Information in practice

Randomised trial of personalised computer based information for cancer patients

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Abstract

Objective To compare the use and effect of a computer based information system for cancer patients that is personalised using each patient's medical record with a system providing only general information and with information provided in booklets.

Design Randomised trial with three groups. Data collected at start of radiotherapy, one week later (when information provided), three weeks later, and three months later.

Participants 525 patients started radical radiotherapy; 438 completed follow up.

Interventions Two groups were offered information via computer (personalised or general information, or both) with open access to computer thereafter; the third group was offered a selection of information booklets.

Outcomes Patients' views and preferences, use of computer and information, and psychological status; doctors' perceptions; cost of interventions.

Results More patients offered the personalised information said that they had learnt something new, thought the information was relevant, used the computer again, and showed their computer printouts to others. There were no major differences in doctors' perceptions of patients. More of the general computer group were anxious at three months. With an electronic patient record system, in the long run the personalised information system would cost no more than the general system. Full access to booklets cost twice as much as the general system.

Conclusions Patients preferred computer systems that provided information from their medical records to systems that just provided general information. This has implications for the design and implementation of electronic patient record systems and reliance on general sources of patient information.

Introduction

Most cancer patients want as much information as possible and wish to be involved in treatment decisions.[1–3] Some argue that tailoring information is important to meet patients' different backgrounds. [4] Computer based methods can be used to tailor information to patients, [5–10] but no major randomised trials have examined the outcome of tailoring information to cancer patients. The importance of the electronic patient record has been recognised in the NHS information strategy. [11] If using medical records to tailor information for patients is worth while then it has implications for the design and implementation of electronic patient records and patients' use of computer based resources such as the internet.

Our primary aim in this study was to compare patients' use and satisfaction, doctors' perceptions, and the costs of a system providing information for patients that was personalised using the medical record with more general computer based information. Subsidiary aims were to compare the effect of providing such personalised information with that of providing conventional information booklets and to assess the impact of providing information on patients' psychological status. Although many information booklets are produced, in practice these are not freely available in hospitals; therefore, computer based information may provide a cost effective alternative. Too much technical information [12 13] and, some argue, access to medical records[14] may increase anxiety, whereas appropriate information may reduce it. [15] We therefore measured these effects.

Participants and methods

Study population and sample

The Beatson Oncology Centre provides specialised non-surgical cancer treatment for patients throughout western Scotland. Between August 1996 and December 1997, 1261 eligible patients with breast, cervical, prostate, or laryngeal cancer were identified from radiotherapy booking sheets (fig 1). Patients receiving palliative treatment, with no knowledge of their diagnosis, with visual or mental handicap, or with severe pain or symptoms were excluded from the study. We obtained ethical approval for the study from the Western Ethics Committee.

Recruitment and randomisation

Eligible patients were sent a letter describing the study and were contacted when they attended the centre, within three days of their starting treatment. At this contact, we gave further details of the study and assessed the patients' eligibility. We randomly

