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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
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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