Learning about death

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This paper outlines briefly some of the research which has been carried out on attitudes to terminal illness and its care. The writer feels that not enough effort is being put into the teaching of this subject in our medical schools and Universities, and that doctors themselves are the ones who often wish to 'duck' the issue of dealing with disability and the dying. However, with the increasing awareness, through both the research and the growing allied literature, the writer feels that there is no longer any excuse for omitting this subject from the curricula for doctors and nurses in training.

Introduction

The facts of modern medicine speak for themselves. We know that we are now faced with an increasing burden of illness and disability whose nature is such that much of it is neither preventable nor curable. People are living longer, to succumb eventually to degenerative diseases, cancer and arteriosclerotic conditions of the heart and the central nervous system. Our hospitals are filled with the ageing, the elderly and the chronically disabled, these categories being, to a large extent, interchangeable. Even government directives, issued under the influence of the latest pressures on the British economy, feebly urge a change of emphasis and a shift of resources from acute hospitals towards institutions and services for the long-term sick and disabled.¹ We know that, in future, much more emphasis must go into caring. Yet there is still a tremendous resistance, at various levels, towards the demystification of medicine and a reluctance to adopt technologies more appropriate to the needs of large numbers of the sick in contemporary society.

Doctors, for the most part, are uninterested in disability and dislike the contemplation of mortality. Essentially activists and interventionists, they are by nature and by training directed to precise diagnosis, followed by the prompt prescription of appropriate remedies. Part of the notable success of modern medicine to date – though its achievements may now have reached a plateau – have lain in specialisation and it is with specialties in mind that most young doctors are trained and to which they eagerly aspire.²

Lately there have been a number of serious critiques of high technology medicine and a range of diagnoses of medicine's own malaise have been

accompanied by equally varying suggestions for change.^{3, 4, 5, 6, 7, 8}

At the bedside or fireside level of medical encounter, doctors have learned to scrutinise the detailed nature of disease processes, whereas the patients have always been more concerned about the effects of illness upon their day to day lives and social functioning than about the pathology which caused their disability. They are concerned with living, with its length and with its quality. Disabilities can have so many different causes that specialists, once they have done their best, are inclined to retire from a depressingly irreversible condition. The patient is expected to manage as best he can, perform as far as possible like a 'normal' person and not bother the busy medical expert with his tiresome niggling complaints and importunities.

The dying patient is even less interesting to the specialist, unless he is an oncologist or a surgeon experimenting with heroic measures for the relief of pain. The dying patient is, *ipso facto*, one of medicine's failures, an unpleasant reminder of the limits of science.

Patients' and doctors' attitudes to terminal illness

But there are also deeply personal reasons for doctors' reluctance to deal with death face to face, to look it in the eye, to look frankly into the eyes of the dying patient. Surveys have been done in America, for instance, which have uncovered a remarkable contrast between the expressed desire of patients and potential patients to be told the truth about their condition, and doctors' equally strong disinclination to do so. We know from studies in the UK^{9, 10} that the main complaint of hospital patients generally is that they are not told enough by their doctors. So it is scarcely surprising if this should be mirrored in the views of patients with a bad prognosis.

The studies referred to below are in no sense a comprehensive series and they are fraught with serious methodological faults in relation to sampling. However, they do carry some broad implications.

In 1950 Kelly and Freisen¹¹ reported from the Department of Surgery at Minnesota Medical School on the results of a very simple minded, not to say crude, exploration of attitudes in this area.

They polled two groups of one hundred patients, one with an established cancer diagnosis (of unspecified nature), the other with some other diagnosis (equally unspecified). All were at the time ambulant out-patients.

The cancer patients were asked outright:*

- 1) Is this the first time you knew about having cancer?
- 2) If you knew previously, how were you told, and when?
- 3) Doctors and relatives sometimes try to protect cancer patients from knowledge of their diagnosis. How do you feel about this policy?
- 4) Patients with cancer are sometimes cured without ever having known they had it. But if others knew of these successes they might be less fearful. What do you think?

