BACUP—the first two years: evaluation of a national cancer information service

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Abstract

The cancer information service of the British Association of Cancer United Patients (BACUP) was launched in October 1985 as a national service to patients and their relatives, the public, and health professionals. Information is provided by telephone and letter by seven nurses trained in oncology. In the first two years over 30 000 inquiries were received: 23 527 (80%) were from women; 9445 (32%) were from cancer patients 11 574 (39%) from relatives of patients, and 2869 (10%) from health professionals. Inquiries came from all over the United Kingdom and from all sections of society but users were predominantly middle class, aged between 30 and 49, and living in south east England. Information about specific cancer sites, treatment, and how to cope was most commonly sought. Nearly a third of all inquiries were related to breast cancer.

Though the service is used more by particular groups focusing on particular diseases, clearly there is a need for a cancer information service in the UK.

Introduction

Many cancer patients want information about their illness and wish to talk about their problems.¹ The provision of cancer information services is an innovative step in health care. The first such service was set up in the United States in 1976. Its aim was to disseminate accurate, up to date information to the general public and health professionals.² Two experimental cancer information "phone ins" in the United Kingdom^{3,4} showed a need for a similar service here.

The British Association of Cancer United Patients and their Families and Friends (BACUP) was launched as a cancer information service in October 1985 by an endocrinologist, Dr Vicky Clement-Jones, to provide information, advice, and emotional support to cancer patients, their relatives, the public, and health professionals. It was her personal experience of ovarian cancer that motivated her to found the service.⁵

BACUP operates from a central London office. Senior cancer nurses, who are trained in communication skills and have access to current publications and information, respond to inquiries by both telephone and letter. The nurses consult members of a panel of medical specialists when necessary. A wide range of questions can be dealt with, but inquirers who ask about prognosis or individual treatment regimens are referred to their own doctor. The telephone service is available during office hours. An answerphone operates at all other times.

To complement the cancer information service BACUP produces booklets describing the different types of cancer, their treatments, and how best to cope. A newspaper designed to be a forum for cancer patients, their families, and health professionals is

published three times a year. A pilot counselling project is being funded, and counsellors are being trained to see patients or their relatives. Assessment of this scheme will continue for two years.

Since a service such as BACUP had not previously been offered in the UK two projects were undertaken to evaluate the service. This paper is based on the first 30 000 inquiries.

Methods

Two tools were used to evaluate the service. A "call record form" is filled in after each inquiry on which information is recorded about both the inquirer and the nature of the inquiry. Eighty nine coded choices of subject are available, covering, for example, nature of the disease, treatments and side effects, prevention and risk factors, and support and counselling services. Demographic details are also collected from first time users of the service unless the nurses consider the questions inappropriate.

A "user survey" questionnaire, developed from pilot interviews, is used for quality control. The questionnaire is sent out to first time users of the service who receive information through the post in response to their inquiry. (The service is confidential and unless callers receive information through the post their names, and addresses are not known.) Questions cover reasons for contacting the service; how easy or difficult it was to talk to and understand the nurse; feelings about contacting the service; and whether the inquirer acted on any suggestions or passed on any information obtained during the inquiry. During the first two years 60 151 user surveys were sent out.

Data from the call record form were entered onto a commercially available interactive database package produced by Metasa Ltd and analysed using a statistical package, which included simple frequency counts, contingency table analysis with appropriate significance tests (Fisher's exact test and the χ^2 test with Yates's correction), means with t tests, correlations, and linear regressions. Data from the user survey were analysed using the Minitab statistical package (Minitab).

Results

CALL RECORD FORM

Since the launch of BACUP in October 1985 the number of calls received both by telephone and by letter have steadily increased (fig 1). The peaks on the graph in fig 1 coincide with media publicity about BACUP. Relatives and friends of cancer patients (11 574; 39.4%) used the service slightly more than patients (9445; 32.1%). Health professionals formed the next largest group (2869; 9.8%) followed by the general public (1469; 5%) and support groups (412; 1.4%). The overwhelming majority of inquirers were

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FIG 1—Average daily use of the cancer information service, including linear regression and five year predictions with 95% confidence intervals (CI) (assuming all other factors remain equal)

women (23 527 (80%) compared with (5227 (18%) men).

