

## PALLIATIVE CARE IN THE COMMUNITY—DIFFICULTIES AND DILEMMAS\*

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When I began in general practice forty years ago, patients with a terminal illness dying at home were cared for by their families, often larger and more concentrated geographically than they are today, and by district nurses, mature, dedicated women, who provided skilled attention and advice, but with limited nursing aids. The general practitioner would call at intervals which became shorter as death approached and would provide the prescriptions for pain relief with possibly a nightly injection of morphine from the district nurse. Looking back on these days, I now feel a sense of guilt in the inadequacy of the care I provided, stemming largely from a lack of knowledge and understanding of the processes that I was observing and the possibilities of bringing greater comfort and relief to my patients in their closing weeks of life.

It has therefore given me immense satisfaction and pleasure to see that care of the dying has developed into a discipline in its own right within the wider body of medicine. By discipline, I am identifying a branch of medicine for which special training is needed and which has its own educational content, a developed research base and a bibliography. Palliative medicine now has all of these and therefore as with general practice is established as a separate specialty within medicine.

I have been asked to speak on the theme of Palliative Medicine in the Community—Difficulties and Dilemmas. I wish therefore at the outset to lodge a complaint against the pessimism of the organising committee who, attracted by alliteration and no doubt influenced by Bernard Shaw, have linked doctors with dilemmas and difficulties. They might even have added the word 'depression'. But if we are to respond to the development of palliative medicine as a discipline, the ethos of that discipline demands that we also include the word 'delight'. That would not be hyperbole, for the discipline has brought a new dimension to medicine and a delight to those of us who have witnessed and experienced the transformation that good palliative medicine can offer to our fellow human beings in a critical phase of their lives.

Living and working in Edinburgh, I have been privileged to observe and participate in the development of the discipline, admiring the initiatives of the Macmillan Home Care Service linked to the Marie Curie Homes and of the Hospice movement where St Columba's here in Edinburgh under the guidance of Derek Doyle has been so influential. Derek was kind enough to invite me to write a foreword to his book on domiciliary palliative care which is part of the Oxford series in general practice. This gave me an opportunity to recognise my great personal debt to him for the role he has played in developing the understanding and skills of this new discipline. I learned from him many things, some of a simple nature and others much more technical. Above all I learned to

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understand the characteristics of pain, how to anticipate it and how to relieve it and thereby permit many patients to lead a meaningful life in contact with friends and family almost to the last moment. I learned too skills in manipulating the medicines at my command to relieve many of the discomforts of the dying.

At the outset of my career in general practice, and following as I did my father and my grandfather in the same practice, I quickly learned that the birth of a child not only brought great joy to parents but produced a strong bonding between the mother and the attendant general practitioner. 'Of course your father brought me into the world' is perhaps one of the most powerful introductory statements that one person can make to another, and certainly influences the relationship between the doctor who undertakes maternity work and the family. The attendant midwife who, almost always, did most of the work, seemed to receive rather less credit except where the newborn girl was blessed with the Christian name of the midwife. If bonding between a general practitioner and a mother and her family is developed at the point of entry to this world, paradoxically it is the quality of the care provided to a patient and a family at the exit from life which provides the greatest opportunity for closer bonding between a general practitioner, the primary health care team and a family.

We live in the age of charters and not least, of course, the Patient's Charter. Charters, however, like much of audit, are based more on quantity rather than on quality. There can be no doubt, however, that in any quality based Charter for Patients, good palliative care, when necessary, should have a prominent place. I suggest therefore that the knowledge and skills of palliative medicine are fundamental and should be possessed by every doctor and every nurse who provides palliative care in the home. Although fewer patients may be dying at home, ninety per cent of the last year of life is spent at home.

This leads to the question of difficulties and dilemmas. I would like to first consider the problems associated with equipping the general practitioner with the knowledge and skills which he or she needs to provide high quality palliative care.

Most vocational trainees begin their year in general practice with no special training in palliative medicine and many in fact have been traumatised, sometimes severely, by their experience in hospital at a junior grade where they have been required to care for patients with incurable conditions who are going to die. They have been faced with situations more difficult than they have ever previously experienced, especially when dealing with young mothers and children. Some of them have found this stress almost intolerable and this certainly has influenced them for the rest of their lives. Often they have been required to impart dreaded news to patients and their families with no proper training in the skills that this requires and they have watched patients dying, disillusioned perhaps by the inadequacy of medicine to prevent the process proceeding to its inexorable end. Many young trainees coming to general practice are apprehensive about their ability to manage these situations and it requires skilled supervision and teaching to overcome these difficulties and fears and move to a situation where they can, with confidence and competence, provide palliative care for the patient and associated support to the family.

