ABC of palliative care

The carers

Amanda Ramirez, Julia Addington-Hall, Michael Richards

In general, most of the final year of life is spent at home, although 90% of patients spend some time in hospital and about 55% of all deaths occur there. The burdens and rewards of caring for people in their last year of life are shared between informal carers (relatives and friends or neighbours) and healthcare professionals working in institutions or in the community.

About three quarters of people receive care at home from informal carers (residential or non-residential), most of whom are women. About a third of cancer patients receive care from one close relative only, while nearly half are cared for by two or three relatives, typically a spouse and an adult child. A smaller proportion of non-cancer patients than cancer patients have access to such informal care, reflecting their older age at death.

Approximately two thirds of cancer patients and a third of non-cancer patients receive some kind of formal home nursing. District nurses are involved in the care of about half of cancer patients and a quarter of non-cancer patients. Palliative care nurse specialists, such as Macmillan nurses, are involved with about 40% of cancer patients but very few non-cancer patients. General practitioners see most patients at least five times during their last year of life, often at home. Healthcare professionals provide care on acute hospital wards and in outpatient clinics, and hospice inpatient staff care for about 17% of cancer patients during part of their terminal illness.

Families and friends as carers

Without the support of family and friends, it would be impossible for many patients to remain at home. It is common for families and, less often, friends to willingly take on the role of informal carer, even though this is often at considerable psychological, physical, social, and financial cost to themselves. More than half of informal carers find the caring "rewarding," 10% find it a burden, and the rest find it rewarding and burdensome in equal measure. Informal carers have a range of needs, including information and education about the patient's illness and how to care for the patient, and psychosocial support.

Information about the patient's illness

Advanced incurable illness raises difficult but important issues for health professionals to discuss with patients and their carers. Being well informed as a carer seems to allay the anxiety provoked by unnecessary uncertainty and unrealistic fears. Adequate information about the illness enables patients and carers to make informed decisions about medical care as well as broader personal and social issues.

It is no longer considered good practice to inform only relatives about a patient's disease and its management and prognosis. Exceptional circumstances may arise when patients (not relatives) clearly indicate to health professionals that they do not wish to discuss their illness or when patients are unable to understand the necessary information.

When communicating with relatives, collusion to protect patients from the truth should be discouraged. Informing only relatives can lead to mistrust and impaired communication between patients and their relatives at a time when mutual support is most needed. Patients may choose to consult with

"The death of Theodore Gericault (1791-1824), with his friends Colonel Bro de Comeres and the painter" by Ary Scheffer (1795-1858). Until the start of this century, most people died at home while being cared for by family and friends

Informal carers

- Most patients want to be at home during their final illness
- Informal carers are vital to the support of patients at home
- Informal carers often have unmet needs themselves
- Anxiety and depression are common among informal carers
- Many informal carers feel isolated, particularly after the patient's death

Needs of informal carers

Information and education about

- The patient's diagnosis
- Causes, importance, and management of symptoms
- How to care for the patient
- Likely prognosis and how the patient may die
- Sudden changes in patient's condition, particularly those which may signal that death is approaching
- What services are available and how to access them (including in emergencies)

Support during the patient's illness

- Practical and domestic
- Psychosocial
- Financial
- Spiritual

Bereavement care

(see later article on bereavement)

their doctor alone, but joint consultations with both patient and relatives avoid the problems that can arise when one or other party is informed first. Only between a half and two thirds of bereaved carers report having received all the information they wanted about the patient's illness.

Education about how to care for the patient

Although most informal carers have no nursing training, they perform simple nursing procedures daily. Family and friends benefit from practical instructions on how to care for patients—for example, how to lift them and how to administer drugs. There is a clear role here for district nurses and palliative care nurses. Carers describe feeling useless and helpless when they are not taught.

Psychosocial support

In the year before the death of a cancer patient, the estimated prevalence of anxiety and depression among informal carers is high—reported to be 46% for anxiety and 39% for depression. About half of carers report problems sleeping, and about a third report weight loss during the year. Carers' anxiety is rated alongside patients' symptoms as the most severe problem by both patients and families.

Professionals can encourage disclosure of carers' distress by asking questions about their perception of the patient's illness and its impact on their life. Mild psychological distress usually responds to emotional support from frontline health workers with effective communication skills. This involves explaining physical and psychological symptoms and challenging false beliefs about death and dying. In addition, carers can be encouraged to express their concerns and fears. In this way rational hope can be engendered and any sense of isolation reduced. More severe psychological distress may benefit from specialist psychological assessment and treatment.

