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Research note

Does writing a list help cancer patients ask relevant questions?

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Abstract

We examined the use of written lists to give patients an opportunity to have their questions answered. Patients undergoing radical radiotherapy for cancer were given a sheet of paper with the simple prompt to write questions and give to the hospital doctor at their appointment 3 weeks later. At 3 months, patients were asked about their use and opinions of the written list. About half of the 478 patients attended with a written list. Fewer patients living in deprived areas used the list compared to more affluent areas. Doctors thought that 34% of patients would not otherwise have asked those questions and 91% of prompted discussions were a worthwhile use of time.

1. Introduction

Many cancer patients, particularly the less educated do not always get the information that they want from consultations. Some have difficulty asking doctors direct questions [1]. Improving patient information is a recognised goal which can be addressed by providing new sources of information, such as touch screen computers [2], videos, or tapes of consultations [3], or by continuing clinical education. The use of checklists [4] and written lists [5,6] has been tried to give patients an opportunity to have their questions answered, although not all doctors like the idea [6]. We have examined the use of written lists amongst cancer patients.

2. Methods

Five hundred and twenty-five patients undergoing radical radiotherapy treatment for breast, cervical, prostate or laryngeal cancer were recruited to a randomised trial of computer based information [2]. Data collected at recruitment included demographic details, newspaper read, and the hospital anxiety and depression scale [7]. Deprivation scores

were identified using postcode of residence [8]. After the randomised intervention [2], all patients were given a sheet of paper with the simple prompt to write questions and give to the doctor at their 3-week appointment. This also reminded doctors to complete a questionnaire about the patient. At 3 months, patients were asked about their use and opinions of the written list.

3. Results

Two estimates can be made of the level of use of the written lists. Of 478 patients who remained in the study at the 3-week consultation we retrieved 341 (71%) doctor questionnaires. Doctors said that 157 (46%) patients had attended with a written list, wanting to discuss questions. Of 438 patients followed up at 3 months, 410 answered questions about the list. Of these, 238 (58%) remembered using the list. There was no difference between these declared users and other patients by gender, age (<60, 60+), cancer site (breast versus other), newspaper read (tabloid versus broadsheet), anxiety or depression (case or borderline case versus other). Fewer patients living in deprived areas used the list (64% of deprivation categories 1–3 versus 53% of 4–7; $\chi^2 = 5.1$; 1 d.f.; $P = 0.02$).

Of 157 patients using the list, doctors did not think that 54 (34%) patients would have asked those questions without it. There was no difference by age, gender, deprivation

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Table 1

Patient use and views on the written list, showing age and type of cancer (B: breast, P: prostate, L: laryngeal, C: cervical) of patient making comment

Site, age	
Examples of questions asked by patients where the doctor thought they would not normally have asked these questions	
B, 56	Since my operation to remove the cancer, do I describe myself as still having breast cancer, or having HAD breast cancer? Other people I have known, who have had similar problems, later developed 'arm' problems: swelling and heavy and ached. Is this relative to breast cancer and what of the consequences if this should happen?
C, 43	When should I think about returning to work. Dr. X mentioned earlier at my initial consultation. I am thinking of visiting family in X to help me recuperate after treatment. Will it be alright?
B, 55	What happens after treatment finishes?
B, 69	Slight rash: normal? Had shingles in this area 15 months ago. Fact sheet on tamoxifen?
P, 53	I have a sore back passage. Can I put cream on it? If so, what? Can the treatment give a reaction to skin, i.e. when wearing plaster as I have had a reaction on my arm?
L, 63	What type of cancer? Possible causes of cancer? Radiotherapy (palliative)? Radiotherapy how many?
Examples of questions listed which doctors rated as not a worthwhile use of their time	
B, 55	I would like to know what kind of breast cancer I have and what my chance is of a full recovery?
B, 37	As part of my general understanding of my treatment I would like to know what the difference is between the initial treatments, then the four more intensive radiotherapy? How soon after my treatment (chemotherapy and radiotherapy) is finished would it be safe for me to have vaccinations (typhoid and hepatitis A) for travelling abroad?
B, 58	What is the long-term side effects of my treatment. Is there any way I can stop the cancer coming back. Does stress play any part in cancer?
Patient opinions of the written list at 3 months follow-up	
Patients who supported the idea	
B, 56	I think this is a great idea. Everyone has wee niggles in their mind and getting these sorted out helps you cope with everything else
B, 40	Yes, because often you forget what you actually wanted to query
P, 71	A good memory aid
Suggestions on how it should be used	
B, 51	I would have preferred to keep the checklist and used it as a prompt. This would have empowered me more as it was difficult to remember everything I have written down. The interview with the doctor was interrupted by a colleague who came to discuss staffing problems. I had to sit for 10 min in the room; my checklist would have come in handy as a memory aid
P, 53	If it was in the day before so they could look at it beforehand
Patients who doubted it would make much difference	
B, 47	The doctor has not got time to spare each patient
P, 72	Since the doctors seemed to be very busy all the time I do not think they would have much time to study checklists

category, newspaper read, anxiety, or depression, between these 'empowered' patients and the rest. Doctors thought 38% of list-users had longer than average consultations, compared to 10% of non-list-users ($\chi^2 = 37$; 2 d.f.; $P < 0.001$). However, doctors said that 91% of the prompted discussions were a worthwhile use of time. There was no difference in nature of questions rated as not worthwhile (Table 1). Of the 379 patients who remembered the list, 234 expressed no opinion, 122 thought it was, and 23 thought it was not, a good idea. Amongst the 23, many perceived lack of doctor's time as the reason.

4. Discussion

Despite being asked to write a list of questions as part of a randomised trial, only about half of the patients used the opportunity. Those from affluent areas were more likely to do so. Fleissig's study highlighted the difficulties outpatients have in asking questions and discussing topics fully at their initial consultation, even when they have thought of

questions in advance as in this study [5]. However, in our study simple prompts to cancer patients to write a list of questions demonstrated reasonable success with, according to doctors, over a third of patients being empowered to ask questions they would not otherwise have asked. Doctors thought it may lead to slightly longer consultations but with few exceptions, felt this was a worthwhile use of the consultation. Assessment of those exceptions shows no obvious reason for being rated not worthwhile. Hypothesised reasons include errors in form filling, doctor's stress, wishes to delegate explanation to the specialist nurse, or lack of understanding about patient's continuing concerns.

4.1. Practice implications

Although our outcome measures were fairly 'crude' and the intervention had only limited success, the cost and negative impact of encouraging patients to bring written lists to the consultation is minimal. This would be worth further evaluation in routine practice. In particular, further

research is needed on how to empower patients from deprived areas to obtain the information they want.

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