The modal age group of all inquirers (known=11 063) was 30-49 (5775; 52.2%); 1833 (17%) were over 60. Table I gives the age distribution of cancer patients who contacted the service and compares the proportion of patients in each age group with the relative incidence of cancer for their age group in Britain.⁶ The percentage of inquiries received from patients in the younger age groups is disproportionately high.

TABLE I—Age distribution of cancer patients who contacted cancer information service compared with national incidence of cancer in those age groups

Age group	BACUP inquiries (n=4587)		National incidence of cancer (n=198 249)	
	No	%	No	%
10-19	14	<1	1 646	<1
20-29	355	8	2 038	1
30-39	1 041	23	5 387	3
40-49	1 090	24	11 294	6
50-59	1 041	23	27 831	14
60 and over	1 046	23	150 053	76

Over 85% of those whose occupation was known were in social classes I, II, and III (non-manual), and under 15% were in social classes III (manual), IV, and V, which make up over half of the population (table II).⁷ Cases where occupation was not stated, inadequately described, or given as housewife (4.9%), retired (2.1%), or unemployed (0.5%) are excluded.

TABLE II—Social class distribution of patients, relatives, and the general public who contacted the cancer information service compared with social class distribution in national population

Social class	BACUP inquiries (n=2 692)		National population (n=2 780 287)	
	No	%	No	%
I	309	11	104 627	4
II	1 242	46	606 659	22
III non-manual	801	30	615 978	22
III manual	207	8	718 011	26
IV	106	4	541 493	19
V	27	1	193 519	7

Information on ethnic background was collected over a six month period. Nurses found it difficult to ask inquirers their race, so data were collected on only three fourths of first time inquirers (n=5606). Most callers were white (5467; 97.6%); 69 (1.2%) came from the Indian subcontinent (compared with 3.6% of the general population); 58 (1.0%) were black (West Indies and Africa, compared with 1.9% of the population); and 12 (0.2%) were Chinese (0.4% in the population).⁸

Table III gives the location of the inquirers according to region and compares this with the distribution of the population in these regions.^{9,10} The use of telephone or letter was influenced by the location of the inquirer; 936 of 7824 (12%) from greater London contacted the service by mail compared with 3229 of 15 940 (20%) in the south east and 4719 of 10 502 (45%) in the rest of England, Scotland, and Wales.

The "subject of the inquiry" (table IV) is subdivided for those people who were aware that they were dealing with metastatic disease and those who thought that the disease had not spread. The most common site of cancer in the inquiries was the breast for both men (16.5%) and women (34.0%), followed by lung and

TABLE III—Location of inquirers compared with distribution of UK population

Region	Distribution of BACUP inquirers		Distribution of national population %
	No	%	
All Thames regions (London)	14 226	53	24
Northern/Yorkshire	1 622	6	12
Trent/East Anglia	1 988	7	12
Wessex/Oxford/South West	3 809	14	15
West Midlands	1 569	6	9
Mersey/North Western	1 688	6	11
Wales	741	3	5
Scotland	930	3	9
Northern Ireland	142	<1	3
	26 715		

TABLE IV—Comparison of inquiries relating to metastatic and non-metastatic cancers