### *Research into family care in the community*

A quarter of a century ago, palliative care was beginning to evolve as a sub-

specialty, stimulated by the growth of the hospice movement. During the 1980s improvement in the quality of palliative care being offered at home was encouraged and during this period we saw the development of domiciliary care in the community. The quality of care provided by general practitioners in the management of the dying patient had received little study, but in line with the growth of the hospice movement there has been an increased expectation for general practitioners to develop their knowledge and competence. Some people have cast doubt on the general practitioner's ability to provide effective and high quality palliative care in the community. As a consequence in 1990 the Royal College of General Practitioners (RCGP), recognising the increasing need for palliative medicine, examined ways and means of influencing the education of general practitioners and the primary health care team in palliative care and, in association with the Cancer Relief Macmillan Fund (CRMF), conceived a project to provide a number of Palliative Care Facilitators based in RCGP Faculties. This project was funded jointly by the CRMF, the Department of Health and the Scottish Home & Health Department.

The objective of the project was to enhance the continuity and quality of care for those with an advanced disease and for their families by providing an experienced general practitioner to work as a Facilitator, with primary care teams to help mobilise existing professional skills. In 1991, four such Facilitators were appointed to College Faculties in England and Northern Ireland, and a joint post for two general practitioners was appointed in North East Scotland. The tasks of the Facilitator were:

1. To review the current state of care for individuals with advanced diseases in general practices in their locality.
2. To act as a source of help and advice to practices wanting to extend their services to such individuals and their families.
3. To encourage resources for teaching which could be extended to local vocational training schemes.
4. To liaise with the College Faculty in promoting educational activities for all members of the primary care team.
5. To establish links with local Hospice units, oncology units, Macmillan teams, Marie Curie nurses, and other palliative care support staff, both statutory and voluntary.

Facilitators were all principals in general practice and were funded for two sessions per week for two years. All began the projects in 1992 and completed them at the end of June 1994.

In four of the Faculties the initial contact with practices was through a questionnaire. These questionnaires were for completion by members of the practice team, including GPs, practice nurses and attached nursing staff. In North East Scotland the questionnaires were sent serially to practices identified as recently having had a patient die with a cancer related illness. This project took place in the Grampian region where 1,000 consecutive cancer deaths were identified and questionnaires sent to the GPs of these patients some weeks after the death enquiring about the care that had been provided. Nurses were given an identical questionnaire. The questions in all the questionnaires centred around pain control and other symptoms, as well as whether or not there were communication difficulties.

### *Questionnaire results*

There was excellent cooperation from the doctors and nurses in Grampian, 90 per cent of whom responded. An analysis of questionnaires from the whole project suggests that in one third of practices there is a partner with a special interest in palliative care, while within the primary health care team one third of practices also have a member with a special interest in palliative care, and this is usually the district nurse. Of the practices 70 per cent had a special arrangement for managing terminally ill patients; however only 12 per cent had audited their care but 78 per cent were aware of, and used, such facilities as Macmillan nurses, Marie Curie nursing services, local hospice care and respite care. However only one half of practices were aware of a specialist domiciliary advisory service in palliative care. About sixty per cent of the practices owned a syringe driver.

Only 9 per cent of the GPs but 57 per cent of the nurses rated themselves as good in managing terminally ill patients. Of the GPs forty-three per cent rated their ability as adequate or worse. Finally, practices were asked specific questions about the last dying patient in the practice that had required care by the primary health care team.

The North East Scotland study highlighted problems with symptom control with particular reference to pain, constipation, nausea and vomiting, and mental distress, with the doctors admitting that 10-15 per cent of these symptoms were managed poorly by the practice. In this study there was an interesting discovery of an apparent difference between the preferred place of death attributed to patient and to carers. Doctors stated that in 68 per cent of the deaths, the place of death was the patient's preference, whereas they also stated that in 80 per cent of the deaths, the place was the preference of the carer. This suggested that the doctors may have been more influenced by the wishes of the carers than the patients in some cases, and it also indicated that they were more likely to be aware of the carer's wishes than the patient's.

The Facilitators made themselves available to visit individual practices on request and in general they were overwhelmed by the positive response to this initiative which was designed to assess PHCT behaviour in palliative care and to provide educational interventions with the whole practice team. The format of these practice based meetings was determined by the practice but they were usually informal with discussions on subjects identified by practice team members. These included case presentations, development of practice guidelines or an examination of team responsibilities in care. Some of the meetings were more formal providing small group workshops with a semi-structured agenda, often using video presentations of consultations and attempts were made to develop new skills in symptom control, communication and counselling techniques. Feedback and follow-up suggests that the visits were well received and the content satisfactory, with many practices indicating their intention to change palliative care behaviour. However, to date no objective assessment of the Facilitators' performance in these meetings has been carried out but an attempt to measure changes in patient care has now been initiated in Scotland as part of a follow-up to the project.

