SHORT REPORT

Carcinoembryonic antigen (CEA) testing in colorectal cancer follow up: what do patients think?

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The carcinoembryonic antigen (CEA) blood test is included in most colorectal cancer follow up protocols, despite little clear evidence for its cost-effectiveness and survival benefit. In this study, patients' views were sought on the use of the CEA blood test in their follow up. Strong associations were found between the age of a patient's children and their concern about cancer recurrence and between concern about recurrence and anxiety about CEA test results ($p < 0.0001$). Many patients expressed a desire for prognostic information, however uncertain or poor. Patients' views should be sought when designing colorectal cancer follow up protocols to ensure their needs are adequately addressed.

In this study we aimed to increase knowledge of patients' attitudes and preferences towards carcinoembryonic antigen (CEA) monitoring. Much debate has recently surrounded the routine use of serum CEA testing in the follow up of patients who have undergone potentially curative treatment for colorectal cancer. In the past few years, evidence for the benefit^{1,2} and cost-effectiveness³ of intensive follow up has grown. Earlier detection of relapse in colorectal cancer leads to improved survival primarily through detection of resectable recurrences.¹ Although surveillance computed tomographic scanning appears to confer the most benefit in this setting, around 20% of patients have an elevated CEA as the first indication of relapse.² There is little doubt, therefore, as to the usefulness of the CEA test, but an absolute benefit in terms of survival has yet to be

demonstrated. Results of an ongoing randomised trial (FACS) addressing this issue are awaited.

The attitudes of colorectal cancer patients to follow up have been previously studied, with patients generally reporting a strong preference for follow up, even if it did not lead to earlier detection of recurrence and despite any anxieties provoked by the follow up visit.⁴ The attitudes of patients towards specific investigations, notably the CEA blood test, have not been formally examined. Expanding knowledge in this regard will help to address more effectively the information needs of patients on this subject.

PATIENTS AND METHODS

In view of the lack of any existing research tool which would be suitable for this purpose, we designed our own questionnaire which was reviewed by the multidisciplinary colorectal cancer team. Following a pilot exercise, in which 20 patients in a district general hospital oncology clinic were questioned,⁵ 100 patients attending an oncology clinic in a regional cancer centre (Edinburgh) for colorectal cancer follow up were enrolled in this study. All patients had had curative resection of a colonic or rectal primary cancer, and the majority had also had adjuvant chemotherapy and/or radiotherapy. Patients were excluded from the study if CEA monitoring was deemed inappropriate in their case (for example, unfit for intervention), if they were known to have metastatic disease, or if it was anticipated that they would find the questionnaire distressing. The study was approved by the local research ethics committee. Written informed consent was obtained, then a questionnaire given.

Table 1 Patient characteristics and their association with fear of cancer recurrence and concern about the carcinoembryonic antigen (CEA) blood test

Patient characteristics	No. of patients (%) n = 91	No. of patients concerned about recurrence (%)	p Value	No. of patients concerned about CEA test (%)	p Value
Sex					
Male	64	13 (20)	0.52	11 (17)	0.23
Female	27	6 (22)		4 (15)	
Age					
≤ 60 years	32	3 (9)	0.07	7 (22)	0.8
61–70 years	39	7 (18)		5 (13)	
> 70 years	20	8 (40)		3 (15)	
General health					
Poor/fair	9	1 (11)	0.06	1 (11)	> 0.2
Good/excellent	82	18 (22)		14 (17)	
Marital status					
Married/cohabiting	76	17 (22)	0.64	14 (18)	0.64
Single/divorced/widowed	15	2 (13)		1 (7)	
Children					
≥ 21 years old	64	14 (22)	0.034	10 (16)	0.06
< 21 years old	10	5 (50)		4 (40)	
Age not stated	4				
Time since curative resection					
≤ 3 years	77	17 (22)	0.06	15 (19)	> 0.5
> 3 years	14	2 (14)		0	