Carers' perspective on place of death

Many patients express a desire to die at home, but carers' preferences for place of death before the event have not been established. Retrospectively, however, three quarters of bereaved carers report being satisfied with the place of death, the proportion being considerably higher when patients died at home than when they died in hospital. Excessive strain on relatives, lack of nursing staff or night sitters, and absence of equipment are common reasons why dying patients are admitted to hospital.

Healthcare professionals

Many different health professionals care for patients in their last year of life—in the community, in hospitals, and in hospices and other institutions. Some staff devote effectively the whole of their working time to palliative care, while for many others it forms only a small part of their formal workload. Unfortunately, no good information exists about this latter group, which deals with most patients with incurable disease. The following discussion is about those who work formally in palliative care.

Psychiatric morbidity and burnout

Working with patients who have incurable disease and those who are dying is widely believed to barrage staff with suffering and tragedy. However, the stress associated with caring for dying people may be counterbalanced by the satisfaction of dealing well with patients and relatives.

The prevalence of psychiatric morbidity among palliative physicians is 25%, similar to that reported by consultants

Failing to meet informal carers' needs

- Carers are often reluctant to disclose their needs to health professionals because they do not think it is acceptable to do so
 - Reasons for this include
 - Not wanting to put their needs for care before those of the patient
 - Not wanting to be judged inadequate as a carer
 - Believing concerns and distress are inevitable and cannot be improved
 - Not being asked relevant questions by health professionals
 - Attention to the needs of carers will often benefit patients—Tired and distressed carers are unlikely to give patients the physical care and emotional support they need
 - A large proportion of dying patients admitted to hospital could be cared for at home if informal carers were given better support
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Sources of support to enable informal carers to look after dying patients at home

Symptom control—General practitioners, district nurses, clinical nurse specialists such as Macmillan nurses
Nursing—Community nurses
Night sitting services—Marie Curie nurses, district nursing services
Respite care—Hospices, community hospitals
Domestic support—Social services
Information—General practitioners, district nurses, clinical nurse specialists, voluntary organisations such as BACUP
Psychosocial support—General practitioners, district nurses, Macmillan nurses, bereavement counsellors
Aids and appliances—Occupational therapists
Financial assistance—Social workers

Risk factors for psychiatric morbidity among palliative care professionals

- For senior professionals, young age or fewer years in post
 - High job stress
 - Low job satisfaction
 - Inadequate training in communication and management skills
 - Stress from other aspects of life
 - Previous psychological difficulties or family history of psychiatric problems
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working in specialties in acute hospitals, junior house officers, and medical students. Palliative physicians in fact report lower levels of specific work related distress or “burnout” than other consultants.

Similarly, hospice nurses in the United States have significantly lower levels of burnout than intensive care nurses. Hospice nurses in Britain have a lower prevalence of psychiatric morbidity than Macmillan nurses and ward nurses, who in turn have a lower prevalence than district nurses and health visitors.

Job stress

The issues reported as stressful by palliative care doctors and nurses seem to be those generic to all health professionals, with overload and its effect on home life being predominant. Poor management and resource limitations, as well as issues of patient care, are also major sources of job stress.

Perhaps counterintuitively, death and dying do not emerge as a major source of job stress among either doctors working full time in palliative care or among non-specialists, including general practitioners and junior hospital doctors. Death and dying are reported as particularly stressful by palliative care nurse specialists when the patient is young, when the nurse has formed a close relationship with the patient, or when several deaths occur in a short space of time.

Nurses working in palliative care report that difficulties in their relationships with other healthcare professionals are a particular source of stress. This stress is often the result of a lack of understanding of roles and sometimes because of poorly defined roles.

Job satisfaction

Palliative physicians have significantly higher levels of job satisfaction compared with consultants working in other specialties. Helping patients through controlling symptoms and having good relationships with patients, relatives, and staff are the most highly rated sources of job satisfaction for palliative physicians.

Levels of job satisfaction are generally high among British nurses, but significantly higher among clinical nurse specialists and hospice nurses than district nurses, midwives, ward nurses, and health visitors. Clinical nurse specialists describe personal relationships with patients and their relatives and having the time to develop these as the greatest source of satisfaction in their work. Other patient related sources of satisfaction for clinical nurse specialists are controlling pain and symptoms and improving the quality of life and death for patients. Nursing dying patients and supporting their families are an important source of satisfaction as long as nurses feel that they have the time, staff, and knowledge to do it well.

Other areas of work that clinical nurse specialists describe as satisfying are relationships with colleagues and other health professionals and teamwork. This is an example of an aspect of work that can be both a major source of both stress and satisfaction.

Improving the mental health of professional carers

Maintaining and improving the mental health of professional carers is essential both for their own wellbeing and for the quality of care that they provide for patients. Strategies for improving the mental health of professionals should be implemented as a whole, so that staff are provided with both the skills and support they need to provide effective palliative care while at the same time ensuring their own emotional survival.