The non-cancer patients were bluntly asked:

- 1) If our tests showed you have cancer, would you want to know?
- 2) (as 4 above).

The results showed that, whereas 89 per cent of the cancer patients declared that they preferred knowing, yet only 73 per cent of this group thought that people in general ought to be told of such a diagnosis. About the same time Branch¹² questioned 105 patients, 51 of whom had cancer. Of the group that were cancer free 48 out of 54 stated a preference for being told. Of the cancer patients, 39 knew the nature of their illness while 9 denied any illness whatsoever.

Samp and Curreri¹³ who investigated 560 cancer patients and their families, found that 87 per cent felt that a patient should be told.

As Oken¹⁴ points out in his useful review of the early literature one of the major sources of unreliability in obtaining responses from cancer patients is the fact that, being so desperately vulnerable and in need, they can scarcely dare to question the wisdom of their doctors. There are grave doubts, too, about the meaning of answers given by people who are at the time in excellent health. Oken himself concentrated on medical attitudes. He used a questionnaire and interviews to study the policies of 219 physicians on the vexed question of 'telling' cancer patients. He remarked in conclusion 'although clinical experience was cited by three-quarters as the major policy determinant, the data bore no relation to experience or age. Instead, inconsistencies, opinionatedness and resistance to change and to research were found which indicated emotion-laden, *a priori* personal judgments as the real determinants. Feared reactions to telling (eg suicide) could rarely be substantiated. Equally undocumented assumptions were given as justifications for telling. Underlying

were feelings of pessimism and futility about cancer. The strong emotions mobilised by our deep and serious concern for cancer patients and by our difficulties in helping them, stimulate denial mechanisms'.

Oken's own research was more sophisticated in design than his predecessors'. He achieved a 95 per cent response rate to his questionnaires. The full results cannot be reported here, but it is worth noting one of the main findings: 'There was a strong and general tendency to *withhold* information. Indeed, a majority tell only very rarely, if ever'.

A superficial poll carried out by the magazine *Modern Geriatrics*¹⁵ sent questionnaires, in 1971, to 23 000 doctors. Only 2707 replied. This highly self-selected group of respondents (95 per cent of whom were general practitioners) replied to the question 'How often do you tell mentally alert terminal patients they are dying?'. Thirty-two per cent stated they almost always advised the patient if asked, but usually not, if not asked. Twenty-three per cent replied 'Seldom', and 21 per cent said 'Never'. The response 'Almost always, whether the patient asks or not' was only given by one per cent.

Judd Marmor¹⁶ discussed 'The Cancer Patient and his family', giving his own opinion in some detail on how to approach the matter. He remarked, 'The personality of the doctor has a great bearing on his ability to discuss a cancer diagnosis with a patient. . . . If the physician himself has a deep fear of disease or death, consciously or unconsciously, it is bound to affect his attitude towards the patient with cancer'.

Marmor made the following points:

- 1) The patient has a legal right to be told.
- 2) Surveys (see above) indicate that a large majority want to be told.
- 3) Patients who have been cured should be told so as partly to dispel the 'myth' of cancer's 'incurability'.
- 4) Many patients are bound to suspect the truth.†
- 5) Patients who know are likely to be more co-operative in follow-up and treatment.
- 6) Patients need to know, to put their affairs in order and in order to decide how best to spend what little life they have left.
- 7) Patients often surprise their doctors by the way they receive such information.

There is no time to deal, in this short paper, with many related topics. For example, children and death¹⁸ or the topic of bereavement^{20, 21, 22} or the matter of the actual care of many categories of dying patients by their relatives and by hospital personnel.^{23, 24} The subject is being exhaustively

*The questions are paraphrased and abbreviated.

†The point explored at length by Glaser and Strauss¹⁷ and by Kubler-Ross¹⁸.

researched, there is a growing literature,* and there is no longer any excuse, on practical or on academic grounds, for excluding its consideration from the training of doctors and nurses. The question is rather, how best can this be achieved.

*Epitomised by the tardy attention given to the psychological impact of cancer by the prestigious UICC.²⁵

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