Table 2 Distribution of questionnaire responses from 91 patients on follow up following curative treatment for colorectal cancer

Questionnaire responses							
Number of patients (%) n = 91							
Do you worry that the cancer may come back?							
A lot	4 (4%)	Somewhat	15 (17%)	A little	58 (64%)	Not at all	14 (15%)
Would you wish to have the test even though it sometimes fails to pick up a recurrence?							
Yes	90 (99%)	No	0	Don't know	1 (1%)		
Would you wish to have the test even though it may cause undue worry by being falsely positive?							
Yes	90 (99%)	No	0	Don't know	1 (1%)		
When you have a blood test at the clinic, do you worry about the result?							
A lot	8 (9%)	Somewhat	7 (8%)	A little	39 (43%)	Not at all	37 (40%)
How reassured are you by a normal CEA test result?							
A lot	49 (54%)	Somewhat	23 (25%)	A little	13 (14%)	Not at all	2 (2%)
						No answer	4(4%)
Out of 100 patients with a recurrence, how many would need to be curable before you would consider the test worth taking?							
100	4 (4%)	50	19 (21%)	10	19 (21%)	1	38 (42%)
						No answer	10 (11%)
If you had no symptoms but a blood test told us your cancer was back, would you wish to know, even if we could not cure you?							
Yes	88 (97%)	No	0	Don't know	0	No answer	3 (3%)

The questionnaire sheet contained information about the CEA blood test, including explanations as to the meaning of false positives and false negatives, followed by questions on demographics, general health, concern about recurrence and specific questions regarding the CEA blood test. All questions, including demographic questions, were categorical, with patients being asked to circle the most appropriate answer. One hundred and eight consecutive eligible patients were approached with a view to possible study entry, and 100 of these consented to participate. Ninety-one anonymous questionnaires were completed in the clinic waiting room or returned by post.

RESULTS

Patient characteristics are detailed in table 1 along with answers to questions regarding their concerns about disease recurrence. Statistical analysis was carried out using χ^2 test statistics except for data relating to gender, marital and family status, to which the Mann-Whitney test was applied. Questionnaire responses are detailed in table 2. There was a strong association between the age of a patient's children (under 21) and their concern about cancer recurrence. The cut-off of age 21 for patients' children was pre-determined and chosen by the investigators as an age at which most offspring are likely to be independent of their parents. The results suggest a trend towards increased concern about cancer recurrence in patients treated more recently, those in good health and in older patients. Concern about the CEA test result was strongly correlated with concern about cancer recurrence ($p<0.0001$).

DISCUSSION

The majority of patients wish to have the CEA blood test as part of their routine follow up for colorectal cancer, despite concerns regarding its sensitivity and specificity and the relatively low cure rate of recurrent disease. In particular, patients with younger offspring were significantly more concerned about cancer relapse than any other group. The trend towards increased concern in older patients is somewhat curious in view of the results relating to the age of offspring. In the analysis of multiple variables in a relatively small sample population, it is possible that the significant associations observed could have occurred by chance. Nonetheless, the trends observed are of interest and can help inform clinicians in planning follow up protocols and in communicating information regarding surveillance tests to their patients. In their

What is already known on this topic

Intensive follow up following curative resection for colorectal cancer is cost-effective and improves survival. The cost-effectiveness and survival benefit of the CEA blood test in colorectal cancer follow up is uncertain.

What this study adds

The majority of patients wish to have the CEA blood test as part of their follow up, despite the low cure rate of recurrent colorectal cancer. Patients with younger children are more likely to experience anxiety about recurrence of their colorectal cancer.

answers and comments, many patients expressed a desire for knowledge about their prognosis, however uncertain or poor. Any survival benefit (or lack of) as a result of CEA testing must be considered alongside the views of patients when making decisions regarding follow up procedures, and their information requirements should be carefully addressed.

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