Subject of inquiry	Metastatic cancer (n=14 218)		Non-metastatic cancer (n=14 754)	
	No	%	No	%
Medical information:		47.0		42.6
Site specific information	2 130		3 373	
Conventional treatment (including side effects)	2 663		2 248	
Alternative treatment	286		181	
Prognosis	468		182	
Metastases	525		48	
Clarification	232		117	
Other	372		146	
Supportive information:		39.3		23.8
Support groups	493		571	
Emotional support	959		478	
Rehabilitation	200		328	
Terminal care/symptom control	486		72	
Communication problems	550		246	
Coping	1 265		807	
Other	1 632		1 008	
Preventive information:		2.1		8.0
Prevention	233		877	
Risk factors	64		298	
Dietary information	555	3.9	619	4.2
BACUP	614	4.3	2 376	16.1
Other	491	3.4	779	5.3

colon cancer. Clearly, men who asked about breast cancer were usually inquiring about a female relative or friend. Figures 2 and 3 compare the frequency of inquiries about cancers in men and in women with the national incidence of these tumours,⁶ irrespective of whether the callers were men or women.

The most common suggestion given to patients was to read the literature that was sent to them, which may have been leaflets from other organisations and photocopied articles as well as our own publications. Another common recommendation was for callers to talk to the doctor concerned in the case.

USER SURVEY

The user survey questionnaires were returned by 2827 of 6015 (47%) users. Table V shows the stated effects of contacting the service on the mood of telephone and mail inquiries. Table VI gives the actions people said they had taken after contacting the

TABLE V—Effect of contacting cancer information service on the telephone and mail inquiries

Feelings after contacting BACUP	Telephone inquiry		Mail inquiry	
	No	%	No	%
Cheerfulness:	1950		692	
Much more cheerful	484	25	110	16
Little more cheerful	952	49	245	35
The same	443	23	280	40
Little depressed	62	3	47	7
Depressed	9	<1	10	1
Worry:	1957		695	
Much less worried	496	25	130	19
A little less worried	900	46	252	36
The same	518	26	274	39
A little more worried	36	2	36	5
Much more worried	7	<1	3	<1

TABLE VI—Actions reportedly taken after contacting the cancer information service

Action	Telephone inquiry (n=1198)		Mail inquiry (n=455)	
	No	%	No	%
Made a doctor's appointment	257	12	54	7
Contacted a support group	240	11	67	9
Contacted another support service	165	8	50	7
Changed eating habits	176	8	97	13
Stopped or reduced smoking	60	3	41	6
Change lifestyle in another way	52	2	41	6
Began breast self examination or arranged for mammography	62	3	41	6
Arranged for cervical screening	39	2	31	4
Went to another doctor for second opinion	57	3	7	1
Other	90	4	26	3

service. The most common actions were to make another appointment with the doctor and to contact a support group or another service. Proportionately more telephone callers than letter inquirers took these steps.

Eighty nine per cent of respondents (2453/2767) described the service as either "useful" or "very useful," and many people reported passing on the information obtained to someone else. Where the caller was a relative or friend two thirds of all respondents (908/1349) shared the information with the patient.

Callers were asked how much difficulty they had had understanding what the cancer information officer told them. Ninety five per cent (1957/2055) found this either easy or very easy, and the others (98) had had some difficulty understanding the information.

Discussion

This paper presents data collected from the first 30 000 inquiries made to BACUP's cancer information service. Characteristically, inquirers are white, middle class, female, and aged between 30 and 39, and inquire about breast cancer. This pattern replicates the findings of the United States National Cancer Institute² and supports Cassileth's study in 1980 of information preferences among cancer patients.¹¹ In contrast, cancer is marginally more common in men than in women, there is a slightly higher incidence among the lower socioeconomic groups, and it largely affects people over 65.

The extent to which women inquirers outnumber men may be explained in part by the fact that women's magazines have shown the most interest in writing about BACUP, though BACUP has also been widely publicised in newspapers and on radio and television. Perhaps women's traditional role as care giver inclines them towards using a health information service.

Although cancer is predominately a disease of old age, inquiries from patients and relatives over 60 were proportionally low. In a society where people have come to expect longevity a diagnosis of cancer in early life possibly has a greater impact.

