PALLIATIVE CARE

An introduction

By Patrick Costello, MRCP Ireland

This article outlines the principles of palliative care. There is strong emphasis on a multidisciplinary approach to caring for patients.

The World Health Organization defines palliative care as the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families.

Palliative care involves taking a holistic and multidisciplinary approach to dealing with the different problems that patients and their families may face. Good communication skills to deal with issues surrounding incurable and advanced disease are vital.

Although patients with cancer have been the main recipients of palliative care, other patients, such as those with acquired immune deficiency syndrome (AIDS) and neurological disorders, for example, motor neurone disease, have also benefited from the palliative care approach.

HISTORY

The first hospice for the dying was established in France in 1842. The modern hospice movement took off in Britain in the late 1960s. This was due in part to Dame Cecily Saunders and others who endeavoured to deal with the unmet needs of the dying.

The first modern hospices were developed in the 1960s and 1970s. Outside hospices, it was clear that patients in hospitals needed better palliative care. This led to the setting up of hospital palliative care teams. The first such team was established in St Thomas’ Hospital in London in 1977. Today, about 340 hospitals in Great Britain and Ireland have hospital support teams or support nurses.

The Royal College of Physicians established palliative medicine as a subspecialty of medicine in 1987 and the Calman-Hine report of 1995 stressed the importance of palliative care in cancer services. Furthermore, the NHS Cancer Plan identified palliative care as a priority (See Panel 1, p212).

Palliative care can also be applied to patients suffering from non-malignant disease. Indeed, the National Service...
Framework for Coronary Heart Disease emphasised the role of palliative care in end-stage congestive cardiac failure.7

Organisation

Palliative care is provided in hospices, in the community and in hospitals (Panel 2). Most palliative care is provided by general practitioners, district nurses, hospital doctors, hospital nurses and other staff. However, some patients require specialist care. The main providers of specialist palliative care are the independent hospices, Macmillan Cancer Relief, Marie Curie Care and Sue Ryder Care. Specialist palliative care is funded partly by the health service, but mainly through local fund-raising or by the aforementioned organisations.

Palliative care is increasingly being provided in the NHS and, today, about one-fifth of hospices are run by the NHS. To be able to provide specialist care, staff are trained in pain and symptom control. They also provide emotional support to patients, relatives and friends and can arrange bereavement follow-up if necessary.

Complementary care is more readily available. This includes aromatherapy and acupuncture. Art and music therapy may even be available in day hospices.

A multidisciplinary team is necessary to provide this specialist care, including doctors, nurses, physiotherapists, chaplains, pharmacists, and social workers. Volunteers also have a big role to play in supporting hospices. In recognition of the important role volunteers play, the United Nations designated 2001 the International Year of Volunteers.

Agencies which support palliative care include the National Council for Hospice and Specialist Palliative Care Services, Help the Hospices and the Scottish Partnership Agency.

Symptom management

The management of any symptom should be based on a consistent and logical approach." Panel 3 lists the principles of good symptom management.

Anticipation Failure to anticipate problems is a common cause of dissatisfaction among patients.10 Intelligent anticipation of problems is vital for good care. For example, failure to alert a general practitioner to a complicated discharge from the hospital could mean that the GP is caught unawares in an emergency situation.

Evaluation and assessment An understanding of a patient’s underlying illness is important when identifying the cause of a specific problem. Careful history taking and examination are required. Also, further investigation may be necessary to establish the cause of a particular symptom.

Explanation and reassurance Explanation and reassurance about the patient’s condition is important in alleviating anxiety. It reassures patients and relatives and can give them some control over events.

Individualised treatment Some patients need higher drug doses while others will benefit more from psychological support. Others benefit from seeing a chaplain. Thus, a multidisciplinary approach which identifies the need of each individual is called for.

Supervision As patients can be very ill and their condition can change rapidly, supervision is essential. For example, if patients are just being started on morphine, it is important to check the next day that they are tolerating the drug, that the dose is sufficient, and that side effects are being treated.

Attention to detail It is important that nothing is overlooked. For example, care needs to be taken that patients do not run out of medication over a weekend when it may be more difficult to get a new supply, particularly if they are on uncommon drugs.

Treatment

This section outlines the treatments available for some of the symptoms

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Panel 3: Principles of good symptom management

Anticipation
Evaluation and assessment
Explanation and information
Individualised treatment
Supervision
Attention to detail

Respiratory symptoms Seventy per cent of patients with cancer will experience significant breathlessness in the last six weeks of life.11 The cause of the dyspnoea should be ascertained and treated if possible (eg, aspiration of a malignant pleural effusion). Symptoms can be controlled with, for example, morphine for pain and benzodiazepines for anxiety.12 Explanation and reassurance are particularly important in reducing the distress and anxiety caused by dyspnoea. Cough can be a distressing symptom in patients with lung cancer. Simple measures such as a change in posture, particularly at night, can be helpful.13 Reversible causes should be treated. For example, a chest infection should be treated with antibiotics. Saline nebulizers and antitussives, such as codeine linctus or morphine, should be used to control other symptoms.

