Managing terminal illness

An ‘Interfaces in Medicine’ conference on the management of terminal illness was held at the College on Wednesday 24 May 1995.

The scope of palliative care

Dr Derek Doyle (Edinburgh) began with some quotes from a straw poll he had conducted on what doctors think about palliative care: “It’s just a fancy name for terminal care’. ‘It’s what we GPs do all the time’. ‘Mainly morphine, as far as I can see’. ‘We don’t do it here, we either cure them or we send them to the hospice’. ‘I leave it to my junior staff, they have more time than me’. ‘I’m only a houseman, but it seems a very important thing to me, and it’s so rewarding’.

Dr Doyle argued that palliative care was no longer synonymous with terminal care. The latter is one part, albeit an important part, of palliative care. The specialty of palliative medicine is ‘concerned with the study and management of patients with active, progressive far-advanced disease in whom the prognosis is limited and the focus of care is quality of life’. Every person has a right to good palliative care, encompassing attention to dignity, pain and symptom control and psychosocial and family care; every nurse and doctor has a responsibility to provide this. Palliative procedures and techniques to ease suffering, such as stenting, ostomies, orthopaedic fixation and paracentesis, should be available throughout the course of the patient’s illness, but must be employed appropriately. He stressed, and this was to become a theme for the conference, that the principles of palliative care were applicable throughout health care, whereas the specialist practice of palliative care should take place during at least the last year of life.

Intuition is not enough: there is a need for education and training of all health care professionals in the principles of palliative care. Many patients want to die at home. The general practitioner and primary health care team have a key role in the provision of good palliative care. In one GP based study almost half of the patients died in hospital and in three-quarters of these cases avoidable suffering and family strain necessitated admission. Other studies have shown that 65% of patients could have died at home with the provision of better palliative care services and skills to underpin the care delivered by the primary care team.

The results of a community survey of 521 patients with Parkinson’s disease carried out between 1989 and 1992 were presented by Dr Robert Jones (Exeter). Physical symptoms were common in this group, and recognition of psychological needs was poor, almost half of patients being significantly anxious or depressed. Education of carers was highlighted as a need, since, even when patients were independent or only moderately disabled, three-quarters of carers were frightened to leave the patient alone for fear of what might happen. He argued that good palliative care for such patients can, and should, be provided in general practice, with access to specialist palliative care services when necessary. The challenge for the palliative care physician is to interact, not only with the patient and the patient’s family, but also with other professionals providing primary, secondary and tertiary care.

Currently specialist palliative care services are involved mainly with patients with cancer. In the 206 palliative care units in the United Kingdom, 95% of the patients have malignant disease as do 85% of the patients seen by hospital palliative care teams.

Julia Addington Hall (London) pointed out the dearth of information about patients dying of non-malignant disease. She presented data from a retrospective epidemiological survey of the last year of life in a random sample of 5,375 deaths as reported by their relatives or carers. Interviews took place about ten months after the death; the response rate was 69%. The findings on death due to stroke and heart disease were compared with the 54% of deaths due to malignant disease. Despite the fact that carers might over-report symptoms, and reports of a patient’s distress might be influenced by their own distress, distinct symptom patterns were apparent. For example, significant levels of pain and distress were reported in patients with heart and stroke disease as well as in cancer patients. Patients dying from stroke were more likely to have lived alone and to have died in residential or nursing homes. Mental confusion, bedsores and urinary and faecal incontinence are common in patients with stroke and so the best way to provide good palliative care in these patients may be by high quality nursing.

Patients with non-malignant endstage disease were less likely to have had symptoms than patients dying of cancer but, in those that did, symptoms tended to be more long lasting; this made heavy demands on the carers. Families looking after patients with stroke and heart disease were more likely to say that it had been a burden, whereas most families caring for a patient dying of cancer found it rewarding.

Open communication with patients with cancer is now generally accepted and is seen as extremely important in palliative care. Three-quarters of carers thought that their relatives definitely or probably knew...
they were dying of cancer. About half the patients with stroke and heart disease were thought to have known they were dying; most of them had worked it out for themselves. Dr Addington Hall pointed out that it is difficult to give a prognosis in non-cancer patients, but if patients surmise that they are dying then we are doing them a disservice by not giving them time to talk and ask questions. She argued that patients with non-malignant endstage disease and their families need a palliative care approach.