The disproportionate use of the service by people in non-manual occupations reflects the results of other studies which show that people in social classes representing manual occupations make much less use of community health and preventive services.¹² The ethnic background of the users appears to be at variance with the distribution of different groups in the population—that is, there were few non-white inquirers. Two possible causes may be that some people do not have English as a first language and proportionately more non-whites fall into the social classes for manual occupations.¹³

Over half the inquiries came from people living in greater London and the south east and the remainder from all over Britain, showing that BACUP provides a

FIG 2—Most common cancer sites discussed by inquirers in relation to women patients compared with national incidence of cancer at that site

FIG 3—Most common cancer sites discussed by inquirers in relation to men patients compared with national incidence of cancer at that site

national service. The cost of long distance calls is likely to be the main reason for this difference, and might be overcome by a freephone service should funding allow this.

The findings show that people require information in two key areas: medical and support services. The need for information about the disease and its treatment justifies the choice of oncology nurses to staff the service and in turn the provision of the medical and specialist advisory board.

As regards cancer site the predominance of inquiries about breast cancer is striking. This is the most common site discussed by men as well as women. Similarly, the number of calls about cervical and ovarian cancers are disproportionately high. A possible influence may be that these conditions feature prominently in women's magazines and have also been the subject of recent controversy over screening and options for treatment. Moreover, it is reasonable to suppose, that the great interest in these cancers is related to their prevalence in younger patients and to issues about sexuality.

Although BACUP was envisaged predominantly as a telephone service, letters make up 30% of the inquiries. The more positive effect on mood reported by telephone inquirers in the user survey, however, suggests that a telephone service may be of particular value. While it is possible that those who returned their questionnaires were more likely to be happy with the service, the user survey produced an overwhelmingly positive response.

BACUP has been in operation for over two years and is now handling an average of 85 inquiries a day. The direct relation between publicity and the number of inquiries received suggests that use will increase as BACUP becomes more widely known.

The establishment of a national cancer information service was the inspiration of a doctor who discovered what it means to become a cancer patient. Vicky Clement-Jones recognised the need for an organisation

which, working in conjunction with the medical and nursing professions, would improve the quality of information and emotional support received by cancer patients and their families. The results in this paper bear out the accuracy of this perception.

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Graphical aid for determining power of clinical trials involving two groups

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Abstract

Physicians need to evaluate clinical research critically, and determining the power of a study is an essential component of research evaluation. This report presents a graphical aid that permits rapid power determination for clinical trials with two groups. Power curves were developed for dichotomous outcomes by setting two tail α at 0.05 and varying the sample size, the control group response rate, and the clinically important difference between control and experimental groups as defined by the user. Use of the graphical aid was demonstrated to a group of 18 medical students, residents, fellows, and faculty in a 15 minute session. Evaluation of the trainees' application of the aid showed a small average bias of -0.0003 and an average variance of 0.006 . Ninety percent of power estimates were within 0.05 of the true value determined by formula.

This graphical aid is recommended as a rapid and accurate method for determining power in the critical appraisal of clinical research.

Introduction

Physicians need to evaluate clinical research critically to keep up to date with current work¹ and to make

sound decisions in patient management.² Critical research evaluation requires an understanding of and ability to use the important components of biostatistical inference.¹ A major issue in evaluating clinical trials is whether the research design has adequate power to show a statistically significant difference between study groups if in truth a clinically important difference exists. The graphical aid presented here is recommended as a rapid and simple method for estimating power. It can be used for evaluating published reports and for teaching the concepts of statistical power to medical trainees.

Many clinicians and researchers are uncertain how to interpret a negative clinical trial. For example, the Danish double blind controlled trial failed to find aspirin effective in reducing the incidence of transient ischaemic attacks or death.³ Dyken, however, questioned, "Does the failure of the Danish study to show any favourable effect mean that the other studies [showing positive effect of aspirin] are wrong?"⁴ To answer such questions power analysis can be used to determine the probability that the trial will find a statistically significant difference when a specified difference really exists. To show how power analysis is used the concepts of type I and type II error in statistical significance testing are briefly reviewed.

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