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- (Accepted 27 January 2006)
doi 10.1136/bmj.38753.524201.7C

Effect of different forms of information produced for cancer patients on their use of the information, social support, and anxiety: randomised trial

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BMJ 2006;332:942-6

Abstract

Objective To explore the hypothesis that different methods of selecting and printing information for cancer patients could improve emotional support by affecting interaction with others, and so lead to improved psychological wellbeing.

Design Randomised trial with eight groups (three factors, 2×2×2). Data collected at recruitment and three month follow-up.

Participants 400 patients starting radiotherapy, of whom 325 with breast or prostate cancer and complete anxiety and depression data were included in the analysis.

Interventions Printed booklets: half had only general information from CancerBACUP about each patient's cancer and half had personalised information from the patient's medical record plus selected general information; half were composed of information chosen interactively by the patient and half were produced automatically with a larger volume of material; and half had additional advice on anxiety management.

Main outcome measures Patients' views of the information, use of their booklets with others; change in reported social support; change in anxiety and depression.

Results The larger booklets produced automatically were more likely to be found useful and to tell patients something new and less likely to be seen as too limited than the booklets produced interactively, but they were also more likely to overwhelm some patients. Personalised booklets were more likely than general booklets to tell patients something new. There was no difference in patients' perceived understanding of their cancer by any of the intervention factors. Patients with personalised information were more likely to show their booklets to others and to think it helped in discussing their cancer or its treatment. There were no major

differences in social support, anxiety, or depression by any intervention factors.


Conclusions Patients were more likely to show personalised information to their confidants than general information. Further research is needed into the effects of sharing information on patients' social support and anxiety.


Trial registration US Government Clinical Trials Database NCT00127465

Introduction

Anxiety and depression are important and common comorbidities in cancer and may affect survival. Providing information and social support may improve patients' psychological wellbeing,^{1 2} but different patients may have different information preferences³ and coping styles.⁴ Patients fare better when the information they receive is tailored to their coping style. Coping style also affects patients' desire for social support, and availability of a confidant and a means by which a patient can engage support are also important.⁵

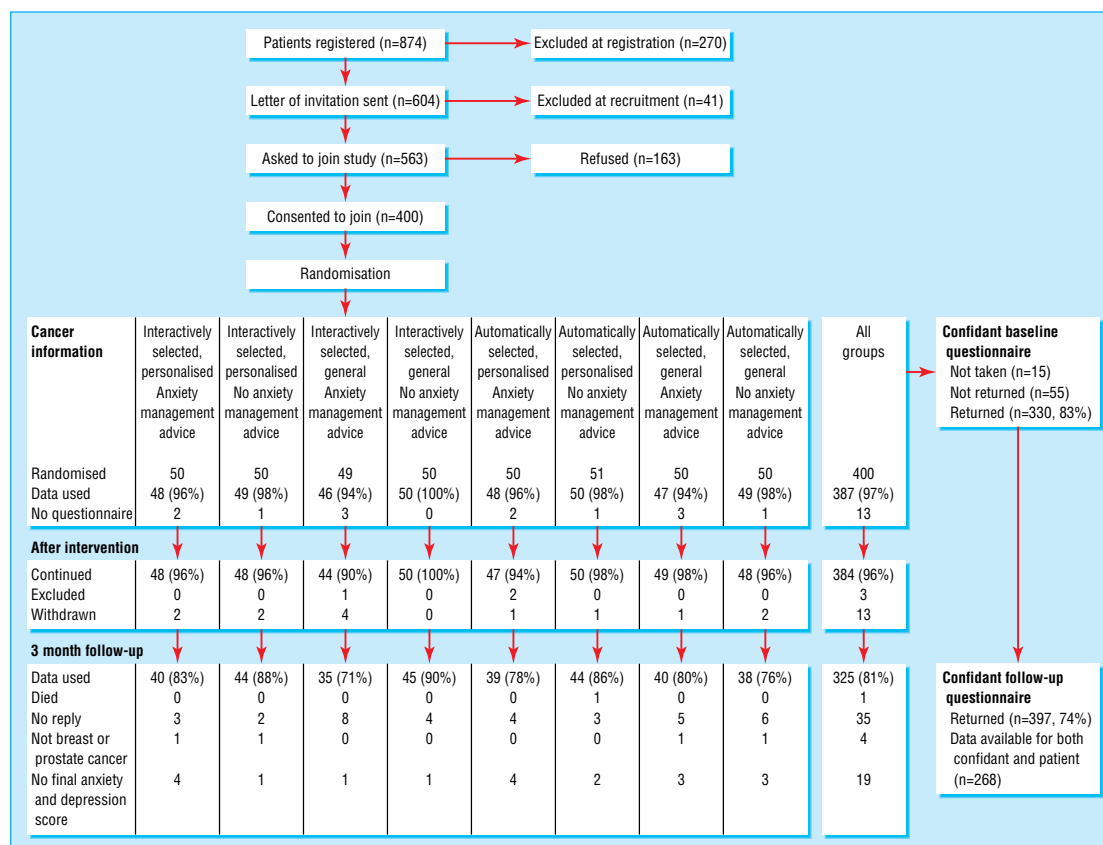
In a previous study we found that patients preferred personalised information to general information.⁶ Unexpectedly, we found that patients with personalised information showed better improvement in anxiety over three months than those with more general information. We knew that patients with personalised information were more likely to show it to someone at home and hypothesised that this might be partly responsible. We have now carried out a randomised trial, with similar patients and setting, to explore the hypothesis that different methods of selecting and printing information for cancer patients

