Contemporary Themes

A comprehensive service for patients with cancer in a district general hospital

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The contribution of drugs to the control of cancer, especially the lymphoid and haematological malignancies and the rarer, solid tumours, has been considerable and their use is increasing. Despite this, however, specialists in cancer chemotherapy are found mainly in regional cancer centres and few have been appointed to district general hospitals in the United Kingdom. Medical oncologists appointed to health districts could do much to improve the quality of care of patients with cancer. This paper outlines the development of a cancer treatment service in the Lancaster and South Cumbria districts since the appointment of a consultant physician with an interest in medical oncology.

Case history

A 21 year old labourer was admitted with appendicitis. At laparotomy enlarged lymph nodes were found along the posterior abdominal wall. This was an undifferentiated malignant tumour. Staining for α fetoprotein gave a negative result but the serum concentration was raised suggesting that the tumour might be of germ cell origin. Staging investigations showed that his disease was confined to the abdominal cavity. He was treated with a five day intravenous regimen using cisplatin, etoposide, and vinblastine, repeated at three week intervals.

The toxicity of the treatment was considerable. He suffered severe prostration, nausea, and vomiting with recovery only days before his next course was due. He was persuaded to complete five treatments, at which time he was in complete clinical and biochemical remission. Some months later his disease relapsed. Radiotherapy was given to the posterior abdominal wall over three weeks and this was accompanied by further severe symptoms of toxicity. After a few more weeks he developed abdominal pain, the serum α fetoprotein concentration was raised, and chemotherapy was restarted.

Vincristine, doxorubicin (Adriamycin), and cyclophosphamide were given by intravenous injection in three week cycles. Though he tolerated this better than the previous combination, he developed severe anticipatory symptoms and needle phobia, the latter despite the insertion of a permanent atrial catheter. His symptoms improved but this time there was no corresponding fall in the serum α fetoprotein concentration. Treatment was stopped after only four cycles and when his pain returned he was given only symptomatic measures. He died some nine months later, 25 months after his first admission to hospital.

PHYSICAL CONSEQUENCES OF THE ILLNESS

This patient's sudden and dramatic illness brought with it considerable discomfort, distress, and inconvenience to him and his family. He lived in a small village some 10 miles from the district general hospital in Lancaster and 80 miles from the regional cancer centre in Manchester. Outpatient attendances or visiting by his family when he was in hospital meant at best a round trip of 20 miles (32 km) and at worst 160 miles (256 km), which was time consuming and expensive. The disruption to family life was extreme. The organisation and planning of simple daily tasks affected not only the patient but also his two brothers; his father, who had retired through illness; and most of all his mother, who ran the home and also kept a part time job to supplement the modest family income. During his illness the patient attended an outpatient clinic on 23 occasions and spent a total of 102 days in a hospital ward, 79 of these in Lancaster and 23 in Manchester. He was usually accompanied by his mother, and she or a family member would invariably visit on each day of a hospital stay.

After treatment the patient would remain in bed at home for variable periods but often for several days until the effects wore off, and this posed an additional problem of providing proper nursing care. His physical symptoms included pain, vomiting, constipation, diarrhoea, hair loss, hallucinations, and paraesthesia. Each required careful assessment, treatment, and monitoring in hospital and at home.

PSYCHOLOGICAL CONSEQUENCES

The patient experienced a range of emotions at different stages of his illness. Fear and anxiety were most pronounced at the outset when he first realised that he had a life threatening disease and in the last few months when

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he knew for certain that his disease was incurable. He was gregarious and intelligent and his life at a stroke was to change dramatically. He was frightened of his illness and he dreaded the treatment. He lost his job and his income and his social life was curtailed. His appearance altered: there were changes in body weight and he lost his hair. He became slowly more dependent on others. In the early days cure was considered a distinct possibility and for much of this time he remained optimistic. Yet even with the disappointment of relapse his attitude remained strikingly positive. Nevertheless, inevitably there were periods of severe anxiety and deep depression both for him and his family.

