TERMINAL CARE IN MALIGNANT DISEASE

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PATIENTS may be referred to hospital in the terminal stages of cancer for specific medical needs or because home circumstances are unsuitable. Other patients may be cared for in difficult conditions at home, because of the wishes of the patients or their relatives. The aim of the present study was to categorize the terminal needs of patients dying from cancer in the city of Manchester, which has a population of over six hundred thousand.

BACKGROUND

In this country there have been two general surveys of the problems of nursing cancer patients in their own homes. The first was undertaken by the Queen's Institute for District Nursing on behalf of the Marie Curie Memorial (1952). Though this was a national survey involving 179 out of 193 local authorities, it covered a biased sample of patients, being confined to those patients who had been visited by a district nurse. The second study was carried out by Glyn Hughes (1960); using a postal questionnaire, the views of family doctors were obtained on the availability and adequacy of local authorities' facilities and the willingness of relatives to accept responsibility for terminal care.

Wilkes (1965) has carried out a survey in Sheffield in which family doctors completed questionnaires about patients nursed at home. No doctor was asked to supply information about more than two patients, and the survey covered only 20% of deaths at home during the study year (it was therefore probably biased by an undue proportion of deaths in small list practices).

In none of the surveys mentioned above were the relatives approached. Collectively, relatives' experience of the terminal care of persons with malignant disease probably makes a considerable contribution to public knowledge about cancer and it may be a major factor in moulding public attitudes towards cancer. It is conceivable that such experience may influence the actions of many who subsequently believe that they may have cancer. This view is supported by the study of Aitken-Swan (1959).

METHOD

The Regional Cancer Registry receives each week, for patients dying in the Manchester region, copies of all death certificates with mention of malignant disease. All such certificates, relating to deaths occurring during April among residents of Manchester County Borough, were used as the sampling frame for the study. Each patient was known to the Regional Cancer Registry, and the clinical abstracts were studied.

In each case the family doctor was written to and was asked to complete a questionnaire which varied according to the patient's place of death. For patients dying at home the doctor was asked to assess the burden of medical and nursing care; whether there was adequate support in the home for terminal nursing; and whether, if a bed had been available in a home for terminal care, he would have tried to arrange admission of the patient to such accommodation. His permission was sought to contact the next of kin. When the patient had died in hospital, a shorter questionnaire was sent to the family doctor asking him on what grounds he had arranged admission to hospital and again requesting his permission to visit the next of kin. The intention was to interview each of the relatives in his/her own home, except where the deceased had been admitted to hospital because of an acute medical or surgical emergency. During the course of the interview a brief description was given of the aim of the study and then the relatives were asked to discuss (at whatever length they wished) the impact on them of the nursing, whether or not the patient had finally been admitted to hospital. During the course of the interview particulars were obtained about the facilities available for home nursing and an assessment was made of the provision for cooking, heating, washing and laundry.

RESULTS

There were 134 death certificates for Manchester residents during the month of April 1969 with mention of malignant disease in either part 1 or part 2.

Seven cases were excluded from further study for the following reasons. In two cases the diagnosis was made only after necropsy (following an acute illness) and in one case the clinical diagnosis of cancer was not confirmed at necropsy. Four entries were confined to part 2 of the death certificate, and the malignancy had played no part in creating terminal nursing problems.

One hundred and twenty-seven certificates remained and a complete assessment has been obtained for 110 patients. There was partial response for the remaining 17 certificates. On three occasions the family doctor wrote back saying he declined to participate, and in seven cases the doctor completed the questionnaire but did not wish the relative to be worried. On two occasions the relative declined to be interviewed. Two relatives had left the area and were no longer traceable, whilst a letter and three visits to the last known address failed to make contact with any relatives of three patients. The over-all non-response rate was 17 out of 127 (13%).

TABLE
ARRANGEMENTS FOR TERMINAL CARE OF 127
PATIENTS DYING FROM CANCER

Hospital admission	
Acute medical emergency	30
Nursing care	44
Home nursing	
Patient's home	44
Relative's home	5
Lived in nursing home	4
Total	127

The table shows the arrangements that were made for terminal care of the 127 patients. Seventy-four of these patients died in hospital; this included four private patients. Thirty of the patients were admitted to hospital for acute medical or surgical emergencies, including three patients who were admitted for pathological fractures. The other 44 patients were admitted to hospital for nursing care. A further 44 patients were nursed in their own homes and five patients had moved to the home of a relative during their illnesses. The remaining four patients were already resident in nursing homes when they developed cancer and they continued to be cared for in these nursing homes. The proportion who died in hospital is almost identical to that in data for England and Wales in 1967 published by the Registrar General (1968).

When each relative was interviewed one point that was discussed was whether or not the patient and the relative would have considered transfer of

the patient to a home for the terminally ill if such a home had been available in Manchester. This point was raised with relatives whether the patient had died at home or had been admitted to hospital for nursing care. The answers to this question must be interpreted with some caution, but on the basis of the answers the patients who were nursed at home have been grouped into two categories. In the first category are those for whom there was no evidence that any other arrangement would have been made even if a bed had been available in hospital or in a home for the terminally ill. Patients have been placed in the second category when there is some possibility that alternative arrangements might have been made. The evidence for this was that either the relative, the family doctor or the interviewer considered that referral was very likely and that not more than one of the three had considered it to be unlikely. The evidence suggested that 24 of the 49 patients nursed at home might have been transferred for terminal nursing. With increasing duration of terminal nursing at home, the attitude to transfer alters. There was no evidence that alternative arrangements were required for 25 of the patients who died at home; only four out of these 25 had required daily nursing care for over three months. Among those patients for whom there was evidence that alternative arrangements would have been acceptable and desirable, 15 out of 24 had required daily nursing care for over three months. This association between duration of nursing care and likelihood of transfer is significant at the 1% level.

