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ARTICLE

Cancer fear: facilitator and deterrent to participation in colorectal cancer screening

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Abstract

Background: Cancer fear has been associated with higher and lower screening uptake across different studies, possibly because different aspects of cancer fear have different effects on intentions versus behaviour. The present study examined associations of three aspects of cancer fear with intention and uptake of endoscopic screening for colorectal cancer.

Methods: A sub-sample of UK Flexible Sigmoidoscopy (FS) Trial participants received a baseline questionnaire that included three cancer fear items from a standard measure asking if: i) cancer was feared more than other diseases, ii) cancer worry was experienced frequently, and iii) thoughts about cancer caused discomfort. Screening intention was assessed by asking participants whether, if invited, they would accept an invitation for FS screening. Positive responders were randomised to be invited or not in a 1:2 ratio. The behavioural outcome was clinic-recorded uptake. Control variables were age, gender, ethnicity, education, and marital status.

Results: The questionnaire return rate was 60% (7,971/13,351). The majority (82%) intended to attend screening; 1,920 were randomised to receive an invitation, and 71% attended. Fearing cancer more than other diseases (OR=2.32, $p<.01$) and worrying a lot about cancer (OR=2.34, $p<.01$) increased intentions to attend screening, but not uptake. Finding thoughts about cancer uncomfortable did not influence intention, but predicted lower uptake (OR=0.72, $p<.01$).

Conclusions: Different aspects of cancer fear have different effects on the decision and action processes leading to screening participation.

Impact: Knowledge of the different behavioural effects of cancer fear may aid the design of effective public health messages.

Keywords: cancer fear; cancer worry; sigmoidoscopy; colorectal cancer; cancer screening

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Conflicts of interest

The authors declare that they have no conflicts of interest.

Introduction

Cancer fear has been implicated both as a facilitator and a deterrent to screening uptake. A meta-analysis of twelve prospective studies in breast cancer found a linear relationship between cancer fear and screening uptake (1). However, two studies examining colorectal screening uptake found no association with fear (2, 3), while other studies of breast screening (4-7), and of prostate (4) and ovarian cancer screening (8), found a curvilinear relationship; with both low and high fear associated with lower uptake.

One possible explanation for the varying results could be that the studies used different measures of cancer fear, and the effects on screening participation could vary depending on the aspect of fear examined (9, 10). Fear is best understood as a multi-dimensional construct, with loosely-coupled cognitive, biological, affective and behavioural components (11). Fear of cancer has been operationalised in many ways, for example: 'worry about cancer', 'cancer-related distress', 'intrusive and avoidant thoughts about cancer', and 'effects of cancer-related thoughts on mood and daily activities' (9). Cancer worry could promote screening uptake as a means of seeking reassurance, at least among individuals who perceive their risk as low, while avoidant or fatalistic views may be a deterrent to screening (6, 9, 10). The observed effect in any individual study could depend on the specific fear indicator used.

Several studies have used multiple item scales covering several different aspects of cancer fear, but have usually combined them into a single fear score to predict behaviour, making it difficult to assess the independent effect of individual fear components (e.g. 5, 12). However, in two studies, one of breast and one of prostate cancer, cancer worry was associated with a stronger intention to obtain screening and more frequent screening, whereas fear about screening itself and its results was associated with lower intention and less frequent screening (13, 14). Wong et al. (15) found similar relationships for colorectal cancer (CRC) in a sample of older adults in Singapore: worry was associated with higher uptake, while fear of cancer being found during screening was associated with lower uptake. A similar pattern emerged in a sample of low income Hispanic Americans (16): levels of cancer worry were higher among those who had received colonoscopy screening, while levels of fatalism were (non-significantly) higher among those who had not been screened.

No study has explicitly tested the relative contributions of cognitive, biological, and affective components of fear on screening participation. We therefore used prospective data from the UK Flexible Sigmoidoscopy (FS) Trial to examine the association between these three aspects of cancer fear and two indices of participation: intention and uptake of screening for colorectal cancer.

Materials and methods

Design

Data for this secondary analysis come from a sub-sample of participants (n=13,351) in the UK Flexible Sigmoidoscopy (FS) Trial who had been sent an extended baseline questionnaire prior to their screening invitation. Data were collected between 1996 and 1999. The UK FS Trial is a multi-centre randomised controlled trial assessing the effect of once-only FS screening in adults aged 55-64 years on CRC incidence and mortality (17, 18). It used a two-step recruitment process to increase statistical power in intention-to-treat analyses. Potential participants (n=375,744) were all adults aged 55-64 years in 506 participating General Practices (GP) across the UK. After exclusions by GPs, 368,142 participants were sent information about the Trial, together with a baseline questionnaire asking about intention to attend FS screening (*'If you were invited to have the bowel cancer screening test, would you take up the offer: yes definitely, yes probably, probably not,*

definitely not). Those who answered 'yes probably' or 'yes definitely' were randomised in a 1:2 ratio to receive an invitation for FS screening or care-as-usual, as per the Trial protocol (17). Ethics approval was obtained from the local research ethics committee for all participating centres.

