

Information needs of cancer patients in west Scotland: cross sectional survey of patients' views

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Catherine Meredith, Paul Symonds, Lorraine Webster, Douglas Lamont, Elspeth Pyper, Charles R Gillis, Lesley Fallowfield

**Radiotherapy
Radiography, Faculty of
Health, Glasgow
Caledonian University,
Glasgow G13 1PP**
Catherine Meredith, lecturer

**Beatson Oncology Centre,
Western Infirmary,
Glasgow G11 6NT**
Paul Symonds, consultant
clinical oncologist
Lorraine Webster, Macmillan
support information
radiographer
Elspeth Pyper, clinical trials
coordinator

**West of Scotland Cancer
Surveillance Unit,
Ruchill Hospital,
Glasgow G20 9NB**
Douglas Lamont, senior
statistician
Charles R Gillis, director

**CRC Communication and
Counselling Research
Centre, Department of
Oncology, University
College London Medical
School, London W1P 7PL**
Lesley Fallowfield, director

Correspondence to:
Dr Symonds.

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Abstract

Objective—To assess the needs of patients with cancer for information about their condition.

Design—Cross sectional survey of patients' views by means of semistructured interview with questionnaire.

Setting—A regional cancer centre and two university hospitals in west Scotland.

Subjects—250 (93%) of 269 cancer patients invited to participate in study who were selected by age, sex, socioeconomic status, and tumour site to be representative of cancer patients in west Scotland.

Main outcome measures—Patients' need to know whether they had cancer, the medical name of their illness, progress through treatment, how treatment works, side effects, chances of cure, and treatment options.

Results—79% (95% confidence interval 73% to 84%) of patients wanted as much information as possible, and 96% (93% to 98%) had a need or an absolute need to know if they had cancer. Most patients also wanted to know the chance of cure (91% (87% to 94%)) and about side effects of treatment (94% (90% to 97%)). When the replies were cross tabulated with patients' age, sex, deprivation score, and type of treatment there was a linear trend for patients from more affluent areas to want more information and those from deprived areas to want less. There was a strong preference for diagnosis of cancer to be given by a hospital doctor (60% (53% to 66%)).

Conclusion—Almost all patients wanted to know their diagnosis, and most wanted to know about prognosis, treatment options, and side effects.

Introduction

Not being told what is wrong with them is the most common complaint that patients make about the medical profession.¹ There is evidence that many doctors in Britain fail to tell patients if they have cancer. A recent survey of gastroenterologists in Britain showed that a third would not tell patients that they had cancer unless they asked.² In 1984 a postal questionnaire of doctors showed that only 44% of consultants and 25% of general practitioners told cancer patients their true diagnosis.³ Since then few comprehensive studies have been carried out to investigate the needs of cancer patients for information.

A small survey of young patients in a medical oncology unit who were receiving radical chemotherapy for mainly uncommon tumours with relatively good prognoses indicated a high desire for information.⁴ This study population, however, was not representative of the general population of cancer patients. The aim of the present investigation was to assess the information needs of all cancer patients in west Scotland.

Patients and methods

We asked 269 cancer patients in west Scotland aged under 75 years to participate in a semistructured interview. All but six of the patients had been told their diagnosis within the previous nine weeks and were seen as inpatients or outpatients at the Beatson Oncology Centre, the Western Infirmary, or Glasgow Royal Infirmary. The patients were selected by quota sampling to ensure, as far as possible, that they were a representative sample of cancer patients in the whole of west Scotland. We used data for 7000 patients listed in the West of Scotland Cancer Surveillance Unit's cancer registry in 1993 to define our sample for the most common cancers (five in men and seven in women) stratified by age, sex, and socioeconomic deprivation. Each patient was assigned a deprivation category according to their postcode sector of residence.⁵ Patients were entered into the study in sequence as they presented until the quotas were filled. The age, sex, and deprivation profiles of the patients who declined to be interviewed were noted.

The questionnaire (modified version of that used by Fallowfield *et al*⁴ and Cassileth *et al*⁶) consisted of one open and nine closed questions. The first question asked patients to give an overall preference for information in general. Subsequent specific questions were aimed at eliciting the patients' attitudes to receiving information about particular aspects of their illness and treatment: the specific medical name of their illness, whether it was a cancer, their progress through treatment, their chance of cure, details of all possible treatments, details of all possible side effects, and how the treatment works. Patients were asked to indicate if they had an absolute need to know, would like to know, or did not want to know about particular details of their illness. They were also asked which health professional they would prefer to tell them about their illness.

