Women's understanding of a "normal smear test result": experimental questionnaire based study

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BMJ 2001;322:526–8

Abstract

Objectives To describe women's understanding of a negative smear test result when presented using the term "normal smear result," as required by the NHS cervical screening programme, and to evaluate the impact on understanding of different ways of presenting the residual risk inherent in such a result.
Design Experimental questionnaire based study.
Interventions Participants were asked to imagine that they had received a normal smear result. The meaning of this result was then presented using different combinations of three different expressions of residual risk of having or developing cervical cancer over the next five years: a verbal probability of absolute risk (low risk), a numerical probability of absolute risk (1 in 5000), or a numerical probability of risk relative to an unscreened woman (five times lower).
Participants 1027 women aged 20 to 64.
Results When informed only that their smear result was normal, 52% (80 of 153 women) of participants correctly understood that this entailed a residual risk of cervical cancer, compared with 70% (107 of 152) given the additional sentence explaining the meaning of a normal smear result using a verbal probability of absolute risk (difference 18%; 95% confidence interval 7% to 29%). Additionally, explaining the results using a numerical probability of absolute or relative risk did not increase the proportion who correctly understood that there was a residual risk of cervical cancer.
Conclusions NHS policy for reporting normal smears needs to change to make it a definite requirement that the reporting of a "normal smear result" is accompanied by a sentence stating that this means a low risk for having or developing cervical cancer in the next five years.

Introduction

Failure to understand the residual risk inherent in a negative screening test result can lead to delays in seeking treatment if symptoms appear, poorer psychological adjustment to the condition for those with false negative results and, in some cases, litigation.[1 2] It is a policy of the NHS cervical screening programme that all women with negative test results are sent a letter informing them of their results. Since 1997 the policy recommendation is that such a letter should use the term "normal smear result."[3] This is to prevent the confusion caused by the use of the term "negative" to refer to an event that women would consider positive—that is, a favourable result. Reporting a negative result as a "normal smear result" is a definite requirement of the screening programme. Furthermore, it is recommended that the letter informing a woman of her result should include a statement that a normal smear result means low risk for having or developing cervical cancer, not no risk at all. This, however, is not a definite requirement, given that there is currently no evidence to support the effectiveness of this statement in achieving understanding. No national data are available on the wording of letters reporting normal smear results. We therefore do not know the extent to which this recommendation is followed. Contact with five screening centres local to the authors produced five different letters. Although all were following the policy requirement not to use the term negative smear result (three used the term "normal smear result" and two "satisfactory smear result"), only one followed the recommendation to explain the meaning of the reported result.

We aimed to describe women's understanding of a "normal smear result" and to evaluate the effectiveness of different ways of presenting the residual risk inherent in a negative smear result. Although there is much literature evaluating the impact of different ways of presenting risk information, relatively little of this has been conducted in clinical settings.[4 5] To date there has been just one study comparing the impact of presenting negative screening results using words and numbers.[6] That study found an advantage of using numbers in addition to words to convey residual risks. Our study was conducted using a general sample of women who were asked to imagine that they had received a normal smear result. This analogue method is commonly used before collecting data in a clinical setting to give some indication of the scale of a problem (in this study, not understanding the meaning of a normal smear result) and the likely effectiveness of any interventions (in this study, different ways of presenting results).

Participants and methods

Participants were recruited throughout England by a research agency (Research Initiatives). Overall, 1027 women aged between 20 and 64 years (mean 37.8 (SD 11.0)) participated in one of two experimental questionnaire studies in which they were asked to

imagine that they had recently undergone cervical screening and received a normal smear result. Refusal rates were not recorded by the agency but were estimated to be lower than 5%. In total, 94% (964 women) of participants had undergone a cervical smear test in the past and 21% (220) had received an abnormal result. Overall, 21% had no formal educational qualifications, and 9% were educated to degree level or beyond. This sample is slightly less well educated than the general population of women aged between 20 and 59 in whom 18% have no formal qualifications and 14% have a university degree (Department for Education and Employment analysis of the spring labour force survey 2000, personal communication). There were no differences in education level of women receiving the different letters informing them of their results in either of our two studies.

Study 1—In the first study, 153 women were told that their smear test result was normal, in accord with the NHS's policy; a further 152 received an additional statement explaining that this meant they were at low risk of having or developing cervical cancer in the next five years.

