Experiences of patients with false positive results from colorectal cancer screening

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SUMMARY. A survey was conducted to study the experiences of patients with false positive results for colorectal cancer. The study patients were participants in a randomized trial of compliance with different methods of colorectal cancer screening by faecal occult blood testing. Fifty four out of fifty six patients (96.4%) with false positive results agreed to be interviewed. An age and sex matched control group of 112 patients with negative test results was identified — 92 (82.1%) returned questionnaires. Thirteen of the patients with false positive results (24.1%) and 19 controls (20.7%) were to some extent distressed by the initial letter inviting them to participate in the screening programme. Thirty seven of the patients with false positive results (68.5%) felt some degree of distress at the initial positive test result and 19 (35.2%) some distress because of delays experienced in the process of being screened. Ten false positive patients had colonoscopy and the median waiting time for this procedure was 10 days — half of the patients found this wait distressing. Nevertheless, 53 of the patients with false positive results (98.1%) felt that it had been worthwhile to have had the test. Generally, colorectal screening was as acceptable to the patients who experienced false positive results as to those with negative results.

Introduction

IT is of great importance to evaluate the costs as well as the benefits of screening tests. Screening may be disruptive to patients, may involve procedures that are inherently distressing or distasteful or may alter subsequent health behaviour.[1] Adverse psychological consequences are most likely in patients initially identified by tests as positive but subsequently discovered not to have the disease.[2] Patients experiencing false positive results in screening programmes for hypertension[3] and for neural tube defects in pregnancy[4] subsequently reported elevated levels of distress. This distress needs to be assessed alongside evidence of the impact of the screening test upon morbidity and mortality. Above all it should be determined whether the adverse psychological aspects of screening, including distress, are regarded by patients as acceptable.

Faecal occult blood tests have been strongly advocated as a means of early detection of colorectal cancer.[5] However, a beneficial effect on mortality has yet to be proven by a randomized trial and neither the economic nor the non-economic costs of colorectal screening have been sufficiently examined.[6,7] There may be particular problems with this screening test as most people find handling faeces distasteful, the dietary restrictions required may cause disruption, and there may be pain, discomfort and distressing delay for those patients with an initial positive test for whom referral to hospital for colonoscopy is required.[8]

This paper reports the experiences of patients with false positive results from faecal occult blood screening. The distress experienced by these patients and the acceptability of the test was compared with the results for patients with a negative test result.

Method

The study patients were participants in a randomized trial of compliance with different methods of colorectal cancer screening by faecal occult blood testing. They were patients aged 40–74 years of a group practice based in a health centre in an Oxfordshire market town. They had all been sent one of three faecal occult blood kits: Haemoccult II (Kline Beckman), Early Detector (Warner Lambert) or Coloscreen Self-test (Cambridge Self Care Diagnostics). The results of the latter two tests were evaluated by the patients but Haemoccult II was sent to the laboratory which sent the results direct to the patient. Half of the patients receiving each kit were asked to restrict their diet (primarily avoiding red meat, fish and certain fruit and vegetables) to maximize the performance of the test. All patients with a positive test result were instructed to contact their general practitioner. General practitioners were asked to refer patients who had restricted their diet and had strongly positive Haemoccult tests for colonoscopy. All other patients with positive tests were asked to undertake six daily Haemoccult tests of their faeces on two separate occasions one month apart, while restricting their diet. The results for these tests were taken to the surgery for interpretation. Patients whose results were positive a second time were referred to the hospital for colonoscopy. Referral to hospital for colonoscopy was on an open-access basis to minimize delays.

One thousand eight hundred and forty two patients were invited to participate in the initial screening. For 79 patients the invitation was returned marked 'gone away'. Of the remaining 1763 patients approximately half (931, 52.8%) accepted the invitation. Sixty seven patients were identified by the first test as positive. Three patients proved to have bowel cancer (true positives) and were excluded from this study. The general practitioner indicated that four patients were inappropriate for interview on the grounds of other illness or domestic situation and four patients had not completed their follow up when the study commenced. Fifty six patients identified by the initial test as positive but subsequently found either by the diet controlled

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test or by colonoscopy to be negative were therefore included in the study: 22 (37.3%) were women. A letter was sent to these 56 false positive patients inviting them to participate in a research interview. Fifty four (96.4%) agreed to participate and were interviewed at home by an experienced research nurse (specifically trained in interview techniques) using a structured interview schedule. The interview schedule covered the following topics: initial reactions to the invitation to participate in screening; feelings about and interpretations of the first and subsequent tests; problems of adherence to dietary restrictions; experiences of and feelings about delays at various stages; experiences of the hospital visit for colonoscopy; and overall views of the test and of the value of medical screening generally.