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Further details of the trial and its implications appear on the BMJ's website
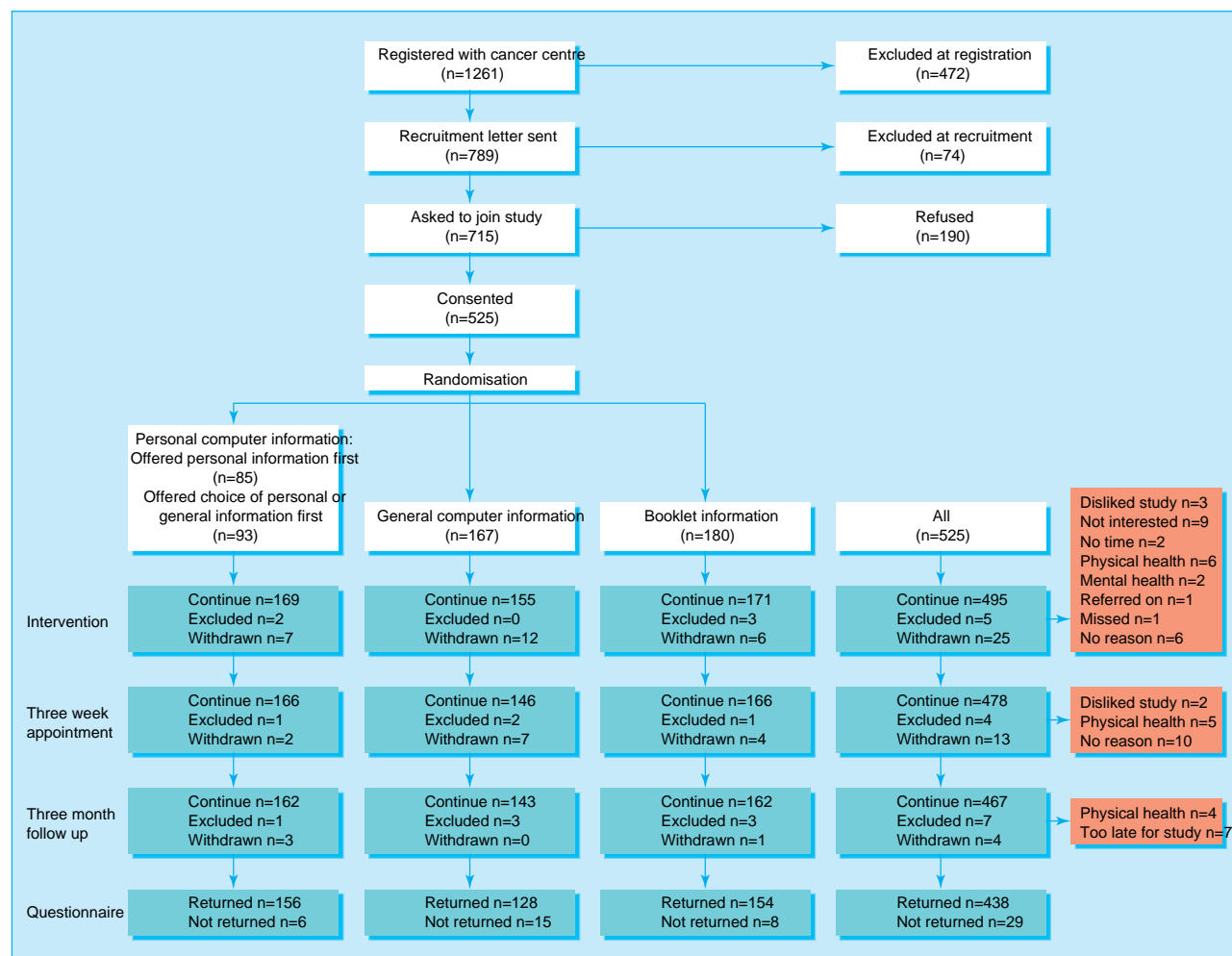
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Fig 1 Flow of patients through trial

allocated 525 patients who agreed to enter the study to one of three intervention groups. (For further details of recruitment and randomisation, see appendix 1 on the BMJ's website.)

Intervention groups

Computer based information
Two groups were offered a "computer consultation" using a touch screen computer (fig 2).

General information group—Patients were offered a system giving general information about cancer organised as a hypertext document.

Personal information group—Patients were offered a system that allowed them to see a summary of their medical record, and from there (via hypertext links) to information about all the concepts and terms mentioned in the record (such as "grade II" being linked to information about what this meant). Half of the personal group was also given access to the general system menu, so that we could measure more directly which system was preferred and used first.

Patients in both personal and general information groups were sent printouts of the information they had viewed. After the intervention, the patients had open access to the same information system via another computer sited in a waiting area.

Booklet information group
Patients were invited to look through a folder of printed booklets and to take as many as they wished. There were folders for each type of cancer containing 47, 32, 34, and 30 booklets for breast, cervical, prostate, and laryngeal cancers respectively.

(For further details of computer systems and book‹lets, see appendix 2 on the BMJ's website.)

Data collection
At recruitment or shortly after, patients were asked about the information they had already been given, what newspapers they read, their use of technology, and what information sources they used.[16] They completed a hospital anxiety and depression scale[17] and mental adjustment to cancer questionnaire.[18]

The intervention took place up to a week after recruitment. The computer systems automatically recorded the time patients spent using the computer and the choices they made, both at the time of their computer consultation and afterwards. For the booklet information group, we recorded the number and type of booklets chosen. Patients' views on the information were obtained from a home questionnaire after the intervention.