Participants

Participants (n=13,351) in a sub-sample of Practices were randomly selected to take part in a psychological sub-study of the main FS trial. These participants received a longer version of the baseline questionnaire that included items on cancer fear, demographics, health, and psychosocial measures. Our sample for analyses of associations between cancer fear and screening intention consisted of this sub-sample (Sample 1). Among those who responded that they would 'probably' or 'definitely' take up the offer of screening, and were therefore entered into the randomisation schedule, 1,995 were randomised to receive a screening invitation. This constituted our sample for analyses of screening uptake (Sample 2). All participants were naïve to CRC screening, which was not part of the UK National Cancer Screening Programme at the time of the study.

Screening intention and uptake

Screening intention was based on the questionnaire responses described above (Sample 1). For the analyses of associations between fear and screening intention, responses to the screening intention question were dichotomised (yes definitely/yes probably vs. probably not/definitely not). Screening uptake was recorded in the clinic (attended vs. did not attend) for all participants randomised to be sent a screening invitation (Sample 2). Clinic records of screening attendance for those who were invited were 100% complete.

Cancer fear

Three aspects of cancer fear were assessed in the baseline questionnaire, each with a single item statement. One item reflected a more cognitive evaluation of cancer fear (*'Of all the diseases there are, I am most afraid of cancer'*), one reflected a more affective response to cancer (*'I worry a lot about cancer'*), and one was more psychobiological (*'It makes me uncomfortable to think about cancer'*). Responses were on 5 point scales: 'strongly disagree', 'disagree', 'not sure', 'agree', and 'strongly agree'. We combined the 'agree' and 'strongly agree' categories for the multivariate logistic regression analyses examining the associations of fear with screening interest and uptake, because we were interested in the effect of the presence of cancer fear. We combined the 'strongly disagree' and 'disagree' categories to create a robust reference group of people without cancer fear, because numbers for the 'strongly disagree' category were small. 'Not sure' was treated as the mid-point because it was physically placed between 'agree' and 'disagree' on the response scale on the questionnaire, but we did sensitivity analyses excluding respondents with 'not sure' responses.

Sociodemographic control variables

Demographic data included age, gender, ethnicity, educational qualifications, and marital status. Age and gender were taken from GP records. Ethnicity was assessed with the question *'which of these best describes your ethnic background'*, with response categories 'White', 'Black', 'Asian', 'Other', 'Do not wish to answer'. Numbers for 'Black' (n=99), 'Asian' (n=183), and 'Other' (n=43) were small, and therefore combined in a 'non-White' category. 'Do not wish to answer' was coded as missing. A single item was used to record education: *'do you have any educational qualifications'* (e.g. School Certificate, GCE O'Levels, etc.), with 'yes' or 'no' response options. In this cohort, born between 1932 and 1943, continuation in education would have depended on passing these examinations taken at age 16. Education is a good index of socioeconomic status (SES) in older adults (19). Marital status was assessed with *'what is your marital status'*, with response categories dichotomised into 'married or cohabiting' and 'not married or cohabiting'. For all demographics, missing data were coded as a separate category.

Statistical analysis

Percentages of respondents intending to attend (Sample 1), and attending (Sample 2), were analysed in relation to each fear indicator. Multivariate logistic regression analyses for each cancer fear indicator individually were used to examine associations with screening intention (Sample 1) and uptake (Sample 2), using the dichotomised variables for screening intention and uptake, and adjusting for differences in sociodemographic characteristics. 'Not sure' was used as mid-point for the cancer fear indicators in these analyses, but a sensitivity analysis was performed in which this category was coded as missing. We also conducted a sensitivity analysis with all categories for the fear items. Bonferroni corrections were applied to control for the family-wise error rate due to multiple comparisons, and a p-value of .01 was used to indicate statistical significance. SPSS version 22.0 was used for all analyses.

