Breaking bad news: starting palliative care

JR Soc Med 1996;89:590-591
SECTION OF HYPNOSIS & PSYCHOSOMATIC MEDICINE, 26 JANUARY 1996

One of a doctor's most distressing tasks is telling a patient that he or she has a lethal illness. Unfortunately, it is often done in an insensitive and inept way, even being delegated sometimes to junior and inexperienced staff. A bad interview builds a barrier that hampers subsequent communication. Bad news must be broken gently.

Nowadays, it is widely accepted that patients have a right to be told the diagnosis and the possible prognosis, but the whole truth may be too much at once: we may need to work round to it little by little. The information may have to include simple anatomy, because even highly educated people can be ignorant about what lies under the skin.

Before the interview the patient will often have picked up hints of a sinister diagnosis. Suspicions may be aroused by the long time taken to reach a firm diagnosis; by vague euphemistic terms used to describe the illness. The behaviour of relatives, who already know, may arouse suspicions as may the arrival of relatives from a distance. Patients should always be told first, although some like to have a spouse or close relative present so that they can hear the news together. Relatives who know before the patient will often try to embargo the truth from the patient. In contrast, patients with non-life-threatening serious illnesses are usually told the diagnosis in a straightforward way.

There is a large variation in patients' comprehension. A doctor may say one thing and a patient may hear another. A doctor may mean one thing and the patient may misinterpret. Telling a patient in the presence of a spouse may aid understanding. The gentle breaking of bad news may well have to be repeated several times. The initial reaction is often one of denial: 'it can't be me'. This may be associated with a feeling of isolation. Anger, bargaining and depression may all be experienced, before ultimate acceptance of the painful truth.

Since the time of Hippocrates it has been known that patients fear the manner of dying more than death itself. The main fear, after pain, is one of loss, whether it be of prospects, family or love. It depends much on the age of the patient. Other fears are those of a distressing end—suffocating, choking or bleeding to death.

Patients with life-threatening illness are upset when their suspicions are confirmed. They then need sensitive, humane and gentle explanation of what may lie ahead. They need to know the aim of any treatment. They need to know why a particular treatment is being suggested. Over-treatment or over-investigation may arouse deep fear. Repeated examination of the patient, particularly of a small area, may be frightening if the doctor makes no comment. Likewise, being given information which differs from that given to relatives, is frightening. The feeling of being unwanted or a burden is very worrying. These fears, too, require sensitive and gentle handling.

The distress of the dying can easily be made worse by misunderstanding. Patients with a mortal illness will understand the palliative intent of surgery, radiotherapy or total parental nutrition as long as they can make sense of what they are experiencing.

Doctors who elect to say as little as possible overlook the need some patients have for accurate and relevant information. Honest information dispels damaging misconceptions, and truth may well be the best antidote to unreasonable fear.

For relatives to be informed before the patient and without his or her consent is still common practice and can be very damaging. Some doctors decline to break bad news because the patient does not ask for it. Others do not pursue the matter when the patient acts as if he does not accept or understand it. They choose to see this behaviour as protective denial, which it may well be. We often forget that doctors are not always easy to approach or question. Patients more usually seek information or confirmation from nurses, or even auxiliaries. These people are less daunting.

Once we have broken bad news, the next decision is about treatment. If no curative therapy is feasible, then palliative care must be considered. This is something every patient has a right to, whatever the illness. The provision of palliative care is the responsibility of every clinician—doctor or nurse, specialist or generalist. Palliative care once started continues to the end. It should continue with active, skilled care as at any other time in the patient's life. An important question is: 'When should specialist palliative care start?' This has been thoroughly addressed by the National Council for Hospice and Specialist Palliative Care Services, which brings together statutory and voluntary providers, all professions, disciplines and cancer charities involved in this field. In the Council's view, published last year in an occasional paper, few people will need specialist palliative care, but the advice of these specialists must be available and accessible nationwide. Wherever the patient is, specialist knowledge and skills will be on hand. Put simply: palliative care should follow the patient. Any doctor, in general or hospital practice, will have access to advice and guidance.

In the UK, there are now over 216 palliative care services with inpatient beds. One-fifth of these units are run by the National Health Service. There are many services operating to complement the work of primary care teams. Some services have day care; some have outpatient and research facilities; all have educational programmes.
addition to these services there are thousands of Marie Curie and Macmillan nurses. Both these groups work in the community but the Macmillan nurses also have a small and different role in hospitals and oncology centres.

The criticism that good palliative care can be found only in elitist charity-run hospices is no longer true. In the past 20 years, the number of hospital palliative care teams (or support teams) has risen from four to 240. This enables most patients to remain in familiar wards or at home while receiving expert advice from the peripatetic team. Until lately, the UK was unique in devoting time, albeit very little, to aspects of palliative care in every medical school, most of the teaching being done by palliative medical consultants. Its example is now being emulated in many other countries.

Note  This report is based on a lecture given by Dr Derek Doyle.

REFERENCES

Derek Doyle
Formerly Director St Columba's Hospice, Edinburgh, Scotland

Sean O'Connell
Editorial Representative, Section of Hypnosis & Psychosomatic Medicine