 This is the abridged version of an article that was posted on bmj.com on 5 April 2006: <http://bmj.com/cgi/doi/10.1136/bmj.38807.571042.68>

 Appendices 1-10, providing further information about the study, are on bmj.com

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Patient flow through study

could improve emotional support by affecting interaction with others, and so lead to improved psychological wellbeing.

Participants and methods

Participants

Location and timing of the study—Patients were recruited between November 2001 and March 2003 at the Beatson Oncology Centre and its satellite centre, which provide specialised non-surgical cancer treatment for patients throughout western Scotland.

Sample size—The target sample was 400 patients, giving 80% power to find a difference of 40-27% in improved anxiety between (for example) 200 given personalised information and 200 given general information only.

Patient selection—A total of 874 patients starting radiotherapy treatment were registered with the study. Of the 563 patients invited to take part, 400 (71%) consented (figure). See bmj.com for reasons for exclusion.

Recruitment

Patients recruited—The 400 patients recruited comprised 275 (69%) women and 125 men with ages ranging from 28 to 82 years with mean age 59 (median 61). Of these, 348 completed follow-up. Patients had had their cancer diagnosed between five and 312 weeks before recruitment. Two thirds (262, 68%) of the patients had breast cancer, and just under a third (118, 31%) had prostate cancer. One woman had cervical cancer, and two men and one woman had laryngeal cancer.

Recruitment data—At recruitment, patients were asked to complete a questionnaire at home. This included questions on their previous computer use, information preferences and coping style, household, and confidant (the person they were most likely to discuss their cancer with); Helgeson's social support questionnaire (HSSQ),⁷ and the hospital anxiety and depression scale (HADS).⁸

Randomisation

All patients were offered booklets based on information from the website of CancerBACUP, a cancer information and support service for patients (www.cancerBACUP.org.uk). We randomised patients to eight groups defined by the three binary factors under study: (a) half received personalised information that included data from their medical records, whereas half had only general information from CancerBACUP for their cancer; (b) half chose information interactively by selecting it with a computer at the oncology centre, and half had a larger volume of material in booklets that were produced automatically; and (c) half had additional anxiety management advice, and half did not.

Interventions

Choices made by patients in our previous study⁶ guided the information we offered. Patients provided with general information only received the booklets *Understanding Radiotherapy, Diet and the Cancer Patient*, and the appropriate cancer-specific booklet. Patients provided with general information and who selected information interactively could choose sections from

the above three booklets and from three further CancerBACUP booklets. These six booklets had a total of 78 sections, and the patients were allowed to choose up to 10 sections from a menu. This relatively limited choice was mainly to test the difference between a small but carefully selected subset of information and a larger more general document. Patients given anxiety management advice had an extra few pages with self help advice based on work in cognitive behaviour therapy for anxiety.

