

Palliative care services: meeting the needs of patients

Mary Armitage and Ian Mungall

Mary Armitage

BSc Dm FRCP,
Consultant in
Endocrinology,
Royal Bournemouth
Hospital

Ian Mungall

MD Dip Pall Med FRCP,
Consultant in
General/Respiratory
Medicine,
Peterborough
District Hospital

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All physicians would wish for a good death for their patients, their families and themselves. We know that while most patients would prefer to die at home, nearly 60% of people in England and Wales die in a hospital, often admitted in the last few days or weeks of their lives. Relatives and carers may see their loved ones die with inadequate pain and symptom control, with high levels of anxiety and loss of dignity in unfamiliar surroundings. Yet the UK led the development of palliative care in the 20th century, with the establishment of St Christopher's Hospice in London by Dame Cicely Saunders, and palliative medicine has been recognised as a medical specialty by the Royal College of Physicians (RCP) since 1987. Much of the service, however, has been developed in the voluntary sector, and hence services remain patchy; the best are excellent, the worst non-existent.

This report highlights the unsatisfactory funding; the NHS funds only approximately 30% of specialist palliative care costs. Eighty per cent of beds are in independent hospices, and this has led to poor overall planning and integration of services and exacerbated the geographical inequalities in service provision. Many physicians are working in isolated units, outside the NHS, without access to study leave or annual appraisal, and supported by specialist nurses and other team members who are themselves on short-term contracts and heavily dependent on charitable funding. Key recommendations in the report emphasise the requirement for increased and sustainable core NHS funding and central planning and commissioning to develop cohesive services across the country.

Services for all patients

The report also outlines the unacceptable variation across different demographic groups and across diagnoses. Until recently, the perception was that palliative services were primarily for those patients dying of cancer and the National Council for Palliative Care has estimated that 95% of those using hospice or palliative care services have malignant disease. Yet 300,000 people die each year from progressive non-malignant disease, and many of the distressing symptoms, such as pain, fatigue, breathlessness, nausea and anxiety are common to cardiac, respiratory, renal, neurological or other pathologies and patients would benefit from palliative care expertise. The

report emphasises the need to increase the provision of services for patients dying of non-cancer related diseases, so that all suffering and dying patients have equitable access to symptom control, and practical, social, emotional and spiritual support.

Much can be learned from the palliative care model that has been developed for patients with cancer. In society in general, and among healthcare professionals, there is an understandable uneasiness to accept incurability and approaching death. Indeed, death may be perceived as a failure of medical care, by both clinicians and patients and their families. The emphasis on cure may lead to inappropriately late referrals and a reluctance to recognise and discuss when the focus of management should move to terminal care. These difficulties are exacerbated in non-malignant diseases, where the time course of the disease may be uncertain, and the transition from active management to the palliative phase of an illness may be difficult to identify. The development of the Gold Standards Framework, with its emphasis on identifying patients for palliative care, assessing their needs, and planning for the future, helps to improve end-of-life care by formalising good, holistic practice. Integrated care pathways (ICP) are also a way of implementing best practice and incorporating guidelines into the care of patients with a specific problem, and in Liverpool an ICP for dying patients has been developed, the Liverpool Care Pathway, which has been widely adopted in local hospital and community services. The report recommends the use of such ICP and further recommends that there should be a local register of patients identified as needing palliative care services in order to plan, review and coordinate services. This information should be available to all general practices, hospitals, hospices, community and social services, allowing better integration and coordination of services, particularly out of hours, or where there is a sudden change in clinical needs.

In order to ensure that palliative care treatments or referrals are initiated early, the report reminds us that clinicians should begin with the general identifier that end-of-life care begins when it would no longer be a surprise should the patient die in the next year. Specific evidence and examples of good practice are given for the management of patients with cardiac, respiratory, renal, neurological and HIV-related diseases in a series of appendices at the end of the

report. However, the majority of deaths in the UK occur in those over the age of 65 years, and the report includes a specific section on the needs of older people, the majority of whom die of cardiovascular, cerebrovascular and chronic lung diseases. Their needs may be very different from those of younger patients dying from cancer, and their end-of-life care may be far from ideal. Care in an acute hospital may focus on diagnosis and invasive investigations and treatments, with underassessment and undertreatment of their palliative care needs, which may be complex, reflecting multiple pathologies, potential for harmful drug interactions, and progressive degenerative disease. Good generic palliative care and geriatric expertise needs to be increased among general practitioners, community nurses and social workers, as well as across the medical areas of hospital activity.

Mental health problems in palliative care are similarly emphasised in Chapter 4 of this report. Many dying patients have psychological needs, with depressive and anxiety disorders, and associated symptoms such as poor sleep, weight loss and heightened distress, affecting quality of life. Patients with existing severe mental health problems, such as chronic psychoses, delirium or bipolar disorders may have particular difficulties in accessing palliative care, and the report recommends better provision of emergency mental health support. One in four patients over 80 will have increasing dementia, alone or co-existing with other conditions. Many of these patients spend their last year in a care home, and as physical problems such as immobility, falls, incontinence, recurrent infections, skin breakdown, nutritional difficulties and so on increase, so the palliative care needs become more complex. End-of-life care is sadly often of low quality, and our understanding of the natural history and the optimal control of distressing symptoms lacking. The report recommends that professionals in all settings and across all specialties need to be aware of and able to address these needs, with significant need for additional training, and liaison between specialists.

