The impact of interval cancers in FOBt screening on adjustment to a cancer diagnosis and attitudes towards screening.

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Background
Nationwide screening for colorectal (bowel) cancer using faecal occult blood testing (FOBt) is offered across the UK. In order for screening to do ‘more good than harm’, adverse effects (including effects on psychological outcomes) need to be kept to a minimum. Although research to date has shown that the adverse psychological consequences of bowel screening are minimal, no work has examined how people feel after receiving a cancer diagnosis following a normal screening result using FOB testing. The aims of this research were to explore whether people are aware that bowel screening using the FOB test is less than perfect and can miss some cancers, and how this might influence their adjustment to their cancer diagnosis and levels of trust in the bowel screening programme. These aims have been achieved.

The research comprised two studies: an interview study and a postal survey. Three groups of people diagnosed with colorectal cancer in Scotland between 2000-2007 were invited to take part (in one or other of the two studies): the first two groups took part in the Scottish Demonstration Pilot of FOBt Screening for Colorectal cancer and either tested negative (the interval cancer group (I)) or positive (the screen-detected group (SD)). The third group were not invited for screening because they lived outside of the area covered by the pilot programme (the non-screened group (NS)).

Although ethical approval for this study was received relatively quickly after funding was obtained (in June 2009), the study did not start until October 2011 because approval was needed from the Privacy Advisory Committee and the Community Health Index Advisory Group. Approval from these committees took time as this study had no precedent.
Study report, 28th January 2014

Study 1: Qualitative exploration of patients’ experience of having an interval cancer.

The aim of this study was to conduct one-to-one telephone interviews with 15 patients from each of the three diagnostic groups. Interviews were conducted with 18 patients in the interval cancer group, 16 in the screen-detected group (although 1 person reported they did not receive a diagnosis of cancer) and 15 in the symptomatic group. Preliminary analysis shows that people in the interval cancer group did not feel high levels of anger about the fact they had completed a screening test but it had not detected their cancer. Understandings of why the test might have missed their cancer centred on explanations from medical staff that their cancer may not have been bleeding at the time of the test, or on interpretations of the ‘pilot’ programme they took part in i.e. that the FOBT was under development as a test for bowel cancer and was clearly not very good.

Study 2: Quantitative assessment of psychological adjustment after bowel cancer diagnosis

The original aim of this study was to send the survey to 130 people in each of the three diagnostic groups. This limit was determined by the number of people in the interval cancer group, however we increased this to 200 per group, because, by the time the study started, more interval cancers had been identified. In the end, 675 potential participants were identified and their GPs were sent the research invitation letters. 142 of the participant invitation letters were not forwarded to the patient because the GP indicated that the patient met one or more of the exclusion criteria (n=70) or the GP practice did not wish to participate in the research (n=72) leaving 533 people who were (apparently) sent a questionnaire (unless the questionnaire was returned, there was no way of confirming the questionnaires had definitely been forwarded to the patient). 311 people completed the survey, a response rate of 58.3%. Of these, 15 did not consent to have their data matched with objective data from National Services Scotland so it was unclear which diagnostic group they fell into, leaving 296 as the principle sample for analysis, a response rate of 55.5%. Completed surveys were obtained from 91 in the interval cancer group, 106 in the screen-detected group and 99 in the non-screened group.

Age, gender, Scottish Index of Multiple Deprivation (SIMD), years since diagnosis, method of diagnosis (interval, screen-detected, non-screened) and treatment received (radiotherapy, chemotherapy) were supplied by National Services Scotland (NSS) (with patient consent). Cancer-related distress (IES-R), depression (CES-D), perceptions of diagnostic delay and attitudes towards screening were measured
in the survey.

Age, gender, time since diagnosis, treatment received and SIMD were controlled for. Perceptions of diagnostic delay differed significantly between the groups (Wald =10.5; df=2; p=0.005), with higher proportions of people in the I and NS groups reporting diagnostic delay than those in the SD group. Attitudes towards screening, although still positive on average, were significantly lower in group I compared with the other two groups (F_{2,266} =47.8; p<0.001). Despite this, the SD and I groups did not differ on cancer-related distress or depression. These preliminary results show that interval cancers appear to have no direct long-term adverse effects on psychological adjustment but do result in less positive attitudes towards FOBt screening. However there is evidence from path analyses currently underway that diagnostic group has indirect effects on adjustment via perceptions of diagnostic delay: a greater proportion of both the I and NS groups reported diagnostic delay, and perceptions of diagnostic delay, in turn, are significant predictors of cancer-related distress. What this means, though, is that the interval cancer group show no differences in psychological outcomes compared with the non-screened group so there is no evidence that having an interval cancer results in poorer psychological outcomes than usually occurs when cancers are detected symptomatically. The results also highlight the emotional benefits of having a cancer detected at screening, as this can reduce cancer-related distress as a result of reduced perceptions of diagnostic delay.

**Publication and dissemination of research.**

Study 2 has already been accepted as an oral presentation at the 35th Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine, held April 23-26, 2014, in Philadelphia, USA. An abstract will also be submitted within the next two weeks to the conference: “Advances in Cancer Screening and Prevention Research” to be held in London later this year. The results of Study 2 are currently being finalised for publication. Once this paper has been submitted, the results of Study 1 will be prepared for publication.
Feedback to participants

Once the results of the studies have been accepted for publication, a copy of the results will be sent to people who expressed an interest in receiving them. (150 of the 311 people who completed a survey indicated they wanted to be sent a copy of the results and 46 of the 49 people interviewed).