Managing patients with cancer

This sad story is by no means unusual and highlights the complexity of caring for patients with cancer. How are these patients managed in clinical practice? The diagnosis is usually made in the district general hospital but what happens next depends on the nature of the cancer and on the interest and skill of the doctor concerned. Few district general hospitals have a specialist with a declared interest and training in oncology. The workload of patients with cancer, which is considerable, is shared among many different specialists. Thus the care patients receive is variable and the management of a particular type of tumour may differ from one hospital to another or even from one specialist to another in the same hospital. The common cancers are generally treated by surgery alone and the outcome is affected more by a delay in diagnosis than by any variation in surgical technique or any decision to give additional drugs or radiotherapy. Differences in management are therefore unlikely to influence survival, though the quality of life, particularly for patients with advanced disease and those requiring terminal care, may vary considerably from one practice to another.

By contrast the rare solid cancers and some haematological malignancies may be influenced greatly by treatment, and access to specialist advice on chemotherapy and radiotherapy is essential. This may not be available locally and referral to a regional cancer centre may be necessary, but the decision to refer may be affected more by distance and convenience than by medical considerations, particularly where chemotherapy is concerned. It is understandable that radiotherapy should be centralised and it is unavoidable that some patients must travel long distances for their treatment. The reasons for centralising chemotherapy services are less compelling for there is less capital investment in expensive items of equipment. Most patients can be treated on an outpatient basis, and for patients living far away absurd and unnecessary situations may arise. For example, patients may travel 100 miles or more for treatment, only to be told to return a week later because of an unsatisfactory blood count; or when given treatment patients may spend their time retching and vomiting on the long journey home. Possibly for these reasons referral is patchy and many patients in outlying areas are not referred. This leads to some patients receiving inadequate treatment or being given treatment inappropriately or, though they should be treated, being denied treatment because they have not seen an expert in chemotherapy. These difficulties can be overcome by specialists from the regional cancer centres holding clinics in the district hospitals, as happens for radiotherapy in the north west region.

In practice patient management is usually shared among any or all of the following: the regional radiotherapist, the regional medical oncologist, the district physician or surgeon, and the family practitioner (and perhaps an expert in terminal care), and responsibility shifts from one to the other at various stages of the patient's illness. Inevitably patient care is fragmented, the quality of care varies, and problems of communication arise and these factors contribute towards the feelings of fear and isolation so commonly experienced by patients with cancer. Cancer is perceived by many as invariably fatal with a painful and protracted death. Yet doctors often avoid discussing these misconceptions or when asked directly give imprecise or frankly misleading information to the patient. Worse, close relatives who are seen separately may be given the truth and then feel obliged to conceal it from the patient, and relationships between them become strained. Even when patients are told that they have cancer much of what is said is misunderstood, distorted, or forgotten and if many doctors are concerned questions may be answered differently, so that conflicts of opinion may be imagined.

A greater awareness of these problems has led to the establishment of groups—often initiated by patients themselves—to provide emotional support for families affected by cancer and to promote a greater understanding of the disease. The past failures of the medical profession to recognise this need and the lack of any coordinated policy within our health care system for such support services might explain the drift by patients towards cancer centres operating outside the National Health Service, such as those in Bristol and Morecambe Bay. Unfortunately, these centres engage in curious treatment strategies for which there seems to be no scientific justification, but we have much to learn from their compassionate approach and the forms of psychological support they offer.

Clearly there is more to managing patients with cancer than devising treatment strategies and administering radiotherapy and drugs. Caring for these patients and their families should be a comprehensive and continuous process, taking the physical and psychological consequences of the disease and treatment into account and following the patient through the terminal stages. This cannot be provided by a visiting cancer specialist, nor can it come easily from a multidisciplinary approach—but it can be provided by a cancer specialist based in the district general hospital.

Cancer services in the Lancaster district

Cancer services in the Lancaster district have been developed in the past seven years since the appointment of a general physician with an interest in medical oncology. Before this the only cancer specialist available to the district was a radiotherapist from the North West Regional Centre in Manchester, who visited—and still does—on a fortnightly basis. When chemotherapy was necessary it had been administered either in the radiotherapy clinic or by local physicians and surgeons, or increasingly by the department of medical oncology in Manchester, some 70 miles (112 km) away. There was no recognised counselling or support service and no established facility for terminal care.