Answers to questions were cross tabulated according to the patient's age (<65 or 65-74), sex, socioeconomic status (affluent, average, deprived), and type of treatment (radical with intent to cure or palliative for suppression of symptoms). Statistical significance was assessed with the log rank test and χ^2 test.⁷

Table 1—Background details of cancer patients interviewed in study and of non-responders and comparison with details of patients listed in West of Scotland Cancer Surveillance Unit's cancer registry. Values are numbers (percentages)

	Study sample (n = 250)	Non-responders (n = 19)	Registry patients (n = 7000)
Age (years):			
15-64	141 (56)	9 (47)	3640 (52.0)
65-74	109 (44)	10 (53)	3360 (48.0)
Sex:			
Men	127 (51)	9 (47)	3276 (46.8)
Women	123 (49)	10 (53)	3724 (53.2)
Socioeconomic deprivation:			
Affluent	35 (14)	3 (16)	980 (14.0)
Average	146 (58)	9 (47)	4116 (58.8)
Deprived	69 (28)	7 (37)	1904 (27.2)
Tumour site:			
Stomach or oesophagus	22 (9)	3 (16)	700 (10.0)
Colon or rectum	35 (14)	2 (11)	1064 (15.2)
Lung	84 (34)	8 (42)	2352 (33.6)
Breast	58 (23)	2 (11)	1568 (22.4)
Cervix	10 (4)	0	196 (2.8)
Ovary	9 (4)	2 (11)	252 (3.6)
Bladder	18 (7)	1 (5)	504 (7.2)
Prostate	14 (6)	1 (5)	364 (5.2)
Type of treatment:			
Radical	176 (70)	9 (47)	—
Palliative	70 (28)	10 (53)	—
Not known	4 (2)	0	—

Table 2—Responses of 250 cancer patients to specific questions about need for information. Values are numbers (percentages)

Question	Do not want to know	Would like to know	Absolute need to know
Whether illness is cancer	11 (4)	59 (24)	179 (72)
What is specific medical name of illness	62 (25)	114 (46)	74 (30)
What is week by week progress	24 (10)	105 (42)	121 (48)
What are chances of cure	23 (9)	77 (31)	149 (60)
What are all possible treatments	34 (14)	80 (32)	134 (54)
What are all possible side effects of treatment	14 (6)	52 (21)	183 (73)
Exactly how treatment works to treat illness	15/75 (20)	91 (36)	108 (43)

Results

The mean time between the diagnosis and interview was 33 (SD 15) days. Nineteen of the 269 patients approached declined to participate. The 250 patients recruited to the study matched the desired sample closely (table 1). A greater proportion of the non-responders (53%) were receiving palliative treatment than were those in the study (28%).

FIRST QUESTION

In response to the first question, on their general attitude to information, 196 of the patients (79% (95% confidence interval 73% to 84%)) wanted as much as possible, 37 (15%) did not want any, and 15 (6%) wanted only good news. Of the 35 affluent patients (deprivation categories 1 and 2), 33 (94%) wanted as much information as possible, compared with 113/146 (78%) of patients with average income (categories 3, 4, and 5) and 50/69 (72%) of deprived patients (categories 6 and 7) (log rank test $\chi^2 = 6.07$ (1 df), $P = 0.014$). The patients' responses were not influenced by age, sex, or type of treatment.

SPECIFIC QUESTIONS

Table 2 lists the answers to the seven specific questions about need for information. Only 11 patients (4%) did not want to know if their illness was cancer, and 238 (95% (93% to 98%)) expressed a need or an absolute need to know. In contrast, 62 (25%) did not want to know the specific name of the illness, and only 74 (30%) indicated an absolute need for this information. The patients also had a strong desire to know the chance of cure and the side effects of treatments, with 226 (90% (87% to 94%)) and 235 (94% (90% to 97%)) respectively expressing a need or absolute need to know.