At their consultation with a doctor, three weeks after intervention, the patients completed a second hospital anxiety and depression scale and mental

Personal information

The Record of Donald Demo

The information in your record has been divided into the following 4 categories. Please touch one of the highlighted words to see your details.

Personal Information
Investigations
Problems
Treatments

There is also general information on the following topics:

About Cancer
Beatson Oncology Centre

Donald Demo: Investigation List

According to your record you have had the following investigations:

US scan   Date: 8/2/96
               Date: 2/4/96
               Results of US scans
TRUS biopsy   Date: 24/4/96
EUA
PSA   Date: 8/1/96
               Date: 18/6/96
               Date: 6/8/96

Donald Demo: Results of US Scans

According to your record, you had a US scan of your urinary tract on 8th February 1996.

The result was:

The bladder didn't empty completely.

You also had a US scan of your kidneys and abdomen on 2nd April 1996 at the Southern General Hospital.

The results were:

Kidneys: normal.
Abdomen: showed a phlebolith in left of pelvis.

General information

Patient Information System

Touch any highlighted phrase for more information on that topic.

Beatson Oncology Centre   About Cancer

Breast Cancer   Cancer of the Cervix

Cancer of the Larynx   Prostate Cancer

Feelings and Emotions   Complaints and Queries

Prostate Cancer

The information has been divided into 7 categories.

Touch one of the highlighted words or phrases below for more information on a topic.

about prostate cancer
prostate cancer: risk factors
symptoms
diagnosing prostate cancer
treatments
self care during radiotherapy
further sources of information

Diagnosing Prostate Cancer

There are several ways of diagnosing prostate cancer and the methods used may differ from person to person.

When patients first go to their family doctor a detailed medical history will be taken, perhaps followed by an examination. A blood sample may also be taken and if necessary the patient will be referred to a hospital consultant called a Urologist.

The investigations may include the following
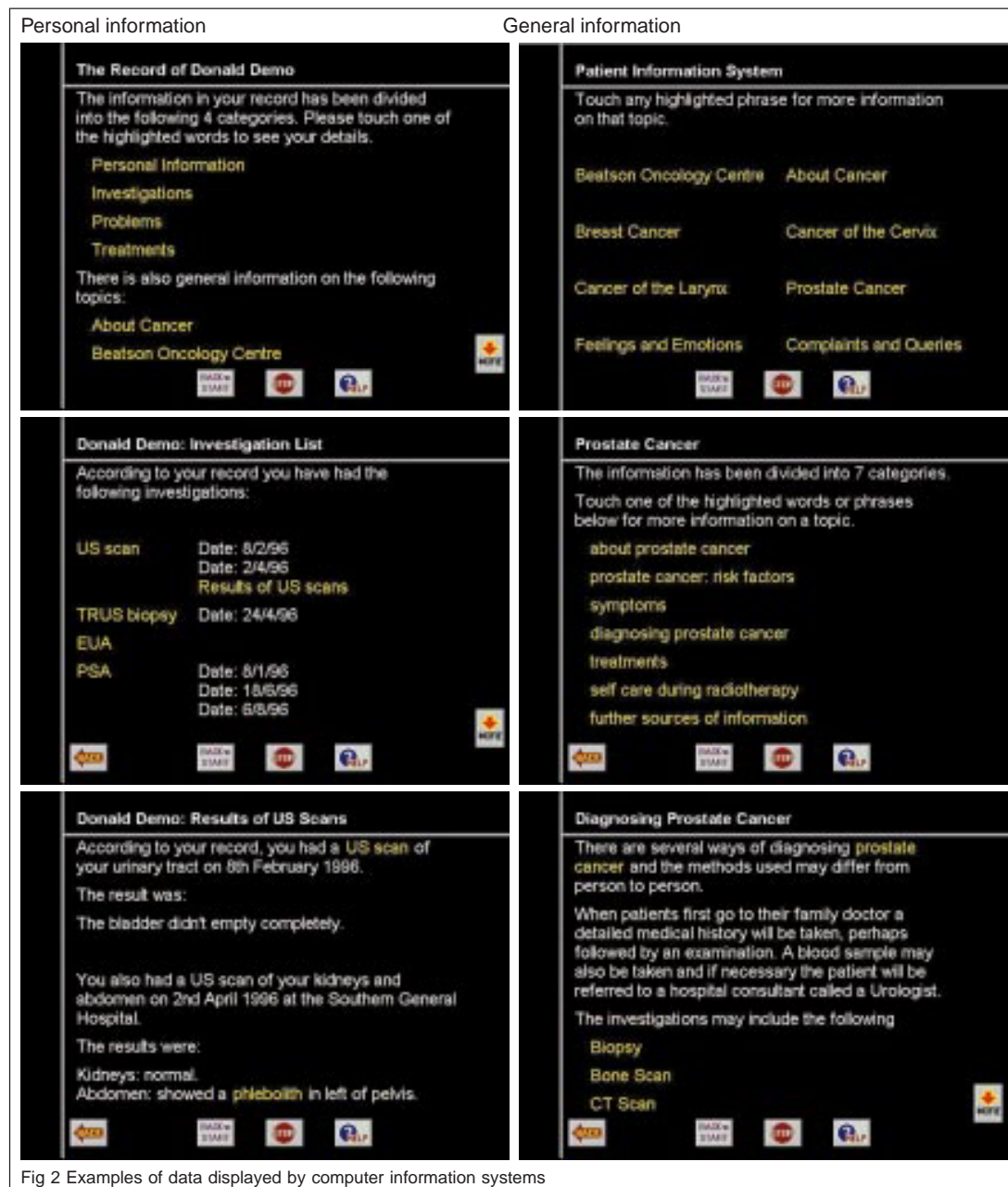
Biopsy
Bone Scan
CT Scan