Workforce, training and research

Palliative care is multiprofessional and multidisciplinary, and many professionals and other allied staff contribute to the care of patients and their families. There is particular need for integration at the health and social care interface and this is emphasised throughout the report, as well as the need for education and training in the generic skills required by many different groups of healthcare professionals. The philosophy of patient-centred care where there is uncertain prognosis and deteriorating health should be common to all clinicians, and training for simple interventions for symptom control is generic across many different specialties and disciplines. There are significant shortfalls in numbers for many of the healthcare professionals in the multidisciplinary team, and this needs to be addressed via commissioning processes. The report addresses the medical workforce requirements in detail, highlighting the need for continued expansion of the numbers of consultants in palliative medicine. Consultants in palliative medicine provide leadership

to specialist teams, provide advice to colleagues in primary and secondary care, as well as providing direct delivery of complex care to patients. They have a crucial role in the strategic planning and development of palliative care services, and in the education and training of medical and other disciplines, as well as significant clinical workloads. Non-consultant career grade doctors have traditionally formed a large part of the workforce, and many are dissatisfied with their roles, support and the opportunities for career progression, and their aspirations need to be addressed. Many of those training or working in palliative care are female, with particular needs regarding flexible training and working.

The report makes it clear that in order to provide the major expansion in palliative care that is required to ensure that all patients have the opportunity of a good death, generic palliative care skills should be a core part of training for all health professionals. The report recommends that from foundation training onwards, each specialty should identify the required knowledge and skills for palliative care within that specialty, and these should be reflected explicitly in the competency-based curricula. Some specialties have large numbers of patients with palliative care needs and the opportunities for joint training alongside palliative care teams should be encouraged. General practice and many of the medical specialties require a high level of palliative care skills.

The report also considers the formidable ethical and personal issues which palliative care physicians face, particularly in respect of treatment decisions (for instance when to withdraw active treatment, when to initiate opiates, how to respond to request for euthanasia) and the tensions which may develop with other professionals. There is further consideration of palliative care in a societal context, both its compass, for instance the medicalisation of issues which many would consider outside the proper province of medical practice, and the duties and obligations which should underpin the work of palliative care physicians. Crucially there is emphasis that compassion alone is not enough and specific reference that 'in this era of evidence-based medicine palliative care must be rooted in firm science'.

However, the report acknowledges that there are little data regarding the efficacy and cost-effectiveness of many palliative care interventions. The difficulties in conducting research in this vulnerable group of patients, often with limited life expectancy, are compounded by the lack of research funding, low commercial interest from pharmaceutical companies, and the problems with coordinating trials across many small clinical units that are outside the NHS. The report calls for more basic research, facilitation of multi-centre trials and research into the models of care provision as well as national comparative audit of services.

It has been said that the only certainty in life is death, and the public and healthcare professionals place great importance on the management of dying. There is much to be done to ensure that all of us experience a good death, in the right place and with the appropriate physical, spiritual and social support. This report makes key recommendations to take this work forward, and clinicians, managers and government need to work together to deliver better care for the dying and for palliative care

Members of the Working Party

Mary Armitage (Chair) Consultant in Endocrinology, Royal Bournemouth Hospital; Richard Berman (Trainee Representative, Association for Palliative Medicine) Consultant in Palliative Medicine, Christie Hospital, Manchester; Ann Blackburn (British Geriatrics Society), Consultant in General and Geriatric Medicine, King’s College Hospital, London; Aine Burns (Renal Association) Director of Medical Education, Royal Free Hospital, London; Martin Fisher (British Association for Sexual Health & HIV) Consultant Physician, The Lawson Unit, Brighton and Sussex University Hospital; Rob George (Centre for Biomedical Ethics and Philosophy, Royal Free and University College Medical School, London) Consultant in Palliative Medicine, Meadow House Hospice, Ealing PCT, London; Fiona Hicks (Association for Palliative Medicine) Consultant in Palliative Medicine, Leeds Teaching Hospitals Trust; Mike King (Royal College of General Practitioners) Professor of Primary Care Psychiatry, Royal Free and University College Medical School, London; Jane Maher (Macmillan Cancer Support) Consultant Oncologist, Mount Vernon Cancer Centre, Northwood, Middlesex; Emma Mason Lecturer in Clinical Pharmacology, Department of Pharmacology, Therapeutics and Toxicology, University of Wales College of Medicine, Cardiff; Ian Mungall (Joint Specialty Committee for Respiratory Medicine) Consultant in General/Respiratory Medicine, Peterborough District Hospital; Bill Noble (Chairman, Association for Palliative Medicine) Macmillan Senior Lecturer in Palliative Medicine, University of Sheffield; Dilly Ridge (Patient Representative) Patient and Carer Network, Royal College of Physicians; Christine Vial (Patient Representative) Patient and Carer Network, Royal College of Physicians; Deborah Watkinson (NCCG Representative,

Association of Palliative Medicine) Associate Specialist in Palliative Medicine, Florence Nightingale Hospice, Aylesbury; John Wiles (Chairman, Joint Specialty Committee on Palliative Medicine) Consultant, Princess Royal University Hospital, Orpington

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