Table 3—Responses of 250 cancer patients to question "What are all possible treatments" by type of treatment, age, sex, and socioeconomic deprivation. Values are numbers (percentages)

	Do not want to know	Would like to know	Absolute need to know	Significance
Type of treatment:				
Radical (n = 175)	16 (9)	57 (33)	102 (58)	} $\chi^2 = 12.64$ (2 df) $P = 0.002$
Palliative (n = 69)	18 (26)	22 (32)	29 (42)	
Age (years)				
15-64 (n = 141)	12 (9)	43 (30)	86 (61)	} $\chi^2 = 9.69$ (2 df) $P = 0.008$
65-74 (n = 107)	22 (21)	37 (35)	48 (45)	
Sex:				
Women (n = 122)	6 (5)	37 (30)	79 (65)	} $\chi^2 = 18.92$ (2 df) $P < 0.0001$
Men (n = 126)	28 (22)	43 (34)	55 (44)	
Socioeconomic deprivation:				
Affluent (n = 35)	3 (9)	10 (29)	22 (63)	} $\chi^2 = 4.98$ (4 df) $P = 0.289$ Log rank test: $\chi^2 = 4.51$ (1 df) $P = 0.034$
Average (n = 144)	17 (12)	47 (33)	80 (56)	
Deprived (n = 69)	14 (20)	23 (33)	32 (46)	

CROSS TABULATION OF ANSWERS

When replies were cross tabulated by age, sex, deprivation, and type of treatment there were no significant differences between answers to questions of whether the patient had cancer, the medical name of the illness, progress of treatment, and how the treatment worked. The patients who were treated radically were more likely to want to know the chance of cure: 165/176 (94%) had a need or an absolute need to know and only 11/176 (6%) did not want to know, compared with 57/70 (81%) and 12/70 (17%) respectively of those treated palliatively (log rank test $\chi^2 = 9.84$ (1 df), $P = 0.002$).

The question eliciting most divergence in replies was that related to treatment options. Younger patients, women, and those who were receiving radical treatment were more likely to want information about all possible treatments (table 3). Socioeconomic deprivation had less effect on answers to this question, although there was a significant linear trend (log rank test $\chi^2 = 4.51$ (1 df), $P = 0.034$), with more affluent patients seeming to want more information. The patients receiving radical treatment had a greater need for information about side effects than did those being treated palliatively: 133/175 (76%) of radically treated patients indicated an absolute need to know compared with 47/69 (68%) of those treated palliatively, while only five (3%) of the radically treated patients did not want any information about side effects compared with nine (13%) of those treated palliatively (log rank test $\chi^2 = 5.09$ (1 df), $P = 0.024$).

PREFERRED SOURCE OF INFORMATION

There was an overwhelming preference for the diagnosis to be given by a hospital doctor: 149 (60% (53% to 66%)) patients expressed this preference compared with 35 (14%) preferring their general practitioner, five (2%) preferring a nurse, and 60 (24%) indicating no preference.

Discussion

The results of this study indicate that cancer patients interviewed wanted much information about their illness—whether their illness was cancer (96%), their chance of cure (91%), and the possible side effects of treatment (94%). As the study population was designed to be typical of cancer patients in west Scotland, this probably reflects accurately the majority point of view in the region and possibly in the rest of Britain.

In this survey most of the elderly patients (age over 65) and most of those receiving palliative treatment wanted to know their diagnosis. This may be a relatively recent trend as about half of a group of patients with inoperable lung cancer who were interviewed before 1981 did not ask for a diagnosis when given the opportunity.⁸ There was more diversity in answers to other specific questions, particularly that concerning the medical name of the illness—only 30% of the patients said that they had an absolute need to know this. This suggests that cancer is seen as the same illness regardless of the site of origin and that the patients did not appreciate that their prognosis could vary greatly depending on the site and type of tumour.