In addition, 112 patients screened as negative by the initial test were individually matched with the false positive patients for age (plus or minus one year) and sex and were identified as controls. Two controls per false positive patient were selected in order to obtain a bigger sample for the more common experience of a negative result. These controls were sent a postal questionnaire containing identical questions to those asked of the false positive patients about their experiences of the screening procedure. Ninety two controls (81.1%) completed and returned the questionnaire.

In view of the incomplete response from the controls, the groups were compared on an unmatched basis so that all respondents could be included. The median age of the false positive respondents was 53.4 years and of control respondents 54.9 years. Using the registrar general's classification of occupations, more of the subjects were classified as social class 4 or 5 than controls (12, 22.2% versus five, 5.4%). This difference may reflect social class differences in interpreting self reported tests as well as differences in morbidity and questionnaire response. No adjustment for social class was attempted in the analysis as the numbers in the study were relatively small and no consistent effect of social class was observed on the variables reported.

The confidence intervals given are based on the exact limits for the binomial distribution given in Geigy scientific tables. The chi-squared test of significance was used.

Results

A minority of patients in both groups were distressed by the receipt of the initial letter inviting them to participate in colorectal screening — 13 in the false positive group (24.1%) and 19 in the control group (20.7%). Five patients in the control group (5.4%) but none of the false positive group were annoyed by the initial letter; the rest of the sample described their reactions as either pleased or neutral. At the time of receiving the letter all of the patients in the false positive group and 85 controls (92.4%) had felt that the test was a good idea. However, 10 of the false positive patients (18.5%) and 13 controls (14.1%) felt concerned that they had been selected to participate in the screening programme for a special reason.

The majority of the patients with a false positive result were distressed to some extent by the result of the first test (Table 1); 12 (22.2%) described themselves as very or quite worried that the test meant that they might have cancer. On the other hand at this stage 38 patients (70.4%) already felt that the test might be a false alarm arising from 'piles' or other causes less serious than cancer. The median length of time between completing the test and seeing the doctor was two days (range 0 to 11 days) and only six patients (11.1%) felt any distress arising from this period of waiting.

Fifty three patients undertook the second series of occult blood tests which required a restricted diet (one patient was referred immediately for colonoscopy). The majority of the sample felt some level of disruption to daily life arising from the dietary restrictions (Table 1). Seventeen patients (32.1%) found some difficulty in planning and keeping to the required diet and six (11.3%) forgot to keep to the diet at some stage.

Table 1. Extent of distress, worry and disruption reported as a result of the screening process by the 54 patients with a false positive result.

	Number (%) of patients	95% CI (%)
How distressed were you at the initial result?		
Very	5 (9.3)	3.1–20.3
Quite	9 (16.7)	7.9–29.3
Slightly	23 (42.6)	29.2–56.8
Not at all	17 (31.5)	19.5–45.6
At that stage how worried were you that you might have cancer?		
Very	3 (5.6)	1.2–15.4
Quite	9 (16.7)	7.9–29.3
Slightly	25 (46.3)	32.6–60.4
Not at all	17 (31.5)	19.5–45.6
How disruptive was the diet?[a]		
Very	2 (3.8)	0.5–13.0
Quite	3 (5.7)	1.2–15.7
Slightly	23 (43.4)	29.8–57.7
Not at all	25 (47.2)	33.3–61.4
How distressed were you by delays in the whole process?		
Very	2 (3.7)	0.4–12.7
Quite	3 (5.6)	1.2–15.4
Slightly	14 (25.9)	15.0–39.7
Not at all	35 (64.8)	50.6–77.3

[a] n = 53 for this question as one patient did not follow the diet.
CI = confidence interval.

Nine patients had positive results on the second test and in total 10 patients were referred to hospital for colonoscopy. The median waiting time for the hospital appointment was 14 days (range one to 21 days). Five of the 10 patients found that this wait was distressing. At this stage only two patients were unworried by the possibility of cancer. Only one patient felt pain and discomfort during the colonoscopy procedure and five patients experienced subsequent abdominal pain. Six patients were found to have polyps.

When asked about their degree of distress with delays in the whole screening process 19 false positive patients (35.2%) felt some degree of distress (Table 1). They were also asked whether they were left with any serious worries and three patients (5.6%) reported such worries.