The patients allocated personalised information that was produced automatically received selected information from the three general booklets plus information from their medical records. The less relevant sections in the three booklets were omitted, so that patients received slightly shorter booklets than did the patients given general information. Patients allocated personalised information that they chose interactively could select topics from their medical record such as "problem list," "treatment list," or "your cancer." We also noted those patients who did not wish to take a booklet.

Follow-up data

Patients were sent follow-up questionnaires three months later. The questionnaires included Helgeson's social support questionnaire, the hospital anxiety and depression scale, and questions about the patients' use and opinions of the booklets and their reported understanding of cancer.

Statistical analysis

Completed data for the hospital anxiety and depression scale were available for 329 (82%) patients. Here we present the results for the 325 patients with cancer of the breast or prostate. See appendices on bmj.com for results on all patients.

We compared both the differences in the anxiety and depression scores at recruitment and at follow-up and in the proportions of patients with scores ≥ 8 (cases or probable cases of anxiety or depression). Patients answered questions about the booklets on Likert scales, and we grouped these according to the modal answer into binary scores. Helgeson's social support questionnaire produces four scores—instrumental, informational, and emotional support (20 = "best") and "negative interactions" (50 = "worst").

Analyses to ensure robustness of results included using difference in scores and in scores grouped by tertiles and quartiles. We examined patients' views and use of the booklets and differences in the social support and the anxiety and depression scores between recruitment and three months by means of general linear models and multiple logistic regression as appropriate. We considered significant results to be important only if they formed a consistent pattern from various analyses.

Results

Baseline characteristics

At recruitment, there was no difference between the intervention groups in terms of anxiety, depression, social support, age, sex, or length of diagnosis. Of the patients who answered the questions, 326/375 (87%) were satisfied or very satisfied with the cancer information they had already received, 231/373 (62%) had

read at least one CancerBACUP booklet. Only 52/382 (14%) had obtained health information themselves from the internet, but 67 (18%) had been given information from the internet by someone else, and 164 (43%) had never used a computer before.

Among the 325 patients with breast or prostate cancer who completed the study, all four of the social support scales were skewed towards having lots of support—median scores were 17 for informational, 20 for emotional, and 20 for instrumental support, and 13 for "negative interactions." A third (99, 30%) had anxiety and 43 (13%) had depression. General linear models used to predict anxiety and depression scores and multiple logistic regression to predict cases or borderline cases of anxiety or depression produced similar results. The negative interactions measure of social support predicted both anxiety and depression at baseline (see bmj.com).

Interactive selection of information

For the 190 patients who selected their cancer information, the average time spent using the computer was 9 minutes (range 2-30). A third required help in using the computer; two thirds chose to use the touch screen, and a third used the mouse.

On average, patients chose eight sections (range 0-10); there was no difference by intervention or other factors. Patients with breast or prostate cancer were similar in the sections they chose (see bmj.com).

Three month follow-up

Patients' opinions of the booklets and perceived understanding—The booklets produced automatically, which were larger than those produced interactively by patients, were more likely to be found useful and to tell the patient something new and less likely to be seen as too limited, but they were also more likely to overwhelm some patients than the booklets produced interactively (see bmj.com). The booklets with personalised information were more likely than those with only general information to tell the patient something new. The patients given automatically produced booklets had higher overall satisfaction scores than those who produced their booklets interactively (54% v 47% with score > 2 ; $P = 0.02$ from general linear models). When asked to rate their current understanding of their cancer, there was no difference by any of the intervention factors. One hundred and thirteen patients (35%) made positive comments about the booklets and 38 (12%) made negative comments, and patients with personalised booklets were more likely to mention the relevance of the information than those given only general information (41% v 15%; $\chi^2 = 9.3$, 1df; $P = 0.002$).

Use of the booklets with others—Compared with patients with general information only, patients with personalised information were more likely to show their booklets to their "confidant" (85% v 70%; $\chi^2 = 10.1$, 1df; $P = 0.001$), to someone else in the household (32% v 19%; $\chi^2 = 6.8$, 1df; $P = 0.009$), and to someone outside the household (33% v 22%; $\chi^2 = 4.3$, 1df; $P = 0.04$). Those with personalised information were more likely than those with general information only to think that it helped in discussing their cancer or its treatment. (80% v 65%; $\chi^2 = 4.2$, 1df; $P = 0.04$).