Fig 2 Examples of data displayed by computer information systems

adjustment to cancer questionnaire. The doctors assessed the patient's participation, anxiety, knowledge, and time spent in consultation and compared these results with those of the "average" patient with that type of cancer.

Three months after the intervention, patients completed a third hospital anxiety and depression scale and mental adjustment to cancer questionnaire, and they were asked about their information preferences and their use of the printed material at home.

Data analysis

We assessed differences in patients' views, doctors' assessments, use of information, and cost of intervention using cross tabulations and x^2 tests. We assessed differences between intervention groups in scores on anxiety and depression scales and mental adjustment

questionnaires using cross tabulations and x^2 tests, Student's t tests, and Mann‹Whitney U tests.

In a subsidiary analysis using multiple logistic regression analysis, we examined differences in patients' anxiety and depression scores by their cancer type, time since diagnosis, age, sex, deprivation category,[10] newspapers read, and use of information in the intervention.

Costs

We calculated current time costs in maintaining both computer information systems, using the cost of a research assistant's salary. We recorded the costs of the booklets taken by each patient. Capital computer costs were written off over four years, with maintenance charges of 5% for years 2‹4. Costs incurred by patients were not included as the interventions took place

during visits for treatment. We modelled four different scenarios and compared their four year cost profiles using a 6% discount rate.

Results

Patients completing the study

Of the 715 patients invited to participate, we recruited 525; 190 (27%) refused to take part (fig 1). Probability of refusal increased with age. Of the 525 patients recruited, 467 continued to the three month follow up and 438 of these returned questionnaires. The 87 who did not complete follow up were more likely to be in the general computer information group (23% v 13%, $x^2 = 8.1$ (1 df), P = 0.004), to not have breast cancer (20% v 14%, $x^2 = 3.83$ (1 df), P = 0.05), live in poorer areas (deprivation categories 4›7, 20% v 11%, $x^2 = 8.3$ (1 df), P = 0.004), and to have had a diagnosis of cancer for more than a year (40% v 15%, $x^2 = 12.9$ (1 df), P < 0.001). There was no difference by age, sex, or newspapers read. A further 47 patients returned an incomplete hospital anxiety and depression scale at three weeks or three months and were not included in the analyses of anxiety and depression scales and mental adjustment questionnaires.