### *Conclusions from the project*

This project has exposed difficulties and dilemmas facing the wider dissemination of knowledge and skills in palliative medicine but has many encouraging features.

Perhaps the most important is the obvious wish of doctors and nurses within their own practices to engage in educational activities that will improve their performance. This is illustrated by the overwhelming desire of primary health care teams to have visits from facilitators or other advisers in this field to discuss the arrangements and performance in the care of dying patients. This presented the first difficulty in that there are too few trained tutors to provide this service at an individual practice level and there is therefore a clear need to increase their number. With regard to teaching methods the study has shown that while the primary health care team enjoys visits to the practice at a personal level and is also very willing to engage in small group activities centring around palliative medicine, doctors, and to a lesser extent nurses, are much less willing to attend lectures and seminars on the subject. This may just be part of a general trend away from didactic education which is occurring across the whole field of medicine but I suspect that in the case of palliative medicine there is a more subtle explanation. I think the work of the Facilitators and the results of the questionnaires confirm that general practitioners and primary health care teams are uneasy, and indeed feel a sense of guilt, at the quality of care they are providing for patients with incurable disease dying at home. They admit this within the privacy of their teams and welcome the support, that comes through a visit to the practice from a skilled professional. In a small group they feel free to express their feelings and exchange information leading to an improvement in the quality of care they provide. If such continuing education is to be provided, it will be essential that core knowledge of palliative medicine is in the undergraduate curriculum. It is fortunate that the Royal College of General Practitioners and the Association of Palliative Medicine have published such a core curriculum, relevant for general practitioners and I suspect, relevant for all doctors. The difficulty here, as always, is to find curriculum time but I maintain that the subject matter is so fundamental to the practice of medicine that it must, if necessary, displace time devoted to other subjects. Not only would this improve the general level of knowledge of doctors on graduation but it would ease the stress of house jobs and help to overcome the present problems of major geographical discrepancies in the provision of hospice care and the associated training support. The Facilitator in Northern Ireland taught palliative medicine in the undergraduate programme at Queen's University where the department of general practice has been responsible for a comprehensive course on palliative medicine for medical students since 1990.

In addition to confirming that general practices are eager to improve the quality of care they provide, identifying the issues where an educational programme would be most profitably directed and how that might be achieved, the project identified some surprising difficulties in the area of relationships. In general practice these difficulties were sometimes internal to the professionals in the primary health care team but, interestingly, the Facilitators found a degree of alienation by some general practitioners towards the services provided by hospices fearing that the hospice staff might take over their patients. Similar territorial issues arose between these Facilitators, all of whom were highly motivated general practitioners anxious to improve palliative medicine, and the Association of Palliative Medicine Education advisers. Only one of the Facilitators in the project was able to develop a flourishing relationship and this suggests there may be tensions here that need to be resolved. Similarly relationships with Regional

Health Authorities were variable because of inadequate understanding of community palliative care among managers and planners. It has to be said, however, that in Scotland the Facilitators took part in the development of national palliative care guidelines and the senior facilitator, David Millar, has been appointed Macmillan GP Palliative Care adviser for Scotland with the strong support of the Scottish Home & Health Department.

#### *Advanced directives*

I used the word 'paradox' earlier in this paper in respect of bonding between patients, their families and their doctors, where care of the dying may to some extent have replaced childbirth. Another paradox, however, concerns the public's attitude to the medical profession in regard to terminal care. As medical technology relentlessly advances, with undisputed benefits, there is nevertheless an increasing fear among the public that in the final stages of life doctors may allow suffering to be prolonged. The engine of medical technology, rightly or wrongly, is seen as having a momentum which is difficult to stop and we have to recognise that for many people 'the last enemy' has now become the fear of excessive medical intervention. As a profession we have failed to offer the public adequate reassurance in this area, for medicine has been locked into the constraints of its own technology, and while all of us benefit enormously from that technology for most of the time, the decision to stop using it is perceived as being difficult. In the leading article of last year's Christmas number of the *British Medical Journal*, David Weatherall, professor of medicine in Oxford, felt impelled to write, 'In almost every field of modern high technology practice, patients are pushed to the extremes of their endurance and not always for reasons that include a careful appraisal of what is meant by the quality of life'. The hospice movement has succeeded in overcoming these fears and I have never heard criticism directed to it from patients or public in regard to unkind prolongation of life, but this is not the case in general hospitals or in general practice. As a consequence the public, who initially stimulated attention to the care of the dying, are now in increasing numbers having to take action to express their wishes to limit medical intervention when death is inevitable. The response, therefore, of members of the public has been to favour the drawing up of documents that give advanced indication of the way in which they wish to be treated should they become mentally incompetent. In many ways it is sad that this should have become necessary, with its implied criticism of medicine, encouraged, of course, by the Law which attempts to protect the public and doctors from any intention to deliberately end life without very special permission, which sometimes has led to the most bizarre situations.