Results

Return rate of the extended baseline questionnaire was 60% (7,971/13,351). Almost all respondents (98%; n=7,780) had a valid response on the screening intention question, and 91% (n=7,327) had complete data on all three cancer fear indicators; this constituted Sample 1. Of this group, 82% intended to take up the offer of screening if invited; with 53% saying they would probably attend and 29% that they would definitely attend. A flow diagram of the inclusion process is presented in Figure 1. Among those who said they would either probably or definitely attend (6,299/7,780), 1,995 were randomised to receive a screening invitation as per the Trial protocol. The majority (96%; 1,920/1,995) had complete data on all three cancer fear indicators; this constituted Sample 2. Of this group, 71% (1,359/1,920) attended. Those who had responded 'definitely' were more likely to attend than those who responded 'probably' (80% vs. 54%).

Cancer fear and screening intention

The first set of analyses examined associations between each fear item and intention to attend in Sample 1 (n=7,327; see Table 1). There were slightly more women (54%) than men (46%) in this sample. More than half (60%) did not have any educational qualifications, the majority (93%) were from a White ethnic background, and 73% were married or cohabiting.

Overall, 59% of respondents agreed or strongly agreed that they were more afraid of cancer than other diseases, 53% agreed or strongly agreed that they felt uncomfortable thinking about cancer, and 25% agreed or strongly agreed that they worried a lot about cancer. As previously reported in this sample (20), Spearman's correlations between the cancer fear items (before the extreme categories were grouped together) were modest: between .36 and .42 (Table 2). This suggests that there is some commonality between these indicators of cancer fear but that they also tap into different aspects (20).

More respondents who reported having cancer as their greatest health fear said they intended to attend screening: 86% vs. 79% of those who were not sure, and 74% of those who disagreed (see Table 3). The same relationship was observed for cancer worry: 89% of those who worried about cancer a lot intended to attend, compared with 83% of those who were unsure, and 79% of those who did not worry about cancer. However, the pattern was different for feeling uncomfortable thinking about cancer: 80% intended to attend among those who agreed with this item, vs. 85% of those who were unsure, and 83% of those who did not agree.

Adjusted logistic regression analyses controlling for age, gender, education, ethnicity, and marital status are shown in Table 3. Having cancer as greatest health fear or worrying about cancer a lot were associated with greater screening intention. Discomfort when thinking about cancer did not affect intention to attend screening. Sensitivity analyses in which the 'not sure' category was coded as missing showed the same pattern: having cancer as the greatest health fear and worrying about cancer a lot were associated with an increased

likelihood to intend to attend screening. Discomfort did not affect screening intention (results not shown). We also repeated the analysis with all the fear categories. The results showed a similar pattern in terms of associations with screening intentions (results not shown); we chose to report the results for the largest sample size.

Cancer fear and screening uptake

The second set of analyses examined uptake among the group who had said they intended to attend screening and were randomised to be invited (Sample 2). There were slightly more women (52%) than men (48%) in this sample, the majority (58%) did not have any educational qualifications, most (93%) were of White ethnic background, and most (75%) were married or cohabiting (see Table 1).

In this group, more than half (64%) agreed or strongly agreed that they were more afraid of cancer than other diseases, 52% felt uncomfortable thinking about cancer, and 28% worried a lot about cancer. The higher percentages of having cancer as the greatest health fear and cancer worry than in Sample 1, and the slightly lower percentage of discomfort thinking about cancer, reflect the associations between these variables and screening intention.

In terms of percentages attending, those who reported higher fear on any of the three fear indicators were slightly *less* likely to actually take part in screening (Table 4). Of those who reported that cancer was their greatest health fear, 70% attended FS screening, compared with 72% for whom it was not. For cancer worry, 65% of those who reported worrying a lot attended screening, vs. 72% of those who did not worry about cancer. For discomfort thinking about cancer, 68% of those who felt uncomfortable attended screening, vs. 77% of those who did not feel uncomfortable.

In adjusted logistic regression analyses controlling for age, gender, education, ethnicity, and marital status (see Table 4), only discomfort thinking about cancer had a significant deterrent effect on screening uptake in those who had previously indicated that they intended to attend (OR 0.72 [0.56-0.91], $p < .01$). We conducted a sensitivity analysis in which the 'not sure' category was coded as missing; this showed the same pattern of results (results not shown). A second sensitivity analysis using all categories for the three cancer fear variables also showed a similar relationship between cancer fear and screening uptake. We therefore reported the analysis with the largest sample size.