Study 2—In the second study, 722 women were given one of four types of letters for reporting normal smear test results. All presented the result as normal and included the additional statement from study 1 explaining that this meant they were at low risk of having or developing cervical cancer in the next five years. Using a two by two factorial design, the women's letters varied to include a numerical statement of their absolute residual risk, a numerical statement of their risk relative to women who had not had a smear test, both of these statements, and neither of these statements (table).

The different versions of the questionnaires were presented sequentially. Participants completed questionnaires unaided. The questionnaire initially asked women to imagine that they had just undergone a cervical smear test and received the letter presented in the questionnaire. Having read the letter, women were asked to state what their result meant in terms of their health now and in five years time. Both questions had six response options: I definitely do not (will not) have cervical cancer, I am very unlikely to have cervical cancer, I am unlikely to have cervical cancer, I am likely to have cervical cancer, I (will) have cervical cancer, and I don't know. Age, marital status, whether or not they had had a smear test, and highest educational qualification were recorded. The second and third response options were taken to indicate correct understanding.

Results

When the women in study 1 were informed only that their smear test result was normal, just 52% (80 of 153 women) correctly understood that this entailed a residual risk of cervical cancer, compared with 70% (107 of 152) given the additional sentence explaining the meaning of a normal smear test result (difference 18%, 95% confidence interval 7% to 29%, $\chi^2 = 10.1$, df = 1, P = 0.001). Those given this additional sentence also had a better understanding of the meaning of the result for their health in the next five years ($\chi^2 = 5.6$, df = 1, P = 0.02). These differences were due to the provision of a simple statement, which reduced the proportion who incorrectly believed that a normal test result meant they definitely did not have cancer now and the proportion who did not know what their test result meant about their risks in five years' time (table). In study 2, the provision of information on numerical absolute and relative risk did not improve understanding beyond that achieved by the additional statement used in study 1 (table).

Across both samples, age, marital status, and screening history were unrelated to understanding. Higher educational levels were associated with better understanding of the meaning of results in terms of health now ($\chi^2 = 8.66$, df = 2, P = 0.013) but not in five years' time ($\chi^2 = 5.05$, df = 2, P = 0.08).

Women's understanding of a normal smear test result on basis of additional information provided with result's letter. Values are percentages (numbers) of women

		Women's responses			
	Statements*	Definitely not	Unlikely†	Likely	Don't know
Perceived likelihood of having cervical cancer now					
Study 1	1 (n=153)	43 (66)	52 (80)	1 (1)	4 (6)
	1 and 2 (n=152)	26 (40)	70 (107)	1 (2)	2 (3)
Study 2	1 and 2 (n=188)	22 (41)	74 (139)	2 (3)	3 (5)
	1, 2, and 3 (n=172)	22 (38)	77 (133)	1 (1)	0
	1, 2, and 4 (n=175)	18 (31)	78 (137)	1 (2)	3 (5)
	1, 2, 3, and 4 (n=187)	17 (31)	79 (147)	2 (3)	3 (6)
Perceived likelihood of having cervical cancer in next five years					
Study 1	1 (n=153)	3 (5)	56 (85)	0	41 (63)
	1 and 2 (n=152)	3 (5)	69 (105)	5 (8)	23 (34)
Study 2	1 and 2 (n=188)	2 (4)	79 (148)	3 (5)	16 (31)
	1, 2, and 3 (n=172)	3 (6)	81 (139)	2 (3)	14 (24)
	1, 2, and 4 (n=175)	4 (7)	81 (141)	1 (3)	14 (24)
	1, 2, 3, and 4 (n=187)	5 (9)	75 (140)	4 (7)	17 (31)

*1, smear result is normal; 2, you are at low risk of having or developing cervical cancer in next five years; 3, chances of this happening are about 1 in 5000; this means that, on average, out of every 5000 women who have a normal smear test result, one will go on to develop cervical cancer. Put another way, 4999 of these women will not develop cervical cancer over the next five years; 4, compared with women who have not had a smear test, you are about five times less likely to develop cervical cancer in the next five years.
†Correct understanding was second or third response options.