Conflicts may arise in trying to meet the different needs of patients, professionals with mental health problems, and the health service as a whole. Strongly held and polarised views

“Grandfather’s little nurse” by James Hayllar (1829-1920)

Strategies for improving mental health of professionals providing palliative care

- Maintaining culture of palliative care despite the shift within health care from service to business, including
 - Autonomy
 - Good management
 - Adequate resources, particularly with regard to workforce, so that high levels of patient care can be maintained
- Providing more effective training in
 - Communication skills—Including role playing of difficult interpersonal situations with patients, relatives, and professionals
 - Management skills
- Providing effective clinical supervision which addresses the physical, psychological, social, spiritual, and communication dimensions of patient care
- Providing a confidential mental health service that is independent of management and covers both personal and work related problems

often exist among doctors, nursing staff, and managers. Both local and more overarching initiatives are required to define and implement policies for identifying, assessing, and treating staff with mental health problems.

Identifying mental health problems

Some workers recognise that they have a mental health problem and seek advice and care from their general practitioner, a mental health colleague, or a national service (such as the BMA telephone counselling service for doctors—0645 200 169). Such professionals might be expected to have less severe mental health problems. Of more concern are those who do not refer themselves. They are identified by colleagues and should be referred to a mental health specialist in their own interests and also to the relevant service manager if there are concerns about conduct and performance that may jeopardise patient safety.

Assessment

Assessment services may either be provided within the institution where the healthcare professional works or, in order to maintain confidentiality, elsewhere by arrangement with other institutions. Such external arrangements may be particularly important for independent hospices. Assessments should be conducted by skilled mental health professionals and should include an assessment of risk to patients as well as the needs of the affected professional.

Before any assessment interview is started, an explicit discussion of confidentiality and its limits is useful. During assessment interviews, it is particularly important that professionals' health beliefs and preferences for treatment should be elicited, explored, and respected. It can be tempting to collude in self management, but this is a disservice to the professionals, who should be relieved of the burden of providing their own care.

Treatment

Treatment should ideally be provided outside the institution in which the professional works. The cornerstone of treatment is psychological therapy, either alone or in conjunction with psychotropic drugs. Choice of treatment needs to be guided by the individual case. Major factors to be considered are professionals' preferences for types of treatment and their interest in exploring and understanding their problems.

Psychological treatments delivered by trained staff are effective and include grief work, cognitive-behaviour therapy, behaviour and interpersonal therapy. Non-specific "counselling" and "support" are of limited benefit in managing complex, severe psychological problems. Many health professionals with less serious psychological problems attest to the benefit of having some form of counselling, but further evaluation is required to corroborate these anecdotal reports.

Providing mental health services to palliative care professionals

The principles are similar to those for any other group of health workers and include

- Ensuring the safety of patients
- Ensuring the optimal care of professionals
- Protecting the long term employment prospects of professionals— For the benefit of affected professionals and of the health service overall

Further reading

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Amanda Ramirez is professor of liaison psychiatry at the United Medical and Dental Schools of Guy's and St Thomas's Hospital, London, and consultant psychiatrist at Lambeth Healthcare NHS Trust, London. Julia Addington-Hall is senior lecturer in palliative care at King's College School of Medicine and Dentistry, London, and St Christopher's Hospice, London. Michael Richards is the Sainsbury professor of palliative medicine at the United Medical and Dental Schools of Guy's and St Thomas's Hospital.

The ABC of palliative care is edited by Marie Fallon, Marie Curie senior lecturer in palliative medicine, Beatson Oncology Centre, Western Infirmary, Glasgow, and Bill O'Neill, science and research adviser, British Medical Association, BMA House, London. It will be published as a book in June 1998.

Fifty years ago

The new NHS: Are we convinced?

The medical profession has lost little time in making an effective rejoinder to Mr. Bevan's reply to the Negotiating Committee. Our correspondence columns show that doctors are now fully alive to the implications of the National Health Service Act and becoming firm in their resolve to say "No" to a Minister whose method of negotiation is to alternate blandishments with threats in his successful attempt to avoid discussing those matters which the Negotiating Committee consider to be fundamental points of

disagreement between the medical profession and the Ministry of Health. The Committee which met the Minister on Dec. 2 and 3 were certainly treated to a brilliant exhibition of dialectical skill. But this was not really the purpose of the meeting with the Minister. The purpose was negotiation, and Mr. Bevan once more proved that his interpretation of the meaning of this word differs from that which is usually accepted. (*Editorial*, 10 January 1948, p 53. See also editorial by Gordon Macpherson, 3 January 1998, p 60.)