Seventy-four patients in this survey died in hospital; 44 of them had been nursed in hospital but had had no other treatment that required the substantial backing of an acute bed in a general hospital. The majority had been nursed in acute medical or acute surgical wards; nine had been cared for in wards with geriatric or chronic sick patients. One patient with cerebral metastases had been cared for in a psychiatric ward. In addition, two patients admitted as acute surgical emergencies with pathological fractures were subsequently nursed for a period of over three months in hospital. It is considered that once the appropriate treatment for the pathological fracture had been carried out these patients' care involved mainly nursing. Thus 46 of the patients who died in hospital required skilled nursing care, but no active medical treatment, in the terminal period.

It is possible to compare the age, sex, marital status and social class of the patients who were admitted to hospital for nursing care with those for patients who remained in their own or relatives'

homes. No difference was observed for age or sex; but fewer married patients were nursed at home, and more patients were nursed at home when the wage owner's occupation was classed as semi-skilled or unskilled manual labour. This latter trend, although based on small numbers, is consistent with previous data (Alderson, 1966) but does not reach the conventional level of significance ($0.05 < P < 0.1$ on a one-tail test).

DISCUSSION

Many relatives who were interviewed during this survey had been very willing to shoulder the difficult burden of caring for a relative suffering from terminal cancer. Many received great help from their family doctor, from the services provided by the local authorities and from their neighbours. There were, however, some relatives who had to struggle against great difficulties. These difficulties included infirmity of the relative, which made nursing a physical burden; lack of suitable facilities in the home, such as the absence of hot running water or an inside toilet; the financial worry of keeping the home going when the sole wage earner was involved; and the problem of caring for young children at the same time. These factors added to the physical burden of disturbed nights and the mental stress of caring for a near relative who was suffering pain and discomfort and was plainly deteriorating.

Russell and Miller (1964), in a study of terminal pelvic cancer, conclude that there is little point in patients with terminal cancer occupying beds in large, expensive hospitals, and they acknowledge that these patients can be intensely lonely in the middle of a busy acute ward. Saunders (1967) discusses the relative advantages and disadvantages of nursing patients in purpose-built accommodation or in the 'treating hospital'. The recent report of the Central Health Services Council (1969) on the Functions of the District General Hospital does not refer specifically to the care of patients terminally ill with cancer; for the care of the younger 'chronic sick' they advocate special units attached to district general hospitals. Aitken-Swan (1959), McIntosh (1963), Russell and Miller (1964) and Saunders (1967) all refer to the strain of home nursing a patient terminally ill with cancer. The aim of the present study was to identify the nursing needs of a representative sample of patients who died from malignant disease. In particular, an attempt has been made to identify the proportion of patients who presented with a nursing problem which was beyond the total resources of the home environment. A separate study is required to define the most

appropriate means of providing special nursing facilities for these patients linked to the general plan for hospital and community care. In this study, out of 127 patients who died from malignant disease, there was evidence that 24 who died at home could have benefited from special nursing provision; whilst 46 patients had required skilled nursing care in hospital, but not active medical treatment. Thus a total of 70 (58%) out of 127 required special nursing care beyond the resources of their homes; it is likely that this proportion might vary month by month from 49% to 67%. These findings are not at variance with the suggestion that domiciliary facilities are made available to support the family doctor and relatives who are caring for patients in their own homes; they imply the need to provide alternative facilities when the burden on the relatives is too great.

A number of patients were admitted to hospital when the home circumstances were good. This finding was based on small numbers and too much weight should not be placed upon it; it does, however, support the hypothesis that there is a vocal group in the community who are aware of the provisions of the National Health Service and demand and obtain special attention.

One small point that was brought up on a number of occasions during the interviewing was the financial hardship that had been caused when the relative was the only person in the family at work. On a number of occasions, in order to care for the dying patient in the home, the relative had had to give up work and lost income. When an unmarried daughter gives up work in order to care for her father dying at home her earnings may be stopped. If the daughter declines to take any responsibility, the patient may have to be transferred to hospital; the daughter continues to earn money, and the father occupies a bed at considerable cost to the Health Service. It seems unfair that a daughter who wishes to nurse her father should be financially penalized for saving Health Service expenditure.

SUMMARY

A study has been carried out on a representative sample of deaths from malignant disease in the County Borough of Manchester. Seventy-four patients died in hospital; 44 of these had been admitted for nursing care, whilst 30 had required active medical treatment. Four patients had been cared for in the nursing homes in which they were resident prior to the development of malignant disease. Forty-nine patients had died in their own or relatives' homes; there was evidence that 24 of these patients could have benefited from special

nursing provision. It is suggested that, in a population of over six hundred thousand, a total of 70 patients, who died from malignant disease in one calendar month, required the provision of special nursing care.

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