CANCER CLINIC

The first priority was to develop an effective and safe service for the assessment of patients for chemotherapy and the administration of treatment. A cancer treatment clinic was established, which has become the base for a comprehensive cancer care service now available to the people of North Lancashire and South Lakeland, a population of some 200 000. Any patient with cancer may be referred, including those with advanced disease who require palliative treatment and terminal care. The clinic is staffed by the oncologist assisted by a consultant haematologist, who together formulate and coordinate the strategy of management for each patient. They are assisted by the pharmacist, who prepares the drugs; the clinic sister, who administers them; and the oncology health visitor, who liaises between hospital and community services. Home visits by the oncology health visitor are a vital extension of the clinic for they uncover misunderstandings of what has been said, unexpressed fears of the illness and the effects of the treatment, and unnecessary suffering from symptoms not properly controlled. This information is valuable to the oncologist for the patient's next clinic visit. Referral outside the district is now necessary only for certain investigative procedures and for radiotherapy. The table shows the range of cancers and numbers of patients referred to the clinic for treatment between 1980 and 1984.

The advantages in centralising chemotherapy services in this way are several. Firstly, it is efficient; patients have blood drawn on arrival, the result is available at the time of consultation, drugs are prepared at one time, and consultation and treatment are carried out speedily and with minimum inconvenience to the patient. Secondly, personnel preparing, prescribing, and administering the drugs become familiar with them, the precautions necessary in handling them, and the likely effects and toxicity of the treatment. Thirdly, it brings patients and relatives into contact with one another and with the various members of the cancer team. Fourthly, it provides an opportunity to measure and monitor the physical and psychological problems of the patients and develop appropriate cancer services.

CANCER WARD

Patients are admitted to a hospital ward for any of the following reasons: for assessing and staging their disease and relieving their symptoms; for

Types of tumours treated in the cancer clinic

	No of cases		No of cases
Lymphoma	61	Stomach/pancreas	9
Hodgkin's	19	Melanoma	8
Non-Hodgkin's	42	Myeloma	7
Colorectal	43	Soft tissue sarcoma	4
Breast	42	Germ cell	3
Acute leukaemia	32	Cervix	3
Lung	24	Oesophagus	3
Ovary	24	Bladder	2
Head/neck	21	Brain	1
Prostate	9		

administering the first course of a new treatment regimen so that symptoms of toxicity can be quickly recognised; and for administering each course of treatment if it is impracticable to manage on an outpatient basis either because of symptoms of toxicity or because of the duration of the regimen. Patients undergoing treatment may be admitted at any time by self referral—for example, with an unexplained fever, for a few hours' delay may be critically important in a neutropenic patient developing septicaemia.

CANCER SUPPORT SERVICE

A practical, clinical approach to managing cancer is not enough. These patients and their families have considerable emotional problems which vary in type and intensity throughout the illness, and it is difficult to manage these in a hospital setting. Analysis of a questionnaire returned by a random sample of 42 patients attending our cancer clinic or ward showed that 22 had experienced severe anxiety symptoms in the preceding week, 15 had been deeply depressed, 15 had extreme feelings of guilt, and seven had felt that their illness was a punishment for past transgressions. Some additional support facility was required to cope with these problems, and in 1984 a cancer support service—"CancerCare"—was launched in the Lancaster district.

The aims of CancerCare are to provide a forum for increasing knowledge of cancer and its prevention; to improve the quality of care for patients and families; to provide encouragement for each other within a social setting; and to meet specific requirements and help alleviate anxiety by relaxation techniques and other methods. CancerCare, a registered charity, has an advisory group with broad lay and professional representation but is organised by a small steering committee which meets monthly to determine policy and strategy and to organise the group meetings and events. CancerCare meetings are held monthly on premises away from the hospital. They are widely advertised and are attended by patients, their relatives and friends, and all the various health care professionals concerned in the local cancer service.

Bereaved relatives and other interested personnel also come. Meetings usually begin with a talk or film on a topic related to cancer and patients have occasionally been invited to describe their personal experiences of the disease. This is followed by light refreshments and a general discussion. There is opportunity to share problems with one another and to meet hospital staff in an informal and relaxed atmosphere. CancerCare has a part time secretariat based in an office in the Royal Lancaster Infirmary. The telephone number is widely advertised in the local press and anyone with any problem related to cancer is invited to call. Patients with medical problems are encouraged to contact their family practitioner. Simple practical or financial problems are referred to the appropriate group member. Emotionally distressed patients can be referred for personal counselling or relaxation therapy.