Use of computer

The average time spent using the computer at intervention was 12 minutes (range 1›44). Of those patients in the personal information group who were offered both personal and general information systems, two thirds (57/88) chose the personal information first. Twenty nine per cent of the patients used the computer again. Patients in the personal information group were more likely than those in the general information group to use the computer between the three week and three month follow ups (20/169 v 4/155, $x^2 = 12$ (2 df), P = 0.002).

Patients' views and preferences

Patients given personal information were more likely to have a high satisfaction score, calculated from seven attributes (table 1), than were those given general computer information (mean difference 12%, 95% confidence interval 0.7% to 23.9%). More patients given personal information thought that the information was relevant and that they had learnt something new.

The patients who received booklet information were more likely to feel overwhelmed with information than were those given computer information, while patients in the computer information groups were more likely to think that the information provided was limited.

At three months' follow up, although 80% of patients expressed a preference for 10 minutes with a specialist nurse or radiographer to computer or booklet information, 20% preferred unlimited time with a computer, and those in the computer groups were more likely to do so.

Doctors' assessment

Doctors thought more patients (35%) in the general computer information group were above average in knowledge compared with both the personal information group (25%) and booklet information group (20%) (P = 0.01). They perceived no other difference.

Use of printed material at home

More of the patients offered booklet information (83%) used the material at home compared with those offered personal information (70%) or general information (57%) ($x^2 = 22.4$ (2 df), P < 0.001). More patients in the personal information group showed the computer printouts to family or friends (36%) compared with those with general information (22%) or with booklets (21%) ($x^2 = 6.7$ (2 df), P = 0.035).

Costs

In the absence of an electronic patient record, the personalised computer information system requires manual extraction of data from patients' case records and would currently cost over nine times the cost of the general information system. With the introduction of an electronic patient record, however, it would cost the

Table 1 Cancer patients' responses to questionnaires sent a few days after they were given information about cancer and after three months' follow up. Values are number (percentage) of affirmative answers to each question unless stated otherwise

	Computer information		Booklet information (n=150)*	Total (n=434)*	P value of difference†	
Question asked	Personal (n=156)*	General (n=128)*			Personal v general computer information	Computer v booklet information
After intervention						
1 Was the information useful?	103 (67)	76 (60)	98 (65)	277 (64)	0.25	0.77
2 Did it tell you anything new?	96 (62)	63 (50)	74 (49)	233 (54)	0.03 (personal better)	0.13
3 Was information relevant?	123 (79)	85 (66)	105 (70)	313 (72)	0.02 (personal better)	0.47
4 Did you find information easily?	132 (85)	109 (85)	117 (79)	358 (83)	0.67	0.07
5 Did you feel overwhelmed with information?	33 (21)	37 (29)	66 (44)	136 (31)	0.15	<0.001 (booklet worse)
6 Was it too technical?	13 (8)	18 (14)	17 (11)	48 (11)	0.13	0.90
7 Was it too limited?	76 (49)	71 (56)	48 (32)	195 (45)	0.22	<0.001 (computer worse)
Satisfaction score >2‡:						
No (%) of patients	68 (46)	41 (34)	58 (40)	167 (40)	0.04 (personal better)	0.77
95% CI of percentage	38 to 54	26 to 42	32 to 48			
At 3 months						
8 Prefer computer to 10 minute consultation with professional?	38/131 (29)	22/110 (20)	12/122 (10)	72/363 (20)	0.12	<0.001 (computer more likely)

Answers given on four or five point scales were recoded as binary responses, with the modal category used as the point of division.
*Individual questions had up to five missing responses: in these cases the denominator used to calculate percentages was smaller than value given.
†From x^2 (1 df).
‡Summation of scores from questions 1›7. Questions 1›4 are "positive" attributes, and affirmative response to each question adds 1 to satisfaction score. Questions 5›7 are "negative," and affirmative response to each question subtracts 1 from satisfaction score. Score ranged from

same as the general system over time as fewer additions would be required.

Despite our buying the booklets at a discount, the average cost of booklets taken was over £7 per patient. A general computer information system would cost 40% of the costs of full access to booklets; even in the first year it would cost less. (For further details of cost‹ ing, see appendix 3 on the BMJ's website.)