A substantial minority of British doctors avoid telling patients that they have cancer.² This well intentioned omission is due to the doctors' feeling that knowledge of the diagnosis will depress and alarm patients and will impair their quality of life. Using the word "cancer," with all its implied connotations, is stressful for both doctors and patients, and there may be many reasons why doctors avoid communicating bad news. Some think that telling patients about their diagnosis and prognosis would precipitate a state of depression.⁹ Doctors have only limited time with each patient, and communication may often have a lower priority than medical treatment. In

Key messages

- Many doctors still do not tell patients when they have cancer in the belief that they do not want to know and that telling them would cause only alarm and depression
- We interviewed 250 patients with cancer to find out what information they wanted
- Almost all the patients wanted to know their diagnosis, and most also wanted to know the chance of cure and the side effects of their treatment
- Younger patients, women, and those receiving radical treatment in particular wanted to know more about treatment options
- The overwhelming preference was for the diagnosis of cancer to be given by a hospital doctor

addition, many doctors feel ill at ease discussing serious illness and dying and resort to euphemisms such as "tumour," "growth," "cyst," or "lesion."¹⁰

However, most of the patients in this study not only wanted to know their diagnosis but also wanted to be told plainly if they had a cancer. Protecting patients from the truth may be counterproductive: lack of information can increase uncertainty, anxiety, distress, and dissatisfaction,¹¹ and there is evidence that the level of psychological distress in patients with serious illness is less when they think that they have received adequate information.^{12 13}

In this study 60% of the patients wanted to be told about their cancer by a hospital specialist. Despite the

increasing use of specialist nurses and counsellors, patients want their doctors to support and inform them about their cancer and its treatment. In order to achieve optimal benefit for patients, doctors need sufficient time and appropriate surroundings as well as knowledge, understanding, and good clinical skills.

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When is referral of Heaf test positive schoolchildren worth while? Prospective study

Helen Booth, Christine Pollitt, E Christina Jessen, David J Hendrick, Andrew J Cant

Recent guidelines for controlling and preventing tuberculosis recommend that no further action is required for children with a grade 2 reaction to Heaf testing in the school pre-BCG screening programme.¹ Fifty seven per cent of district health authorities, however, still recommend referral for such children.² Furthermore, no guidance is given regarding contact tracing of children who are confirmed to be tuberculin positive but who have no signs or symptoms of clinical disease. We prospectively studied the results of screening children referred to our childhood tuberculosis clinic after a positive school Heaf test from January 1991 to August 1994 and tracing the contacts of these children.

Methods and results

Newcastle Health Authority currently recommends referral of children with a positive Heaf test result of grade 2 or above to our childhood tuberculosis clinic. Tuberculin sensitivity is confirmed with a Mantoux test: 0.1 ml of 1:1000 purified protein derivative, read after 72 hours. Palpable induration of greater than 5 × 5 mm in children without a history of BCG vaccination and 10 × 10 mm in those with such a history is considered

positive. Children with active tuberculosis based on clinical and radiological examinations are notified and started on a regimen of antituberculous drugs. Children with tuberculin sensitivity but no evidence of clinical disease are recorded as "Mantoux positive only" and offered prophylaxis with isoniazid.

Contact tracing follows locally established guidelines. All close family contacts have a chest x ray picture taken. All adults from the Indian subcontinent under 40 years old and children have a tuberculin sensitivity test in addition.

Details of all cases of tuberculosis and children who were Mantoux positive only are entered on to a database. Data on children referred from the school BCG programme and the results of contact tracing during the study period were extracted from this source.

Seventy eight schoolchildren (median age 12, range 5-14 years; 41 boys) were referred with positive Heaf test results and confirmed to be tuberculin positive (table 1). Six (four girls, two of whom were from the Indian subcontinent) had abnormal results in chest radiographs and were notified as having sputum smear negative pulmonary tuberculosis. Five of them (one from the Indian subcontinent) had been initially referred with Heaf test grade 2 positivity.

Two hundred and sixty nine out of 479 (56%) named contacts were screened. Two contacts of children with active tuberculosis had pulmonary tuberculosis: one was a younger white sibling, the other was an Indian mother with a cavitating apical lung lesion. Three contacts of children who were Mantoux positive only, all from the Indian subcontinent, were notified as having active tuberculosis: two were siblings of one index case, the other was a father

Department of
Respiratory Medicine,
Newcastle General
Hospital, Newcastle upon
Tyne NE4 6BE
Helen Booth, senior registrar
David J Hendrick, consultant
respiratory physician

Department of Paediatric
Infectious Diseases
Christine Pollitt, paediatric
registrar
Christina Jessen, senior
registrar in community
paediatrics
Andrew Cant, consultant in
paediatric infectious diseases

Correspondence to:
Dr Cant.

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