Changes in social support—Changes in informational support ranged from -12 to 12, in emotional support

Mean change in anxiety and depression scores* for 325 cancer patients from recruitment to follow-up by type of cancer information provided and change in social support scores

Type of cancer information	Change in anxiety score at follow-up			Change in depression score at follow-up		
	Mean (SD) change	P value†		Mean (SD) change	P value†	
		Corrected	Not corrected		Corrected	Not corrected
Selection of information:						
Automatic	-0.1 (3.1)	0.28	0.19	0.1 (2.8)	0.82	0.57
Interactive	0.3 (2.9)			-0.1 (2.8)		
Personalisation of information:						
Personalised	-0.4 (2.9)	0.36	0.35	0.3 (2.8)	0.06	0.11
General	0.3 (3.0)			-0.3 (2.8)		
Anxiety management advice:						
Advice	0.1 (2.8)	0.31	0.19	0 (2.6)	0.33	0.25
No advice	0 (3.2)			0.1 (3.0)		
Helgeson's social support scores						
Instrumental support:						
Worsening	0.6 (3.2)	0.61	0.60	0.6 (3.4)	0.78	0.56
No change	-0.2 (3.0)			-0.1 (2.5)		
Improved	0.4 (2.6)			-0.3 (3.0)		
Informational support:						
Worsening	0.2 (3.2)	0.57	0.45	0.4 (3.4)	0.03	0.04
No change	0.2 (3.0)			0 (2.4)		
Improved	-0.1 (2.6)			-0.3 (2.6)		
Emotional support:						
Worsening	0.4 (3.0)	0.24	0.18	0.7 (3.5)	0.37	0.40
No change	-0.1 (3.0)			-0.3 (2.5)		
Improved	0.3 (2.6)			0.2 (3.0)		
Negative interactions:						
Worsening	1.0 (3.0)	<0.001	<0.001	0.7 (2.9)	0.003	0.003
No change	-0.3 (2.7)			0 (1.9)		
Improved	-0.5 (3.1)			-0.7 (2.9)		

*From hospital anxiety and depression scale.

†P values are presented from two general linear models. "Not corrected" is from a model of change in anxiety (or depression) score as a function of the three intervention factors and changes in social support scores (continuous factors). "Corrected" is as above but also corrected for the following factors: cancer type (breast or prostate), age (continuous factor), time (in weeks) since diagnosis (continuous factor), attitude to information, newspaper read, coping style (monitoring or blunting), "Did it change your ideas?" and "Shown it to significant others?"

from -10 to 7, in instrumental support from -8 to 7, and in "negative interactions" from -11 to 22. On the "negative interactions" scale, 42% of patients with personalised information deteriorated, compared with only 24% of those with general information only. Patients who were given anxiety management advice were more likely to have deteriorated on the instrumental support scale than those not given the advice (27% v 13%).

Changes in anxiety and depression—At follow-up, 145 patients (45%) had improved anxiety scores. The percentage improvement ranged from 33% (13/39) in those given automatically produced, personalised information with anxiety management advice to 55% (21/38) in those given automatically produced, general information with no anxiety management advice, but there were no significant differences between the three intervention factors (allowing for interactions between these). There was no difference between mean anxiety scores at baseline (5.9) and follow-up (6.0), nor in the percentage of patients with scores ≥ 8 at baseline (31%) and follow-up (33%). None of the three intervention factors was a significant predictor of change in anxiety in a general linear model (table). Patients who had worsening negative interactions had worsening anxiety ($P=0.005$). There was no difference between mean depression scores at baseline (3.4) and follow-up (3.4), nor in the percentage of patients with scores ≥ 8 at baseline (14%) and follow-up (13%).

Discussion

This study's hypothesis was generated from our previous work⁶ in which the percentage of cancer patients with anxiety declined among those given personalised information, whereas it remained the same for those given general information only. Those with personalised information were more likely to have shown it to someone else, and we hypothesised that this might lead to improved social support and reduced anxiety.