Psychological status

There were no significant changes in the patients' depression scores or mental adjustment scores between the start of treatment and follow up at three weeks and three months. However, 327 (84%) of the patients showed improvement in anxiety scores, of whom 255 (65%) improved in the first three weeks. At three months, 37% of patients in the general computer information group were still anxious compared with only 19% in the personal information group (mean difference 18%, 95% confidence interval 3.7% to 26.5%) (table 2). Exploration of other predictors by multiple logistic regression showed that type of cancer, age, sex, and type of newspaper read were all predictors of anxiety, but type of intervention remained a significant predictor with more patients in the general computer information group being anxious. (See appendix 4 on the BMJ's website for details of the intention to treat analysis).

Discussion

Recruitment and follow up

The validity of our results is affected by patients' declining to take part in the study, many of whom may not have wanted more information. More patients in the general computer group failed to complete the three month follow up. It may be that use of the personal rather than general computer information helped to retain the patients' interest, but the evidence is inconclusive.

Personalised v general computer systems

The NHS information strategy [11] emphasises the importance of electronic patient record systems for clinical information but suggests the internet for patient information. Although most patients in this study preferred more time with a professional to computer or booklet information, one in five did not, and for all patients a computer could provide complementary information. However, the patients preferred the personalised information system to the general one and were more likely to use both computer and printout.

There was little difference in doctors' perceptions of the intervention groups. All the doctors at the Beatson Oncology Centre were willing collaborators in this study, and few clinicians now object to controlled patient access to medical records. Other reasons for combining patient information with electronic patient records include patients' audit of records [14] and easier maintenance of integrated health service systems.[19] Routine use by patients should be built into electronic patient records as they are implemented over the next few years.

Computers systems v booklets

Written information is important. [20] [21] More of the patients offered booklet information used the material

Table 2 Percentages of 391 cancer patients completing all three hospital anxiety and depression scales who displayed anxiety or borderline anxiety. Adjusted P values are shown from multiple logistic regression

	Hospital anxiety and depression scale		
	At start of treatment	At 3 weeks	At 3 months
Intervention groups			
Personal computer information	38	23	19
General computer information	37	28	37
Booklet information	32	18	22
P value of difference	>0.05	>0.05	0.001
Baseline characteristics			
Age (years):			
<60	48	33	35
> 60	22	11	15
P value of difference	0.0006	0.006	0.005
Time since cancer diagnosed (months):			
<4	35	20	23
4‹12	37	26	29
>12	27	13	20
P value of difference	>0.05	>0.05	>0.05
Sex:			
Female	44	30	32
Male	20	9	14
P value of difference	0.02	0.01	0.002
Type of cancer:			
Breast	43	29	31
Other	25	13	18
P value of difference	>0.05	>0.05	0.03
Deprivation category:			
Deprived	37	30	30
Average	38	23	27
Affluent	28	16	21
P value of difference	>0.05	>0.05	>0.05
Newspaper read:			
Tabloid	40	27	30
Broadsheet	29	16	18
P value of difference	>0.05	0.01	0.003
Intervention behaviour			
Information seeker*:			
No	37	24	27
Yes	35	21	26
P value of difference	>0.05	>0.05	>0.05
User of information at home:			
No	41	32	36
Yes	34	19	23
P value of difference	>0.05	>0.05	>0.05

*Defined as the top third for each group: those who spent 8 minutes on the computer (total time) and those in booklet information group who chose 8 or more booklets.

at home than did those given computer printouts, but the patients given personal computer information were more likely to use printouts than those given gen‹ eral computer information and were most likely to show their information to others. The printed booklets were more attractive than computer printouts, although these could be improved. Printed booklets are expensive, and tailored computer printouts could be produced more cheaply.

More of the patients offered booklets felt overwhelmed by the amount of information available, possibly because of the large number of booklets from which to choose. Providing a more restricted set of booklets, or nurse guidance in their selection, might have produced different results.

