

Psychological impact of human papillomavirus testing in women with borderline or mildly dyskaryotic cervical smear test results: cross sectional questionnaire study

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Abstract

Objective To describe the psychological impact on women of being tested for human papillomavirus (HPV) when smear test results are borderline or mildly dyskaryotic.

Design Cross sectional questionnaire study.

Setting Two centres participating in an English pilot study of HPV testing in women with borderline or mildly dyskaryotic smear test results.

Participants Women receiving borderline or mildly dyskaryotic smear test results tested for HPV and found to be HPV positive (n = 536) or HPV negative (n = 331); and women not tested for HPV with borderline or mildly dyskaryotic smear results (n = 143) or normal smear results (n = 366).

Main outcome measures State anxiety, distress, and concern about test result, assessed within four weeks of receipt of results.

Results Women with borderline or mildly dyskaryotic smear results who were HPV positive were more anxious, distressed, and concerned than the other three groups. Three variables independently predicted anxiety in HPV positive women: younger age ($\beta = -0.11$, $P = 0.03$), higher perceived risk of cervical cancer ($\beta = 0.17$, $P < 0.001$), and reporting that they did not understand the meaning of test results ($\beta = 0.17$, $P = 0.001$). Testing HPV negative was not reassuring: among women with abnormal smear test results, those who were HPV negative were no less anxious than those who were not tested for HPV.

Conclusions Informing women more effectively about the meaning of borderline or mildly dyskaryotic smear test results and HPV status, in particular about the absolute risks of cervical cancer and the prevalence of HPV infection, may avoid some anxiety for those who are HPV positive while achieving some reassurance for those who test HPV negative.

Introduction

Human papillomavirus (HPV) is present in almost 100% of cervical cancers¹ and HPV positivity is associated with high grade pre-invasive lesions in women with borderline nuclear change or mild dyskaryosis. Given the relatively high rates of borderline or mildly dyskaryotic cervical smear test results, HPV testing

could be used to stratify women for higher or lower risks of developing cervical cancer, and to manage them accordingly. A pilot study was mounted in England to evaluate the clinical, economic, and psychological consequences of this strategy; this paper assesses the psychological consequences.

No data are yet available on the psychological impact of HPV testing in conjunction with cytological screening. Surveys of highly selected groups of women who have undergone HPV testing for a variety of reasons have had equivocal findings, with some showing raised levels of distress²⁻⁵ and others not.^{6,7}

Although HPV testing may raise anxiety in women who test positive, it has the potential to reassure those who test negative that their risks of developing cervical cancer, given a borderline or mildly dyskaryotic smear test result, are lower than women who with HPV infection.¹ This study aimed to describe the psychological impact of HPV testing in women with borderline or mildly dyskaryotic cervical smear test results and to examine the predictors of this impact.

Methods

Participants

We recruited our sample from two of the three centres taking part in the English pilot study of liquid based cytology and HPV testing. During the pilot, all women with borderline or mildly dyskaryotic test results over a five month period were invited to participate, as were the first 13 women each week who received a normal test result (we estimated this number was needed to achieve similar numbers in each group). All borderline or mildly dyskaryotic smear samples were tested for human papillomavirus. When the pilot was completed, the first 42 women each week over a five week period with borderline or mildly dyskaryotic results but no HPV test results were also recruited, half from each of the two centres. In total, 2183 women were sent questionnaires and up to two reminders. The final sample of 1376 (63%) women comprised 366 women who had received a normal result and 1010 who had

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Table 1 Emotional outcomes after receipt of results of smear test among women tested or not tested for human papillomavirus (HPV). Values are adjusted means (SE)

Variable	Normal result (n=366)	Abnormal result		
		HPV negative (n=331)	Not tested for HPV (n=143)	HPV positive (n=536)
State anxiety (S-STAI-6)	36.4 (0.7)*	37.6 (0.7)†	37.7 (1.2)†	39.6 (0.6)‡
Emotional distress (GHQ-12)	2.0 (0.1)*	2.1 (0.2)†	2.4 (0.3)†	2.8 (0.2)‡
Concern about test result	5.2 (0.1)*	8.8 (0.1)†	9.1 (0.2)†	9.7 (0.1)‡

Means with the same symbols do not differ ($P>0.05$) by planned linear contrasts. Means with different symbols in a given row differed significantly.

received a borderline or mildly dyskaryotic smear test result. In the latter group 331 were HPV negative, 536 were HPV positive, and 143 had not been tested.

Clinical management

The written information that accompanied the test results varied according to test result and sometimes across centres. In general, information given to women with an abnormal smear said they had minor abnormalities and did not have cancer. Information for women tested for HPV described HPV as a common infection of the cervix that does not usually need treatment. Further details are on bmj.com. Clinical management also varied.

Borderline or mildly dyskaryotic test result, HPV positive—In centre 1 all HPV positive women were referred for colposcopy. In centre 2, only women over 35 were referred for colposcopy. Those below 35 were invited for a repeat smear and HPV test after six months. If dyskaryosis or HPV infection persisted, these women were referred for colposcopy.

