a prophylactic basis, given three to four hourly, rather than waiting to palliate pain when present. They should be given orally for as long as possible but the rectal route should not be forgotten since many are available in the form of suppositories. When parenteral administration of an opiate analgesic is indicated this should not be withheld. Dosage must be sufficient to control symptoms but when physical relief is

obtained and the patient becomes comfortable it may then be possible to decrease the quantity of medication.

Cytotoxic drugs may also have a place in analgesia, as do physical methods such as nerve blocks and radiotherapy, particularly where pain is associated with spinal cord compression or bowel, bladder or uterine haemorrhage. Both infection and hypercalcaemia are known to exacerbate pain and these conditions should be actively sought and appropriately treated.

Eating and drinking are everyday activities which become major problems if nausea or vomiting is present. Cyclizine provides effective relief from these symptoms and the painful colic associated with obstructive vomiting may be relieved by a combination of diphenoxylate and atropine (Lomotil). Metoclopramide is less appropriate as an anti-emetic in terminal care since it is more liable to cause extrapyramidal reactions in the dehydrated patient. Anorexia may respond to the tasteful preparation and presentation of savoury foods which are usually more appetizing than sweet foods to those who are ill. If the patient has dysphagia this is sometimes alleviated by antacids. Careful attention to oral hygiene may prevent a sore tongue and nystatin preparations are useful if candida infection develops on the tongue or oral mucosa. The simple measure of offering ice to suck will relieve the dry mouth which is a common symptom of dehydration. Another major physical problem requiring relief is insomnia, often alleviated by chloral hydrate or diazepam. However, sleeplessness is often associated with depression which may require treatment with antidepressant drugs such as amitriptyline. **Cerebral metastases can produce dementia or delirium which may respond dramatically to dexamethasone.**

With decreasing mobility and increasing analgesic intake, constipation becomes a common complaint requiring treatment with suppositories or oral laxatives. Diarrhoea is sometimes another problem in terminal illness and when spurious diarrhoea, secondary to faecal impaction, has been excluded, kaolin preparations are useful remedies. The discomfort of either bowel or bladder incontinence should be minimized by the provision of absorptive pads and waterproof sheets but may eventually require further attention such as urinary catheterization. A laundry service is an invaluable aid to both patient and family in such situations.

Dyspnoea is a most distressing symptom which may be alleviated by oral salbutamol or by aminophylline suppositories and the patient may feel less distressed if oxygen is available. However, it may be necessary to tap pleural effusions in order to relieve respiratory embarrassment. Other disturbing symptoms are a chronic hiccough, which often responds to chlorpromazine, and a chronic itch from which relief may be obtained by antihistamines.

Fungating growths and pressure sores require frequent dressings and it is both kind and useful to protect the patient from the unpleasant odour of such lesions by using a deodorizer. Instruction of the family in good nursing care and the provision of sheepskin pads are valuable in avoiding physical suffering for the patient.

Relief of Emotional Suffering

In considering the total care of the terminally ill the provision of emotional relief must not be forgotten. Physical pain and its treatment have been considered but

there are other facets to pain. Emotional distress can be a real problem if the patient feels rejected by society. This may occur if the patient's appearance has changed. For example, he may have developed a large growth on his face or may have undergone mutilating surgery. A woman may feel that her personality has been altered and her femininity compromised after a mastectomy or hysterectomy. Emotional distress may be intense when a patient has to forfeit independence and accept weakness and dependence on others. There is emotional stress in adjusting to a new social situation such as hospital where all personal privacy may be lost. Patients may feel isolated if surrounded by staff who do not have confidence to face the problems of a dying patient and who lack understanding of ways to help overcome these problems. All staff involved in terminal care require instruction in counselling techniques and need to be able to cope with their own reactions to death in order to provide support. Time should be taken to talk with patients about daily happenings and their immediate interests. Existing social contacts should be maintained and, if necessary, new ones encouraged.

Problems may be prevented if information is effectively communicated and this should be given in a kindly, optimistic and simple way that is still recognizable as the truth. As the illness progresses the patient may wish to know more about his condition and past lies only serve to create barriers and promote anxiety. The doctor should understand that the patient will not immediately be able to accept that he has a terminal illness and that he has to go through a series of stages in acceptance. Firstly, there is a stage of denial, either verbal or manifest in behaviour. Secondly, there will be a stage of anger asking "why me?", or blaming someone for not detecting this diagnosis at an earlier stage. Doctors must be aware of the reason for this hostile behaviour and not aggravate it. Thirdly, patients go through a stage of bargaining, trying to "buy off" the disease. Most bargains are kept as secrets between the patient and God but by being aware of this it may be possible to discover and alleviate irrational fears or guilt. Fourthly, the patient may become depressed when the truth can no longer be avoided and though he may mask this with superficial cheerfulness antidepressant medication in addition to counselling may be required to overcome this depression. In time further discussion will lead to a final stage of acceptance in which the patient is quiet and sleeps a lot, often just preceding his death. Throughout these stages it should be remembered that the knowledge that someone cares and is ready to share concern may well be much more important than details about diagnosis and prognosis.

After giving relatives news that the patient has a terminal illness they should be given the opportunity to ask questions and a second interview, after the impact of the news has been absorbed, should be arranged. In talking with relatives lack of information may cause uncertainty and nurture anxiety or bitterness. The whole programme of terminal care is much easier for everyone in a family who see God as the God of life and death and who regard death as a continuum of living. But even here help should be offered to enable the bereaved to adjust to their separation from their loved one. Relatives need advice and support before and after the patient's death, for death is not the end of professional responsibility to the family. Remembering this is good preventative medicine in combating subsequent pathological grief reactions.

CONCLUSION

The effectiveness of the care of the patient in his terminal illness depends on the efficiency of the primary care team. The general practitioner must supervise treatment at home, organizing 24 hour cover which reassures the family that trusted help will always be available. He should have a plan of care knowing where the hospital or hospice may provide useful services and knowing that there will be good communication between these sectors and the primary care team. He should also provide drugs as necessary to alleviate symptoms and should ensure the availability of adequate aids for home nursing by enlisting the help of voluntary and social services as appropriate. The Health Visitor should particularly be involved in the care of the elderly and of children. Such services as domiciliary chiropody, physiotherapy or occupational therapy may enhance the patient's comfort, although these are not available in all areas. The place of a spiritual counsellor is of great practical value and his involvement must not be forgotten. Prior to the patient's death visits should be as frequent as necessary to ensure that effective care is taking place and after death relatives should also be visited to enable them to share their grief and then continue to live in a state of mental and physical health.

REFERENCES

- ¹ National Terminal Care Policy. *J R Coll Gen Pract* 1980; **30**, 466-471.
- ² Reilly PM. Terminal Care Study 1981 (to be published).

ACKNOWLEDGEMENTS

I wish to thank Professor W.G. Irwin and Dr. W.R. Rowney for their assistance and encouragement in the preparation of this article, Professor D.A.D. Montgomery for his advice, Dr. P.M. Reilly for information regarding terminal care in Belfast and Mrs. Margaret Fisher for typing the manuscript.