What is already known on this topic

Various studies have examined different ways of "personalising" computer based information for patients

There has been no randomised trial testing the assumption that personalisation using the medical record is worth while

What this paper adds

This randomised trial showed that cancer patients thought a system giving them information based on their medical record was better than one giving only general information

Patients were more likely to use the personal system again and to show the printouts from that system to their family

There were no major differences in doctors' perceptions of the patients, but patients using the general information system seemed more anxious at three months' follow up

The study has implications for the design and implementation of electronic patient record systems and of patient information systems

It is unclear why more patients in the computer groups thought that the information given was limited. The information presented was more complex than in other local systems.[22–24] However, the patients received printouts only of the material they inspected during the computer session, so they did not have additional information to work through at home, as the booklet group did. Furthermore, the patients spent a relatively short time using the computer and may not have realised the depth of information available.

Improvement in anxiety

We did not directly try to reduce anxiety but measured it in case giving patients access to their medical records increased anxiety.[14] Our results suggest the converse. There was some evidence that the patients given general computer information were more anxious than other patients at three months. Although we did not collect information on physical health to which anxiety might be related[25 26] and doubts have been expressed about the use of the hospital anxiety and depression scale among cancer patients,[27] we think that the observed difference in anxiety at three months is most likely explained by the interventions. As more patients given personal information used their printouts with their family, we could hypothesise that this contributed to the difference.

Others have found that general information given after a consultation can inhibit patients' recall of the consultation[28] and that patients used audiotaped consultations to inform their family of their situation.[29] Whether providing patients with information helps to reduce their anxiety may depend on their coping style[30–32] and warrants further study. Finding information on the internet can be difficult, and more thought is needed about its role as a primary information source for patients.

(See appendix 5 on the BMJ's website for a discussion of the feasibility of our computer system and of alternative computer based forms of patient information.)

Conclusions

This study strongly suggests that patient information should be linked to electronic patient records. Patient information booklets are expensive, and computer based information could prove cheaper. However, further study is needed of how information, particularly from general sources, affects anxiety.

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Cross sectional survey of patients' satisfaction with information about cancer

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Most patients with cancer want as much information as possible appropriate to their personal needs and circumstances.[1 2] We surveyed the views of cancer patients entering a randomised trial of computer based information.[3] We examined their need for information and their satisfaction with information received and how these varied with their demographic, social, and psychological characteristics.

Patients, methods, and results

Eligible patients were those planned to receive radical radiotherapy, who knew their diagnosis, were without visual or mental handicap, and were without severe pain or symptoms causing distress. Of 715 patients asked to take part, 190 refused, 25 stating they did not want more information. Of the 525 participants, 309 had breast cancer, 129 had prostate cancer, 22 had cervical cancer, and 65 had laryngeal cancer.

Data were collected at the recruitment interview, from a questionnaire the patients completed at home shortly after, and from their case notes. Data included the information patients would like,[2] a hospital anxiety and depression scale,[4] the newspaper patients read, and deprivation category (derived from postcode).[5] Using χ^2 tests and multiple logistic regression analysis, we compared the patients' sources and perceived quantity of information received and their satisfaction with this information, as binary variables, with their age, sex, cancer site, newspaper read (tabloid v broadsheet), deprivation category, and anxiety and

depression scores (table). Information need[2] ("as much as possible" v other) was considered both as a response variable and as a predictor of sources and satisfaction.

Four out of five patients wanted as much information as possible. In univariate analysis, newspaper read, deprivation category, having a connection with the health service, age, and time since diagnosis were predictors of information need. In multiple logistic regression analysis, however, only newspaper read and age remained predictors.

One in five patients were not satisfied with the information given. Univariate analysis showed that dissatisfied patients were much more likely to be depressed and were marginally more likely to be anxious or to want as much information as possible. In multiple logistic regression age, sex, and depression were predictors of dissatisfaction. Fifteen per cent of patients said there had been many differences in what they had been told by health professionals. Multiple logistic regression showed that these patients were more likely to be anxious.

Patients with breast cancer and readers of broadsheets had received more information and from more people than patients with other cancers but were not significantly more likely to be satisfied. The location of the clinician who gave the diagnosis had no effect on how much information patients had received. Younger depressed patients who wanted as much information as possible were less likely to be satisfied even though they had received more information than others. A third of patients said there were other things that they

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