Dr Ilora Finlay (Cardiff) spoke from the hospital perspective on the relevance of the palliative approach beyond cancer. She illustrated how an accessible palliative care team, which was willing to help, could support other clinical teams in caring for patients with a wide range of diseases including cardiorespiratory failure, rheumatological and neurological disease, inherited disorders such as the muscular dystrophies and cystic fibrosis, and patients suffering pain from leg ulcers or vascular disease. Many referrals were for pain and symptom control, but others included requests for help in dealing with distress in patients, their families and in staff, and to provide a second opinion on difficult issues such as patient competence and the ethics of clinical decision-making. Sometimes the reason for referral was ‘who else can we ask?’

The needs of patients with endstage respiratory disease were highlighted by Dr Charles Shee (Sidcup). There is a marked difference in the services available for patients with malignant and non-malignant lung disease. Endstage lung disease is predominantly caused by chronic obstructive pulmonary disease (COPD) which accounts for 5% of all deaths but 13% of adult disability in this country. Severe airways obstruction with proven hypoxia has a poor prognosis, half of the patients dying within two years. The single most important measure in improving quality of life and preventing disability is to stop smoking. Mobility and quality of life of patients with COPD are usually limited by breathlessness and by the vicious cycle of increasing inactivity, decreasing fitness, increasing isolation and sense of loss of normal life and function which often leads to low self-esteem and high levels of anxiety and depression. Home oxygen can prolong survival but without substantially altering the patient’s reported quality of life. There is evidence that pulmonary rehabilitation programmes, encompassing multidisciplinary assessment, education about medication, relaxation techniques and psychosocial care, along with graded, supported exercise plans can help these patients. Most studies have shown no change in objective measures of the patient’s lung function, but exercise tolerance, reported symptoms and quality of life changed for the better. Services for patients with chronic lung disease are already improving through initiatives such as the British Lung Foundation’s ‘Breathe Easy’ campaign and through the provision of pulmonary specialist nurses, but Dr Shee suggested that these patients’ palliative care needs to be improved by attention to psychological care and a more holistic approach.

Sally Derry (Solihull) was a nurse manager in cardiology before she became the matron of a Marie Curie hospice. She started her presentation with some textbook definitions of heart failure. All these definitions referred to a failing pump but neglected to mention the patient. Once any remediable underlying cause has been ameliorated, the treatment of heart failure is essentially palliative. The prognosis is poor: half of the patients with severe, and approximately one quarter with moderate, heart failure will require terminal care within one year. The symptoms experienced by patients with heart failure are similar to those of patients with cancer, although breathlessness and insomnia cause greatest distress. Active treatment of heart failure needs to be continued until late in the patient’s illness to avoid rapid worsening of symptoms. Opioids, often at lower doses than those necessary in cancer patients, can ease breathlessness and insomnia, and should be prescribed more often.

It is vital to acknowledge the psychological impact of heart failure. The heart is often seen as the seat of emotion, and indeed the essence of ourselves, and difficult psychological issues will often come to the fore. Drawing a family tree with the patient may provide insight into the way heart disease is perceived, especially where there is a strong family history. Ms Derry concluded her talk with her own definition—‘severe heart failure is a terminal illness associated with distressing symptoms and which has a profound effect on the patient’s life’.

The management of pain in late stage non-malignant disease was reviewed by Dr Chris Glynn (Oxford). Such pain seems to confer no clear biological advantage, nor is it ennobling or uplifting. Anxiety, unhappiness and anger or frustration are nearly always a feature of chronic pain. The way these emotions feed into chronic pain reflects the patients’ physical and emotional coping mechanisms and their disability. The emotional component of the pain may be helped by pharmacological and non-pharmacological strategies, but only if patients are prepared to address the issues and wants to improve.

Physical management of the pain should be largely pharmacological and the risk/benefit ratios for each potential treatment must be carefully considered. Dr Glynn argued that there is seldom any role for ablative neurosurgical procedures in patients with chronic non-malignant pain. In elderly patients, opioids may provide greater pain relief with fewer side-effects than non-steroidal anti-inflammatory drugs. He went on to discuss the limitations of epidural drugs in the management of the minority of patients with chronic non-malignant pain who require invasive procedures. Pain control is usually improved but this is limited by the present drug delivery systems which are not suitable for patients with a long life expectancy. Further
work is needed to elucidate whether relieving pain or dealing with disability would most improve patients' quality of life.