Discussion

This is the largest study to date to have recorded information on cancer fear before a screening invitation was offered, to have clinic records of uptake as well as reported intention, and to explicitly compare different aspects of cancer fear. In terms of screening intention, we found evidence that the cognitive/affective aspects of cancer fear (cancer as greatest health fear, worry about cancer) were significant facilitators of screening intention, while the more psychobiological aspect (discomfort thinking about cancer) was not significantly related to screening intention. Once those who were interested in screening were invited, the cognitive/affective aspects of cancer fear did not have any residual effect on actual behaviour (screening uptake). In contrast, discomfort thinking about cancer, which had not affected intention, was a deterrent to taking part in cancer screening in this sample who had already indicated an intention to attend.

These findings lend support to the idea that different aspects of cancer fear may have different behavioural effects, but also that they may exert their effects at different stages in the decisional process. In line with results from earlier studies (13, 15, 16), we found that cancer worry facilitated screening through enhancing intention to attend – perhaps motivated by a desire for reassurance, while a more visceral negative response to thinking about a cancer acted as a deterrent at the action stage. The distinction between influences on intention and action are an important emerging area of work in helping to understand the

'intention-behaviour gap' (21). Although the behavioural effects of these three aspects of cancer fear may be different, a previous study has shown that their sociodemographic correlates are largely similar, with women, and those without educational qualifications and from ethnic minority backgrounds most affected (20). In addition to the different ways in which cancer fear is experienced (i.e. as worry, distress, intrusive thoughts, etc.), some authors have noted that there may also be individual differences in the object of cancer fear and the associated behavioural effects (e.g. fear of a cancer diagnosis, fear of dying from cancer, etc.; see for example, 10), although these distinctions were beyond the scope of the present study.

Some cross-sectional studies have assessed the effects of cancer fear by using *past* screening uptake as the outcome (e.g. 4, 5, 8). The disadvantage of this approach is that past screening results may influence subsequent cancer fear; a problem known as 'reverse causality' (9). The present study avoids the problem of reverse causality because cancer fear was measured in a screening naïve sample *before* any screening invitation. It thus contributes to our understanding of the influence of different aspects of cancer fear on intentions *and* behaviour, and also stresses the importance of measuring behaviour (and not only intentions) when assessing health behaviours.

One limitation of the present study was that data about cancer fear and screening interest were collected at the same time, meaning that the possibility of reverse causality remains an issue for the associations between cancer fear and screening interest. This causal direction can only be established through further longitudinal or interventional studies.

Our study also had other limitations. Response rate to the baseline questionnaire (60%) was good for a community-based survey, but still meant we had no information on intentions on the 40% of non-responders. Participants could see that the questionnaire was about cancer and those with higher levels of cancer fear may have been less likely to return it. If cancer fear is a cause of non-response, then the high proportions of those endorsing the fear statements would in fact be an underrepresentation of the prevalence of cancer fear in older adults. The cancer fear measures that were used were not specific to CRC. Although many previous studies have used specific CRC fear measures to determine the effect on intentions and uptake of screening (e.g. 2, 22), we had chosen more general measures because they may better reflect cancer fear as experienced by the general population (i.e. as a non-specific "fear of cancer", rather than a specific "fear of CRC"), and because they allow for future comparisons of the behavioural effects of these aspects of cancer fear across different types of cancer screening. In addition, we used single item measures. However, the moderate correlation between the items, the different endorsement rates, and the differential relationships with screening interest and uptake support the idea that the items represent different aspects of cancer fear that may need to be distinguished if we seek to understand the behavioural effects of cancer fear (9, 10).

The trial design imposed limitations because it specified only inviting respondents who expressed some interest in attending. We therefore do not know how many 'non-intenders' might actually have attended if they had received an invitation, nor whether the associations between cancer fear and screening uptake would have been similar in this group. Future studies that invite all potential participants to take part in screening – regardless of screening intentions - would reduce any bias that may have been introduced by the sampling method used in the current study. Finally, in the questionnaire, 'not sure' was presented as the midpoint of the response scale for the cancer fear indicators, between disagree and agree. This category was also used as the midpoint for the analyses. However, some participants may have interpreted this response option as 'don't know', rather than as midpoint of an agreement scale, as demonstrated by others (23). We therefore carried out sensitivity analyses omitting respondents who endorsed 'not sure', which did not change the broad pattern of results.

Conclusions

The results of this study confirm that cancer fear can be a facilitator or a deterrent, depending on the specific aspect of fear. Having cancer as the greatest health fear or worrying a lot about cancer facilitated intentions to attend, while finding thoughts of cancer uncomfortable did not affect intention but was a deterrent to actual uptake. Learning more about the make-up of cancer fear, and having more nuanced analyses of the behavioural effects, might help in the design of effective public health messages.