Borderline or mildly dyskaryotic test result, HPV negative—All women were asked to attend for a repeat smear and HPV test six months later. If dyskaryosis, HPV infection, or both, was found, women were referred for colposcopy.

Borderline or mildly dyskaryotic test result, HPV not tested—All women with this result were asked to attend for a repeat smear test after six months. If the repeat smear showed borderline changes, mild dyskaryosis, or worse, women were referred for colposcopy.

Normal smear test result—Women receiving a normal result with no previous abnormal smear test results were returned to routine recall.

Study hypotheses

The formal hypotheses tested were that women with normal results would have anxiety scores significantly lower than all other groups; that women with borderline or mildly dyskaryotic smear test results who were HPV positive would have significantly higher scores than the other three groups; and that women with borderline or mildly dyskaryotic smear test results who were HPV negative would have lower anxiety scores than those who had abnormal smear test results but had not been tested for HPV.

Our study had at least 80% power to detect small or medium differences in outcomes between the groups.

Outcome measures

Anxiety was assessed using the short form of the state scale of the Spielberger state-trait anxiety inventory,⁸ prorated to give a scale range from 20 to 80 ($n=1288$). The population norm for women is 35; scores above 49 are found in patients with a diagnosis of anxiety disorder.

General distress was assessed using the 12 item general health questionnaire (range 1-12) with a clinical cutoff score of 4 ($n=1343$).⁹

Concern about the smear result was assessed using two seven point rating scales (range 2-14) asking women how concerned, and how reassured, they felt about the result. Higher scores indicated more concern ($n=1352$).

Perceived risk of developing cervical cancer was assessed using a seven point scale assessing women's perceptions of their likelihood of developing cervical cancer in the next 10 years.

Understanding of smear result was assessed by asking women to state what they believed their result meant for their current health (see table 3 for response options). The correct responses for all women is that they were very unlikely, or unlikely, to have cervical cancer.

We also recorded age, highest educational achievement, ethnic origin, and history of smear results.

Analysis

We tested the study hypotheses using ANCOVA to control for differences between the groups in age, education, centre, and smear history. We compared: normal versus all abnormal borderline or mildly dyskaryotic test results; borderline or mildly dyskaryotic test results in HPV positive women versus all other groups; borderline or mildly dyskaryotic results in women who were not tested for HPV versus borderline or mildly dyskaryotic and HPV negative. We used linear trend analysis to confirm the predicted pattern of responses across the four study groups, and multiple linear regression to ascertain the best predictors of anxiety in women who received HPV positive results.

Results

The four study groups differed in age, educational level, and whether or not this was their first smear test (see bmj.com). We controlled for these three variables, and for centre, although it was unrelated to any of the outcome variables in the study.

Results of our main analysis are given in table 1. They confirmed two of the three research hypotheses. Firstly, the group with normal test results had significantly less anxiety ($P=0.028$), distress ($P=0.040$), and concern ($P<0.001$) than the three groups with abnormal test results, taken together. Secondly, the HPV positive group had significantly higher anxiety ($P=0.002$), distress ($P=0.001$), and concern ($P<0.001$) than the other three groups taken together. The third hypothesis was not supported: women who had abnormal smear test results who were HPV negative did not have lower anxiety ($P=0.949$), distress ($P=0.409$), or concern ($P=0.394$) than women who

Table 2 Perceptions of the threat of cervical cancer of women given different results of a cervical smear and human papillomavirus (HPV) tests. Values are means (SEs) unless otherwise stated

Perception	Normal results (n=366)	Abnormal results		
		HPV negative (n=331)	Not HPV tested (n=143)	HPV positive (n=536)
Perceived severity (2 seven-point scales)	12.4 (0.1)*	12.3 (0.1)*	12.1 (0.2)*	12.3 (0.1)*
Perceived risk (seven-point scale)	3.7 (0.1)*	3.9 (0.1)*	4.1 (0.1)*	4.4 (0.1)†
% (No) unsure what HPV is	54 (199)	38 (125)	62 (89)	25 (133)
Perceived importance of HPV in the development of cervical cancer (by women who knew what HPV is)	5.9 (0.1)*	5.9 (0.1)*	5.3 (0.3)†	5.8 (0.1)*

Means with the same symbols do not differ ($P > 0.05$) by Tukey post hoc tests. Means with different symbols in a given row differed significantly.

Table 3 Understanding of the meaning of smear test results of women given different results of cervical smear and human papillomavirus (HPV) tests. Values are percentages (numbers)

Statement	Normal result (n=366)	HPV negative (n=331)	Abnormal results	
			Not tested for HPV (n=143)	HPV positive (n=536)
I definitely do not have cervical cancer	31 (112)	12 (39)	15 (21)	12 (63)
I am very unlikely to have cervical cancer	39 (143)	29 (94)	19 (27)	19 (103)
I am unlikely to have cervical cancer	27 (97)	38 (125)	39 (56)	35 (187)
I am likely to have cervical cancer	0	5 (16)	8 (11)	8 (44)
I have cervical cancer	0	0	0	0
I don't know	3 (12)	16 (53)	19 (27)	26 (137)

had abnormal smear test results but were not tested for HPV.