From our current study, patients with personalised information were more likely to think that it told them something new, but the difference in satisfaction between personalised and general booklets was less obvious than previously. Automatically produced booklets were preferred to shorter ones chosen interactively. There was clear evidence that patients were more likely to show personalised information to confidants and to think that it helped in discussion, but this was not reflected in improvement in measures of social support.

Cross sectional analysis of the data at recruitment and follow-up provides evidence that the quality of the relationship between patients and their confidants (as measured by the "negative factors" scale) was significantly associated with their level of anxiety and depression. This measure was a significant predictor, independently, of who the confidant was or whether the patient lived alone. Furthermore, worsening

What was already known on this topic

Anxiety and depression are important comorbidities in cancer and may be affected by provision of information about cancer and by social support

Patients may have different information preferences and coping styles that need to be taken into account in the way cancer information is presented

What this paper adds

Patients found greater amounts of automatically selected information about cancer more useful than lesser amounts chosen by themselves

The study confirmed that patients were more likely to show information personalised to confidants and others, but a hypothesised link between showing information to confidants and improved social support was not found

This study, unlike an earlier one, showed no difference in anxiety levels between intervention factors, including anxiety management advice

anxiety was associated with worsening negative interactions.

Comparison with previous study

Unlike in our previous study, we found no overall improvement in patient anxiety in this study. The percentage of patients with anxiety at recruitment was lower (31% *v* 38%) but did not change. Patients in the present study were generally better informed than five years previously which might partly explain the lower level of anxiety at baseline, but it cannot explain the absence of the differential effect of personalised versus general information.

Implications of results

In the previous study all patients were encouraged to write a list of questions to ask their oncologist one week after the intervention. Other researchers have shown the possible beneficial effect of prompt sheets and written lists on anxiety.⁹ Although the use of written lists in our previous study was applied to all groups, it may have led to further reduction in anxiety and possibly had a greater effect in those with personalised information. The other explanation is a chance effect in our earlier study.

The single “information intervention” with anxiety management advice in this study did not reduce levels of anxiety. More proactive methods of cognitive behaviour therapy are more likely to be worth while in the management of cancer related anxiety. Patients’ coping style and information preferences did not seem to have a strong effect on the impact of the different types of information.

Conclusions

Our present and previous studies suggest that the claim that patients like personalised information and are more likely to show it to their confidant is robust. However, further research is needed into the effects of sharing information on patients’ social support and anxiety.

We thank the patients who helped with the study; Joanna Rule for permission for the use of CancerBACUP booklets; Anna Leibowitz and others at CancerBACUP for comments on the study, radiographers and all other colleagues at the Beatson Oncology Centre, Glasgow; colleagues at the University of Plymouth who commented on the paper; colleagues on email lists who visited our website (www.macs.hw.ac.uk/~diana/paccit/index.htm) and commented on the study design; and Anne Anderson and the PACCIT programme (www.paccit.gla.ac.uk/) for support.

Contributors: See bmj.com

Funding: This study was funded by the ESRC/EPSRC People at the Centre of Communication and Information Technology (PACCIT) programme (Grant number L328253024).

Competing interests: None declared.

Ethical approval: The Western Local Research Ethics Committee approved the study.

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(Accepted 26 January 2006)

doi 10.1136/bmj.38807.571042.68

Endpiece

A match for heaven and earth?

The shallow knowledge that is the fashion classifies medicine as a mere technical skill. This shows unawareness that the power of a doctor in aiding the world may be a match for that of Heaven and Earth.

Why?

Heaven and Earth give life to men but cannot make men free of sickness. When men are sick they beseech Heaven; Heaven is unmoved. They call upon Earth; Earth is silent. If their sickness does not abate, they must turn back and seek healing from a doctor. With a doctor—if one finds the right man for it—agonising pain will cease, the emaciated will grow stout and strong, and those on the verge of death will not die. Is it wrong to say that the physician’s power is a match for that of Heaven and Earth?

Valerie Hansen in *The Open Empire, a History of China to 1600* (Norton, 2000) notes a Yuan temple inscription cited by Robert Hymes in “Not quite gentlemen? Doctors in Sung and Yuan” *Chinese Science* 1987;8:53

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