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Table 1. Characteristics of Sample 1 and Sample 2.

	Sample 1 N (%) [*]	Sample 2 N (%) [*]
Sample size	7,327 (100.0)	1,920 (100.0)
Age in years (mean, SD)	60.0 (2.9)	60.0 (2.9)
Gender		
Male	3,351 (45.7)	916 (47.7)
Female	3,976 (54.3)	1,004 (52.3)
Educational qualifications		
Yes	2,522 (34.4)	706 (36.8)
No	4,382 (59.8)	1,109 (57.8)
Missing	423 (5.8)	105 (5.5)
Ethnicity		
White	6,774 (92.5)	1,783 (92.9)
Not White	325 (4.4)	81 (4.2)
Missing	228 (3.1)	56 (2.9)
Marital status		
Married or cohabiting	5,326 (72.7)	1,443 (75.2)
Not married or cohabiting	1,872 (25.5)	443 (23.1)
Missing	129 (1.8)	34 (1.8)
Greatest health fear		
Strongly disagree	232 (3.2)	47 (2.4)
Disagree	1,391 (19.0)	323 (16.8)
Not sure	1,410 (19.2)	326 (17.0)
Agree	3,156 (43.1)	882 (45.9)
Strongly agree	1,138 (15.5)	342 (17.8)
Worry		
Strongly disagree	842 (11.5)	186 (9.7)
Disagree	3,578 (48.4)	929 (48.4)
Not sure	1,048 (14.3)	270 (14.1)
Agree	1,511 (20.6)	442 (23.0)
Strongly agree	348 (4.7)	93 (4.8)
Discomfort		
Strongly disagree	277 (3.8)	74 (3.9)
Disagree	1,931 (26.4)	517 (26.9)
Not sure	1,265 (17.3)	340 (17.7)
Agree	3,315 (45.2)	857 (44.6)
Strongly agree	539 (7.4)	132 (6.9)

^{*}Unless otherwise stated, values in this column represent absolute numbers and percentages of the sample.

Table 2. Spearman's correlations between the cancer fear indicators for Sample 1 and 2.

		Worry	Discomfort
Sample 1 n=7,327	Greatest health fear	.42	.38
	Worry		.36
Sample 2 n=1,920	Greatest health fear	.42	.36
	Worry		.39

All correlations are significant at $p < .001$

Table 3. Percentages, adjusted odds ratios (OR) and 95% confidence intervals (95% CI) for intending to attend FS screening ('yes probably'/'yes definitely'), by each cancer fear indicator (Sample 1; n=7,327).

	Intending attend N (%)	to Adjusted OR† (95% CI)
Sample 1	5,996 (81.8)	-
Greatest health fear	1,207 (74.4)	Ref
(Strongly) disagree	1,108 (78.6)	1.30 (1.09-1.54)*
Not sure (Strongly) agree	3,681 (85.7)	2.32 (2.01-2.69)*
Worry		
(Strongly) disagree	3,481 (78.8)	Ref
Not sure (Strongly) agree	870 (83.0)	1.38 (1.15-1.65)*
Discomfort		
(Strongly) disagree	1,645 (88.5)	2.34 (1.99-2.75)*
Not sure (Strongly) agree	1,834 (83.1)	Ref
	1,076 (85.1)	1.22 (1.00-1.47)
	3,086 (80.1)	0.88 (0.76-1.01)

* $p < .01$

† Adjusted for age, gender, education, ethnicity, and marital status.

Table 4. Percentages, adjusted odds ratios (OR) and 95% confidence intervals (95% CI) for attending FS screening, by each cancer fear indicator (Sample 2; n=1,920).

	Attended N (%)	Adjusted OR† (95% CI)
Sample 2	1,359 (70.8)	-
<hr/>		
Greatest health fear	267 (72.2)	Ref
(Strongly) disagree	238 (73.0)	1.10 (0.78-1.55)
Not sure (Strongly) agree	854 (69.8)	1.06 (0.81-1.38)
<hr/>		
Worry	807 (72.4)	Ref
(Strongly) disagree	202 (74.8)	1.19 (0.87-1.63)
Not sure (Strongly) agree	350 (65.4)	0.83 (0.66-1.05)
<hr/>		
Discomfort	456 (77.2)	Ref
(Strongly) disagree	230 (67.6)	0.68 (0.50-0.92)§
Not sure (Strongly) agree	673 (68.0)	0.72 (0.56-0.91)*

*p<.01

§ p=.012

† Adjusted for age, gender, education, ethnicity, and marital status.

Figure legends

Figure 1. Flow diagram of study inclusion