A team approach to terminal care: personal implications for general practitioners

DAVID ALDRIDGE, PhD
Senior Research Fellow, Department of General Practice, St Mary's Hospital Medical School

PART of my work as a counsellor is concerned with the management of terminal illness within the community using a coordinated approach. This work focusses on what the illness and its treatment means to the patient and his or her family. In practice this means working with a wide range of services and professionals, from the medical interventions of the oncologist to the spiritual guidance of priests.

In talking to colleagues and general practitioners I have come across a number of recurring concerns about the management of terminal illness which may have implications for the management of chronic illness, particularly in the light of current interest in community approaches to primary health care. The first of these concerns is about the problems which arise with cooperation between professionals. The second is about the personal difficulty which cancer and some chronic illness poses for individual doctors.

When talking to general practitioners about the management of dying patients I have come across an attitude to the hospice movement, to hospital consultants and towards 'counselling' by other professionals which borders on antipathy. The root of this antipathy appears to lie in a feeling that the function of the general practitioner, as family practitioner and as the coordinator of primary care, is being usurped and that his or her expertise is being invalidated. Perhaps this concern has just cause, for in a coordinated approach to the management of cancer the general practitioner can be left in the position of a spectator when other professionals exercise their particular expertise.

For example, in a recent discussion at a postgraduate medical centre about the management of a patient suffering from chronic leukaemia, who subsequently died, the general practitioner referred to the consultant as the 'great white chief' and deferred to his clinical decisions about treatment. The important gatekeeping function of hospital entry was also removed from the control of the general practitioner and was negotiated between the patient and his consultant. Furthermore, the patient proved to be knowledgeable about his own medication, having trained and practised as a dentist, and this removed yet one more realm of influence from the general practitioner. At another level, the supportive function of the specialist nurse (supplied by the consultant haematologist) and the presence of a family counsellor and the local priest, while recognized as important, left the general practitioner wondering what role he had to play in relation to 'his' patient.

What was perhaps most striking was the reaction of the medical practitioners to the parish priest. The general practitioner ended his description of the involvement of other professionals by saying, ironically, 'and here comes the vicar!' By disparaging, or at best questioning, the role of the priest the general practitioner was raising an important issue. Who in the community is to be involved in the health care needs of patients? Are these needs met solely by health professionals or is health something which we can all contribute to as professionals and laity? To reject the role of the priest is to deny a vital contribution to the broad health care needs of the patient. In dealing with the dying the spiritual needs of the patient, and those with whom he lives, are very important. The existential issues of personal and family loss, feelings of abandonment and the questioning of life's purpose are not necessarily best handled by the general practitioner, no matter how compassionate he or she may be.

Following on from this concern about the role of the parish priest the general practitioner also felt that counselling for the family provided by a specialist counsellor usurped another area of the general practitioner's expertise. Although the family doctor thought the counselling was valuable, he also saw it as problematical because it 'stirred things up' and upset the children. I was left wondering how general practitioners could on the one hand embrace counselling as valuable and on the other hand reject it as 'stirring things up' and whether they could really understand the nature of counselling the dying, or accept other professionals in their role as counsellor. Perhaps it is because counselling the dying raises disturbing issues about the meaning of our own lives, about personal success and therapeutic efficacy, about our response to a loss of bodily functioning, and about our emotional lives and our relationships with those we live with. It would be interesting to discover whether 'stirring things up' is seen as a difficulty because it upsets patients or because it upsets doctors.

A second issue which developed from this discussion at the postgraduate centre was that of the difficulty faced by general practitioners when working with patients who are chronically ill for a prolonged period of time or when working with patients who have cancer. This issue manifests itself as a fear of 'catching' cancer or even a belief that the early signs of a chronic illness are developing. One of the difficulties the practitioner then faces is that he is wary of touching the patient, which is further compounded by the fear that the patient will perceive this wariness.

Ironically, it is these seemingly irrational, but very human, issues which patients have difficulty in raising with their general practitioner. While doctors may have a developing body of sophisticated scientific knowledge, and many like to believe that they operate from a particular theoretical model, they are still human. It is this very essence of our humanity — the irrational — which none of us can deny despite our training. Rather than deny these fears we can use them to understand ourselves and our patients.

However, a further concern is that we might not be offering our medical practitioners personal support to discuss these areas of their work. If talking about such issues is seen as stirring things up, and this too is perceived negatively, then the very things which need to be talked about are suppressed.

These are important issues for the delivery of health care and the management of chronic illness in the community. In the light of a movement towards prevention and self-care, along with a demand for patient participation in health care issues and the reorganization of the health service to promote 'community care' then we need to address the implications of general practitioners moving from their role as 'individual expert' to that of 'facilitator' and 'guide'. The practical difficulties are that few of us are trained to work cooperatively or to judge therapeutic success when divorced from individual endeavour. To say that health care workers already work as a team is to miss the point. Many of us work in parallel with others in the team, yet few of us work in true cooperation or are willing to share or acknowledge the therapeutic efficacy of those trained in other disciplines.

Doctors may also need to ask themselves whether belonging to a profession which emphasizes competition and deifies the cure as therapeutic success is the correct way to promote health care in the coming years. The health care of the old, the incurable and the dying are challenges which face doctors professionally and personally. Perhaps this is the time when we need to develop our expertise together. To do so we will have to be confident about what we have to offer, and not be threatened by the expertise of others. One step towards this will be the abandonment of the concept of 'my' patient and the acceptance of joint endeavours.

Address for correspondence
Dr David Aldridge, 7 Knightstone Court, Obridge Road, Taunton, Somerset TA2 7QA.