Gastrointestinal symptoms Mouth problems are common in palliative care patients. Dry mouth can be due to drug therapy and can be treated by stopping these drugs (if possible), mouth care and the use of artificial saliva. Oral candidiasis is due to general debilitation and the use of steroids. Treatment includes nystatin and fluconazole.

Nausea and vomiting are also common. Vomiting may be more noticeable, but constant nausea may be more distressing. A good history, an abdominal examination, and appropriate investigations (eg, serum calcium) are used to ascertain the cause. For example, nausea in a patient with lung cancer may be due to hypercalcemia or due to brain metastases. The cause should be treated if possible. An appropriate antiemetic should be prescribed (see Table 1, p213). Non-drug measures such as acupuncture and acupressure can also be useful.

Constipation can be troublesome. It may be due to the tumour itself, inadequate food and fluid intake, generalised weakness, or drugs such as morphine and anticholinergics. Patients on morphine, in particular, need to be on a regular laxative of sufficient strength. Despite using maximum doses of laxatives, constipation can persist in some patients. Suppositories and enemas may be necessary. Transdermal fen-
tanyl is associated with less constipation than sustained-release oral morphine.19

Bowel obstruction can cause distressing symptoms, including pain, nausea and vomiting. There are many causes of bowel obstruction and symptoms vary according to the level of the obstruction.16 Patients with ovarian cancer, in particular, are prone to developing obstruction.18 Symptoms can be controlled with drugs rather than intravenous fluids and nasogastric tubes.2 Drugs often have to be given through a syringe driver because of vomiting in patients. Diamorphine is usually also necessary to treat background pain. Colicky pain is treated using an antimuscarinic such as hyoscine butylbromide. An antemetic such as haloperidol can be used to control nausea and vomiting.

Confusion Acute confusion may be due to infection, drugs, hypercalcaemia or brain tumours. It is important to find the cause and treat it if appropriate. For example, the confusion could be caused by an infection which can be cleared up with antibiotics. For some patients in the terminal stages of their illness who become acutely confused, it may be inappropriate to carry out investigations to determine the cause of their confusion. Drugs such as haloperidol can be used if a patient becomes excessively agitated but non-drug measures such as the reassuring presence of a relative may suffice.19

Paediatrics

Terminal illnesses are relatively rare in children and palliative care services for them are not as developed as those for adults. About 1,200 children a year in England and Wales die from a terminal illness.20 Of these deaths, 40 per cent are due to malignancies, while the rest are associated with neurodegenerative disorders such as Duchenne muscular dystrophy. Childhood terminal illnesses are caused by a large number of conditions which may be rare (eg, neurodegenerative disorders) and which present with a relatively small number of therapeutic problems.21 A huge burden is placed on families when a child has a terminal illness.

Drug therapy can play an important part in the care of children with a terminal illness. There are a number of problems with the use of drugs in children. Drug manufacuters do not recommend certain drugs for use in children either because of proven problems, but more often because of a lack of information.21 Children absorb, distribute, metabolise and excrete drugs differently from adults. Dystonic reactions to metoclopramide are more common and itching due to opioids occurs more frequently.21 The side effects of corticosteroids (rapid weight gain, changed body image and mood swings) usually outweigh the benefits.21

Children of adults with terminal illnesses may also need support, and organisations such as The Castle Project can be of help. They provide psychological support and can bring together children who are in similar circumstances to form support groups. Sometimes family members need a short break from each other, particularly during school holidays. The Castle Project can arrange to take children out on short trips.

Corticosteroids

Corticosteroids are frequently used in palliative care.22 They are used in emergency situations such as spinal cord compression, raised intracranial pressure, superior vena cava obstruction, and tracheal compression. Dyspnoea due to lymphangitis carcinomatosis can benefit from steroids. Steroids may provide benefit in bowel obstruction21 and can be used for pain relief by reducing nerve compression. Appetite, energy levels and general well-being can also be improved by using steroids.

Unfortunately, corticosteroids are associated with several side effects which patients may find unacceptable. This is particularly true if patients need to take steroids for a prolonged period. The aim should be to take the smallest dose of steroid for the shortest time. Patients need to be informed of the risks when taking steroids and should be supplied with steroid treatment cards. Steroids are best given before 6pm to prevent insomnia.