Discussion

Mindful of the analogue nature of this study, our results suggest that the policy of the NHS cervical screening programme for reporting normal smear test results needs to change to make it a definite requirement that the reporting of a "normal smear result" is always accompanied by a sentence explaining that this means a low risk for having or developing cervical cancer in the next five years. In our study we used the term "low risk" to convey an absolute risk of 1:5000. The numerical probabilities associated with verbal expressions of likelihood vary widely.[7] Further work is needed to determine whether other verbal probabilities such as "very low risk" or "small risk" are more effective than "low risk" at communicating the residual risk inherent in a negative smear result and whether additional wording is required to convey the fact that a normal smear result is good news. While the results of the current study require replication in a sample of women undergoing cervical screening and receiving their own normal smear results, we do not anticipate that the results would be very different from those presented here, given that 94% of the sample were or had been participants in the NHS cervical screening programme.

What is already known on this topic

Women find the use of the term negative to reflect a favourable outcome confusing

In 1997 the NHS cervical screening programme made it a requirement for screening centres to report negative test results as "normal smear results"

What this study adds

Only about 50% of women understand that the term "normal smear result" means there is a residual risk of having or developing cervical cancer in the next five years

Use of a simple statement explaining that a normal test result means there is a low risk of cervical cancer improves understanding

Understanding is not improved further by the use of numerical absolute or relative probability information

Currently, 3.5 million women a year in England and Wales receive a negative test result on cervical screening. Adopting our recommendation has the potential to avoid as many as half a million women a year being falsely reassured. It remains to be determined how understanding can be improved for the remaining women who continue to see a normal smear result as meaning no risk of having or developing cervical cancer. Attention could focus on information given to women before screening as well as on the information given at the time of the results. The recent General Medical Council's guidelines on consent emphasise the importance for those undergoing screening to understand, before having the test, the meaning of all possible test results.[8] The effectiveness of different ways of presenting this information at the time of undergoing the smear test needs to be evaluated. Concerning how best to present the residual risks, we found no advantage of using numerical risks, which have been found to be effective in communicating residual risks in other contexts.[6] It is possible, however, that those women presented with numerical information were less likely to perceive the risk of cervical cancer to be greater than it is. Other ways of presenting risks using combinations of different types of numbers, words, and pictures, need evaluating for cervical and other screening programmes.

We thank Bernadette Collins and Hazel Showell for help with data entry.

Contributors: TMM was the principal investigator and took the lead in designing the study and coordinating data collection, and wrote the first draft of the paper. VS contributed to the design of the study. PS calculated the residual risks inherent in a normal smear test result and drafted out the risk statements. VS and PS contributed to the statistical analysis and commented on drafts of the paper. TMM will act as guarantor for the paper.

Funding: This research was funded by a grant from the NHS cervical screening programme. TMM is funded by The Wellcome Trust.

Competing interests: None declared.

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(Accepted 7 December 2000)

One hundred years ago

The surgical treatment of migraine

During the last five and twenty years I have never failed to treat successfully the most inveterate and severe cases of migraine by the introduction of an ordinary tape seton through the skin at the back of the neck.

My last case, and the one which has induced me to make this communication, is that of a lady who has never for the last six years escaped many weeks without "a brain storm" of such severity that she has been completely prostrated with violent headache and sickness for periods extending from twelve to twenty-four hours. Since the introduction of a seton some months ago she has not had a single attack.

As the use of the seton has gone out of fashion, and probably the younger members of the profession have never seen it used, I may perhaps be allowed to explain for their benefit the *modus operandi* more in detail. The skin at the back of the neck is grasped between the finger and thumb of the left hand, and behind the fingers a long-bladed scalpel is forced so as to transfix the skin. Before the knife is removed, a long probe provided with a suitable eye is passed through the wound, using the knife as a guide. The scalpel is then, withdrawn. A piece of ordinary household tape half an inch wide is then attached by a ligature to the eye of the probe and the probe pulled through the wound, bringing the tape with it.

Four inches of tape are left free at each side, and these are gently tied together to prevent the tape being accidentally withdrawn.

Instructions are given to the patient to move the tape from side to side each day. The interposing skin between the point of entrance of the seton and that of exit naturally varies with the thickness of the skin of the individual patient, and in some cases may only be an inch, whereas in others there may be a distance of 2 inches.

The operation, if performed with moderate dexterity, need only occupy half a minute, and nitrous oxide is all-sufficient as an anaesthetic.

The seton ought to be worn uninterruptedly for three months at least in the first instance, and should the symptoms recur a second seton ought to be introduced.

Walter Whitehead, consulting surgeon, *Manchester Royal Infirmary*
(BMJ 1901:i:335)