The introduction of advanced directives in the UK has been slower and less legalistic than in the USA, but the BMA has now declared, 'its strong support for the principle of an advanced directive'. The House of Lords select committee on medical ethics commended the development of advanced directives, while the crown prosecution service and the King's College centre for medical ethics, giving evidence to the select committee of the House of Lords, expressed the view that suitably drafted advanced directives are already legally valid in the UK, an opinion reflected by the Law Commission. General practitioners therefore will require to be informed, and consider carefully, the advice they give to individual

patients and be clear regarding the limitation of advanced directives as well as the consequences of their content.

### *Spiritual wellbeing*

In one definition of palliative medicine, the concluding words are 'interventions are directed at maximising patient comfort through thorough symptom control, carer support and attention to spiritual wellbeing'. Attention to spiritual wellbeing is something that doctors, nurses and other members of the primary health care team undoubtedly find difficult and there are dilemmas in defining their role. I suspect that the issue is often left unaddressed. Spirituality is often confused with religion or faith and medical and nursing professionals may feel that it is beyond their professional boundary. But spiritual issues, although related, may be separated from religious ones and most thinking human beings, during their lives have thought about and reached some intellectual conclusion on the meaning of life and any transcendental dimension. However, few have translated their intellectual positions into consideration of how they as individuals anticipate their own deaths. In a poignant article only last month, one of the foremost authors of textbooks on the care of the elderly and a writer on palliative medicine, described how he had received the news of his own impending death from malignant disease. He confesses that he had never considered how he himself would react to receiving a serious diagnosis about himself. We know that the majority of persons who know that they are dying welcome the opportunity of discussing these issues with a sympathetic person who is willing to give them the opportunity to do so. General Practitioners and nurses, whatever their personal religious beliefs may be, need to be trained to allow the patient to talk, to give expression to feelings and, most probably, fears. The carer needs to learn when to drop the protective shield of the professional and enter a more intimate and personal relationship with the patient where these matters can be discussed. Since the middle of the 18th century the pre-occupation of medicine has been reductionist. Medical knowledge has become a derivative of physics, chemistry, microbiology, and now ever deeper into the genes down to the molecular level and all within a philosophy of logical positivism with its condemnation of implications of purpose. Intuitively, physicians and patients know that medicine transcends the natural sciences on which it is based. The mechanistic idea of the universe without transcendent reference is seen to offer inadequate explanation, not only by theologians but also by many biologists and physicists.

Where the patient or family is in contact with the clergy, then the responsibilities of the carers are eased, for modern clergy are trained, much better than doctors, in how to support the dying and the issues of bereavement and grief.

While preparing this paper I took the opportunity to discuss with doctors, nurses and health visitors their policies and practice in relation to bereavement and the follow-up of families where the death may have been of a small child or an elderly person. This obtained a very variable response, but undoubtedly revealed feelings of guilt. This is a matter which is inadequately discussed and where initiatives are largely left to individuals rather than being practice policies, although of course there are exceptions to that generalisation. There are therefore undoubted difficulties and dilemmas regarding the extent to which a bereavement should be followed up in the subsequent months by a member or members of a primary health care team. Every case requires to be considered individually and

to be related to the nature of the death and bereavement and the contact with a range of supporting services and organisations. What seems to me to be essential, is that the file should not be closed following the bereavement visit to the family immediately after a death. An understanding of grief and its phases is an important area for doctors and more specific training is needed for the whole primary health care team if compassionate and skilled care is to be provided in the aftermath of death. With the growth of ever larger group practices, medical records, for example, should allow a doctor or a nurse to recognise the anniversary of a significant death.

Providing good quality palliative care in the community therefore presents many challenges to doctors and primary health care teams and not least, of course, to medical education. It is significant that the theme of palliative medicine should today command the attention of a symposium in this College.

### REFERENCE

Royal College of General Practitioners and Cancer Relief Macmillan Fund, 'GP Palliative Care Facilitator Project 1992-1994', the Report of an evaluation.