All groups viewed cervical cancer as extremely serious (table 2), but they differed in their perceptions of the risk of developing it ($P < 0.0001$): women who were HPV positive perceived their risks as greater than all other groups. Perceptions of risk followed a significant linear trend ($P < 0.0001$) when the groups were ordered in ascending order of actual risk. Forty one per cent of women stated they were unaware of what HPV was, including a quarter of HPV positive women.

The groups also differed in their understanding of their results ($\chi^2 = 194.13$, $df = 12$, $P < 0.001$; table 3). Women with abnormal results were less likely than women with normal results to understand (correctly) that they were very unlikely, or unlikely, to have cervical cancer. Women with abnormal results, whether tested for HPV or not, were less likely to know what their results meant than did women receiving a normal result ($P < 0.001$), with 26% (95% confidence interval 22% to 29%) of those who tested HPV positive stating that they did not know what this meant for their health.

Only three variables independently predicted anxiety in HPV positive women: age, with younger age being associated with higher anxiety ($P = 0.033$); perceived risk of developing cervical cancer ($P < 0.001$); and not knowing the meaning of the smear test result ($P = 0.001$). The latter two variables also predicted distress and concern ($P < 0.001$)

Discussion

Informing women with borderline or mildly dyskaryotic smear test results that they are positive for HPV is associated, at least in the short term, with raised levels of anxiety, general distress, and concern, compared with women receiving normal or cytologically abnormal smear test results. Anxiety, distress, and concern were higher when the perceived risk of developing cervical cancer was greater, and in women who reported not understanding the meaning of their test results.

The mean level of anxiety in this sample was similar to that seen in general medical and surgical patients just before surgery.¹⁰ In women informed of a borderline or mildly dyskaryotic smear test result, receiving an HPV negative result was not reassuring.

Some anxiety is to be expected after receiving abnormal cervical smear test results. However, raised anxiety can impair patients' ability to process complex information and lead to a bias towards processing threatening information.¹¹ We are carrying out a six month follow up to see if these effects endure, but evidence from systematic reviews suggests that they will have dissipated.¹²

Women receiving borderline or mildly dyskaryotic test results know that their chances of developing cervical cancer are higher than if they had received normal results. Of concern, however, is the magnitude of that perceived risk.¹³ Most of these women (406/484: 84%) perceived their risks of developing cancer in the next 10 years at or above the midpoint of the scale, suggesting they perceived this outcomes as quite likely or very likely; this suggests a large overestimate of the true likelihood. Providing women with the absolute likelihood may diminish their perceived risks and, in turn, diminish anxiety, distress, and concern.

Perceptions of the prevalence of a health threat also affect how serious it is perceived to be, with threats perceived as more common being seen as less serious.¹⁴ Women were informed that human papillomavirus is "a very common infection of the cervix," but we do not know how they interpreted this. It is estimated that about 20% of young women and about 5% of women aged over 35 are infected at any one time.¹⁵ In women with borderline or mildly dyskaryotic cervical smear test results the prevalence is higher.¹⁵ Informing women of the actual prevalence of HPV infection could therefore reduce their anxiety, distress, and concern.

An appreciable number (22% (217/1003)) of women with abnormal test results did not know what their results meant. In HPV positive women, not knowing what their results meant was associated with

What is already known on this topic

Anxiety after receiving abnormal smear test results can be reduced by the provision of clear, salient information

Surveys of the psychological impact of human papillomavirus (HPV) testing carried out on highly selected samples have produced inconclusive evidence

No population based studies have evaluated the psychological impact of HPV testing in conjunction with cervical smear testing

What this study adds

HPV positive results in women with borderline or mildly dyskaryotic smear test results are associated with anxiety, distress, and concern beyond that associated with the abnormal cytology result

Anxiety, distress and concern are greatest in women who perceive themselves at greater risk of developing cervical cancer and who report not knowing what their results mean

extremely high levels of anxiety, but we do not know if this association is causal.

Limitations of study

The generalisability of the results is limited by the sample. Although the response rate of 63% is good for a mailed survey,¹⁶ the sample under-represents women from ethnic minority groups and women with no educational qualifications. Given the association between educational level, knowledge, and understanding of complex health information,¹⁷ our study could under-represent the distress that HPV testing can cause in general population samples of women undergoing cervical screening.

Conclusion

Studies are needed to determine, firstly, how to avoid some of the anxiety, distress, and concern caused by positive results on HPV testing and, secondly, how to provide some reassurance for women receiving negative HPV results.

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Ethical approval: Southmead Local Research Ethics Committee (Reference No 076/01) and Northumberland and Tyne & Wear Health Authority Local Research Ethics Committee (Reference No 2001/247), which covered the laboratories that conducted the screening.

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