CancerCare employs qualified therapists who use yoga, massage, and breathing techniques to help patients and family members with severe anxiety. These are given in small group sessions or on an individual basis depending on the patient's preference or clinical circumstances. Cassettes and relaxation tapes are supplied on request.

CancerCare has also sponsored a counselling course for volunteers. All were women, most had nursing training, and many have continued to meet together in a growth and development group. The oncology health visitor introduces these people to selected patients (at the patient's request) for simple counselling and support. In addition, there is an established network of volunteer helpers in the outlying communities who can be directed to patients' homes to help with practical tasks such as shopping, transporting, and sitting with patients.

On the broader educational front CancerCare promotes publicity material for cancer screening, antismoking, and dietary campaigns working closely with the district health education officer. It sponsors an annual public lecture delivered by a national cancer expert.

Through its fund raising activities CancerCare has provided several items of equipment including massage couches, couches for patients receiving cytotoxic drugs, a decompression sleeve and pump for patients with mastectomy, and syringe drivers for the administration of analgesics in the home.

It is difficult to measure the impact of CancerCare on the quality of care for patients and their families in its first year but there are several encouraging signs. Attendance at meetings is rising and patients, relatives, and friends who come once usually become regular attenders. They show a lively interest

in formulating the group's programme. Relaxation therapy sessions are fully booked, families are coming forward for counselling. Patients are being referred direct to CancerCare by family practitioners. Group members are arranging their own social activities and fund raising events beyond those organised by CancerCare. There is a strong feeling among all the health care professionals concerned that the morale of patients in general and of the cancer team as a whole has improved considerably since its inception.

FACILITIES FOR TERMINAL CARE

Until the appointment of the medical oncologist there was no special provision in the Lancaster district for patients with terminal cancer. Inpatient facilities have been developed in one small part of an outlying hospital and these are soon to be relocated in a new purpose built unit in Lancaster. The considerable capital cost was raised by public donation. Nursing and medical staff have been trained in terminal care.

Case history continued

How did this extended cancer service help our 21 year old patient and his family cope with his illness? He was first seen by the medical oncologist when the histology report which suggested cancer was known in the early postoperative period after the laparotomy in June 1983. The findings were discussed in simple terms and the importance of further studies to determine treatable possibilities was put to him. When he had recovered from surgery he was referred to the Christie Hospital, Manchester—some 80 miles (128 km)—from his home for full staging investigations. The diagnosis having been established and investigations completed he returned to Lancaster for treatment. The oncology health visitor met him and his family for the first time during his first admission for chemotherapy. There were considerable difficulties in controlling the symptoms of drug toxicity, and these were managed by discussion between the oncology health visitor and the general practitioner, medical oncologist, and community district nurse, as appropriate. Subsequently abdominal radiotherapy and later restaging investigations were carried out in Manchester.

When he relapsed in July 1984 he developed severe depressive symptoms and anxiety related to restarting chemotherapy with all its associations of toxicity. He developed anticipatory panic and vomiting and an aversion to needles. Much support and counselling was required including relaxation therapy and, later, hypnosis. This enabled further courses of treatment to be given in July 1984 and again in November 1984, which resulted in an excellent symptomatic response. When he relapsed again in February 1985 he talked about his fears of dying for the first time. Much time was spent with the family helping them to communicate with each other and with the patient. When pain became a problem several treatment options were explored, including acupuncture, and a thermal cushion was provided by CancerCare. Admission for control of symptoms was required on two occasions, each time directly to the ward after discussion between the oncology health visitor, general practitioner, and consultant, without the need for domiciliary visiting or outpatient consultation. His terminal illness was managed in a single room in hospital surrounded by his family and friends. Bereavement counselling followed and his mother continues to contribute towards CancerCare.

Conclusion

Centralising radiodiagnostic and therapeutic services makes good sense from both a practical and a financial point of view. Nevertheless, much can be done to improve the quality of care for patients with cancer, especially in districts far away from the regional cancer centres. One way of achieving this is to appoint to district general hospitals general physicians with an interest in medical oncology. While they could cooperate with the regional cancer centres in following established treatments or engaging in treatment trials, their main tasks would be to develop adequate support services including terminal care and to monitor and improve the quality of cancer care in their area.

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