Towards the end

Patients in the terminal phase may become too weak to take oral medication.24 Anyway, many of these are often unnecessary in the terminal phase.

An alternative route needs to be found for essential medication. Oral opiates can be converted to an appropriate dose of diamorphine and given subcutaneously through a syringe driver.

For patients who have been on anticonvulsants (possibly to prevent brain tumour-induced seizures), midazolam can be administered by adding it to the syringe driver.

Some patients can be troubled by terminal restlessness. This can be distressing to the patient, relatives and staff. There may be an obvious cause for this, such as pain or urinary retention. If reversible causes have been excluded or treated and the patient remains agitated, an anxiolytic such as midazolam is necessary. This can be given when required and can be added to the syringe driver.

Terminal ill patients may be unable to clear upper airway secretions because they are too weak to cough or swallow. This can cause noisy ventilation commonly referred to as “death rattle”. This can be distressing to relatives, other patients and staff. Explanation and reassurance are necessary. Changing the position of the patient can help. Drugs can be used to prevent more secretions but have little effect on secretions that are already in the airways.21

Suction can also be used but only when the patient has lost consciousness.

Drug therapy

Palliative care patients are frequently on several drugs because of the various problems associated with their illness. This means that interactions are more frequent. For example, a patient may be on a non-steroidal anti-inflammatory drug for pain and steroids for brain metastases. Together, these drugs increase the risk of peptic ulceration. Gastric protection in the form of a proton pump inhibitor can be beneficial. It is important to discontinue unnecessary drugs (eg, cholesterol-lowering drugs).

In palliative care, a lot of drugs are used for an unlicensed indication or given through an unlicensed route.26 In practice, physicians take the responsibility for using unlicensed drugs.27 The risk of harming the patient needs to be carefully balanced against the benefit of using these drugs.

Consideration needs to be given to the size, shape, taste and form of medication.28 Non-oral routes are frequently used, such as transdermal (fentanyl), sublingual (lorazepam), subcutaneous (diamorphine) and transmucosal (oral transmucosal fentanyl citrate).

To improve compliance, patients can be given a written list of their drugs, with explanations (in everyday language) of what the drugs are used for. This is preferable to simply giving them verbal instructions. Explanation is vital not just to improve compliance, but to alleviate unnecessary anxiety. For example, patients started on co-danthramer may be concerned that they have developed haematuria when in fact it is the co-danthramer that is the cause of urine discoloration. Special compliance devices are available but do rely on the patient being able to operate them.29

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**Table 1: Drugs for nausea and vomiting**

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<thead>
<tr>
<th>Cause</th>
<th>Antiemetic</th>
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<tr>
<td>Gastritis, gastric stasis and functional bowel obstruction</td>
<td>Metoclopramide</td>
</tr>
<tr>
<td>Chemical causes, eg, hypercalcaemia, and renal failure</td>
<td>Haloperidol</td>
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<tr>
<td>Raised intracranial pressure and motion sickness</td>
<td>Cyclizine</td>
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ROLE OF THE PHARMACIST

Hospital, community and hospice pharmacists are an important source of information and support for patients, their carers and prescribers. It is recommended that they form part of the multidisciplinary hospital palliative care team. The role of the palliative care pharmacist is to give advice on drug uses, side effects, formulations, cost, and drug interactions. Taking part in research, audit, education and guideline design are also important roles.

Because syringe drivers are commonly used, a practical working knowledge of them is important as is experience of which drugs to use in a driver and knowledge of drug compatibilities. The pharmacist can also help in arranging the procurement of uncommon or named-patient drugs.

The pharmacist can help with drug compliance by giving good advice on the best drug to use in the first place. Explaining to patients and carers about the function and importance of each drug helps. The appropriate use of compliance aids can be helpful.

Since patients in the terminal stages often move between their home and different institutions (hospice, nursing home, hospital) good communication and liaison is vital. This can be with members of the palliative care team, the primary care team (general practitioner, district nurse), hospital team or with other pharmacists. For example, it is important that if a patient goes home from a hospice on an uncommon drug (e.g., octreotide), the community pharmacist is informed so that he can obtain supplies of the drug.

Panel 4 contains a list of some palliative care resources.

ConCLUSION

Palliative care complements the medical care a patient receives. With the incidence of cancer set to rise in the coming decades as a result of the ageing population, palliative care will assume greater importance. As cancer treatments improve, patients will tend to live longer with their cancer. Other patient groups, such as those with chronic heart failure and respiratory failure, share many of the problems of cancer patients and can benefit from the palliative care approach.

Over the past 30 years, palliative care has made enormous progress. The challenge in the coming decades is to build on this progress and to improve patient care even further.

References