The issue of paradoxical pain was tackled by Dr Henry McQuay (Oxford). The term has been variously and poorly described and this has complicated discussions on the subject. Paradoxical pain has been described as pain which is made worse by escalating morphine doses, and it has been suggested that this may be due to antagonism of morphine by one of its metabolites, morphine-3-glucuronide (M 3-G). Dr McQuay pointed out that M 3-G can cause allodynia and hyperalgesia but it does not bind to opioid receptors and therefore cannot compete with morphine for receptor sites. He felt it unlikely that a sub-population of patients metabolised morphine abnormally to give high levels of M 3-G and suggested an alternative term, 'runaway pain', to describe the situation when a patient's morphine dose suddenly needs to be escalated as control of their pain is lost. Causes include progressive disease, the development of a new, less opioid responsive pain, and psychological factors. He was unimpressed with the suggestion of trying an alternative opioid. A patient's response to treatment is influenced by the drug given, the dose and the patient's psychological state at the time and Dr McQuay reiterated that chronic non-malignant pain often has an enormous psychological component.

Neuropathic pain can be very difficult to control. Whilst the probability of neuropathic pain responding to morphine is low, trying to predict opioid responsiveness is unhelpful and patients should have the benefit of an adequate trial of opioids where outcome measures should be pain relief or unmanageable side-effects; if these are unacceptable, alternative drug measures or invasive procedures should be tried.

Barbara Monroe (London), a social worker based at St Christopher's Hospice, made the point that terminal illness is a family affair and that the family is a valuable resource in caring for the patient, who will spend most of his/her time living, whilst dying, at home. Families often need help in communicating with their children. Not giving information, and so allowing the children to substitute their own fantasies, increases distress. The challenge is to provide acceptable, accessible care within the cultural framework of the family. We need to respect families and work in partnership with them, remembering that we are responsible to, not for, them. Most families are ordinary, and therefore a little help goes a long way. Palliative care is, at its best, preventive health care. Helping a family to face illness and death potentially alters how that family copes with bereavement and therefore alters their quality of life in the future. There is a need to develop ways of identifying those families who need specialist and/or continued support. This speaker provocatively suggested palliative care specialists are in danger of giving the impression that they have all the answers. This is not the case, and she warned against the 'saviour syndrome'.

Specialists and generalists

The 'interface' under discussion at this conference was that between palliative care specialists caring for patients dying of cancer and general practitioner and other health care professionals looking after patients dying from other causes. It was, therefore, disappointing that the audience comprised mainly physicians working in cancer and HIV based palliative care. The presentations and discussions were thought-provoking but there was an air of 'preaching to the converted'. The most lively debates were between generalists and specialists and there were important messages for both. The relatively young specialty of palliative medicine cannot afford to be complacent and does not have all the answers. If palliative medicine consultants are to advise on the care of patients with non-malignant disease they must remember that they do not have the same knowledge and understanding of the underlying conditions as those directly involved in that patient's care. However, important principles can be highlighted; quality of life, pain and symptom control, psychosocial and family care and spiritual support. Expertise is available in these areas from specialists. General physicians and surgeons need to adopt a more holistic approach to patient care and to remember the importance of symptom control and psychological factors in patient care. A change in emphasis is needed from treating the condition to treating the patient. Many speakers underlined the importance of effective interdisciplinary teamwork.

Dr Gillian Ford, Medical Director of the Marie Curie Memorial Foundation, drew attention to the interface theme of this conference. 'Addressing symptom control and psychosocial issues is seen as an integral part of the care of patients with cancer.' Do other patients with endstage disease not have the same needs, or are their needs not being recognised?' The speakers had addressed these issues with skill and compassion, and the overwhelming conclusions were that patients with endstage disease other than cancer had needs which were not being met, either at home or in hospital. These needs require the same attention to detail and research that distinguishes the approach to problems of late stage cancer. Specialists in palliative medicine have a responsibility to be active in this field through sharing resources and working within a multi-professional, interdisciplinary framework to help in meeting this challenge. A book based on the proceedings of this conference will be published by the College in June.