Both the patients with a false positive test and the controls were asked about their overall feelings with regard to being screened — only one false positive patient (1.9%) and four controls (4.3%) felt angry or annoyed by the experience of the test. Fifty three false positive patients (98.1%) and all of the controls felt that it had been worthwhile to have the test. Only one of the false positive patients (1.9%) and four controls (4.3%) felt that it would not be important to go to the doctor if they experienced bleeding of the rectum in the next year (Table 2). Similarly, only two of the false positive patients (3.7%) and none of the controls said that because of their experience they would be less likely to take part in similar medical screening procedures in future. With regard to their attitudes to screening tests generally, both groups felt them to be worthwhile and a good idea.

Table 2. Attitudes to screening among patients with false positive and negative results.

	Number (%) of patients	
	False positive patients ($n=54$)	Negative patients ($n=92$)
If you were to experience bleeding from the rectum within the next year, how important would you think it to go to the doctor?		
Very important	49 *(90.7)*	63 *(68.5)*
Important	4 *(7.4)*	25 *(27.2)*
Not particularly important	0 *(0.0)*	4 *(4.3)*
Not at all important	1 *(1.9)*	0 *(0.0)*
	(χ^2 = 8.3, 1 df, $P<0.01$)	
Do you feel this experience has influenced whether you would take part in other medical screening?		
More likely to take part	21 *(38.9)*	49 *(53.3)*
Made no difference	31 *(57.4)*	43 *(46.7)*
Less likely to take part	2 *(3.7)*	0 *(0.0)*
How worthwhile do you think it is for doctors to conduct such tests?		
Very worthwhile	52 *(96.3)*	79 *(85.9)*
Quite worthwhile	2 *(3.7)*	13 *(14.1)*
Not very worthwhile	0 *(0.0)*	0 *(0.0)*
Not at all worthwhile	0 *(0.0)*	0 *(0.0)*

Discussion

Studies of outcome of screening tend to focus on conveniently measured quantities such as mortality and financial costs, and overlook other dimensions such as psychological costs.[9] This study was conducted to establish the extent of distress experienced by patients who proved to be false positive when screened for colorectal cancer, and to examine whether the experience of the test was acceptable to this group of patients. The results indicate that a minority of patients may experience distress, particularly arising from fears of cancer provoked by the initial test result. Such concerns are increased in the patients who are required to be investigated by colonoscopy.

In faecal occult blood screening the patient is expected to take responsibility for the procedure and for dietary restrictions. Studies of extent of compliance with the test have produced widely varying rates[10] and in this study a substantial number of patients found difficulty with or forgot to keep to the dietary restrictions required to maximize the efficiency of the test. Despite such problems, the patients with a false positive test found the experience of screening as acceptable as the control group. The great majority of both groups reported the screening to have been worthwhile, felt that their experience had not diminished their readiness to participate in other medical screening tests and generally approved of the principle of screening. Thus, patients with a false positive test who had welcomed or accepted the initial invitation to participate in the screening did not become more critical of screening as a result of their experiences. It is possible that the six patients who were found to have polyps viewed themselves as having been saved from cancer rather than as 'victims' of a false alarm.

It is of significance that many patients felt that screening had been worthwhile and retained the view that screening in general was very worthwhile despite the distressing experiences arising from false positive results. It may be that attitudes were not accurately reflected in the results obtained from interviews as the interviews were conducted after the alarm had been proved false. It is likely that more people would have reported distress if they had been interviewed at the time of the event. Against this, it can be argued that it is longer term psychological distress which is the chief concern. It is also important that the interviews were conducted by a trained interviewer who was able to clarify potential misunderstandings in questionnaire items. Moreover patients' views were obtained by a number of different questionnaire items and the similarity of results suggests some convergent validity. The possibility that using an interview for one group and a postal questionnaire for the other biased the results was not directly examined, but was unlikely to be responsible for the very favourable responses of the interviewed group compared with the patients with negative results. It is also worth noting the results of a study of women's reactions to the experience of identification of abnormal cells from cervical screening in which a minority of women experienced significant distress arising from the screening process.[11] All of the women, however, remained very favourably disposed to the principle of screening.

It is of some concern that 4% of those with a negative test result should feel that it was not particularly important to go to the doctor if they experienced bleeding of the rectum. Although the numbers are small, this may be an instance of false reassurance arising from a negative test.

The results of this study suggest some practical considerations which might reduce distress. Some patients thought that there may have been a special reason why they had been asked to participate. The invitation should explain the process of patient selection more clearly. Other patients were distressed by the period of delay before they could take their positive test result to the doctor. Consideration needs to be given to ways of making appointments more convenient for patients in this situation. It is encouraging that only two patients were sufficiently distressed by their experiences to be less likely to take part in other medical screening tests. However, it must also be remembered that this was a research intervention in which particular care may have been taken to communicate with patients and to respond to concerns. General practitioners must therefore monitor carefully the possibly adverse consequences of this and similar screening interventions.

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