SHORT REPORT

Attitudes to self-sampling for HPV among Indian, Pakistani, African-Caribbean and white British women in Manchester, UK

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Objective: To examine attitudes to self-sampling for human papillomavirus (HPV) testing among women from contrasting ethnic groups.
Setting: Manchester, UK.
Methods: Two hundred women of Indian, Pakistani, African-Caribbean and white British origin were recruited from social and community groups to participate in a questionnaire survey. The questionnaire included items on attitudes to self-sampling and intention to use the test.
Results: Willingness to try to use the test was high, and women did not foresee religious or cultural barriers to self-sampling; however, a large proportion of women were concerned about doing the test properly. This concern was greatest in the Indian and African-Caribbean groups.
Conclusions: Although women's willingness to try self-sampling for HPV is encouraging, worries about carrying out the procedure correctly must be addressed if women are to feel confident about the results of self-sampling methods and reassured by a negative result.

In recent years, there has been a growing interest in the use of self-collection methods for obtaining samples for medical tests. In the context of screening, self-sampling technology has the potential to increase coverage by overcoming both infrastructural barriers in developing countries, and individual barriers such as time constraints or embarrassment (e.g. in the case of gynaecological examinations) in established programmes.

Most research in this area has focused on self-collected vaginal samples for the detection of sexually transmitted infections (STIs).[1,2] One such STI is human papillomavirus (HPV), high-risk types of which are now acknowledged as the main aetiological agent in the development of cervical cancer.[3] HPV testing is increasingly being recommended in cervical screening and the management of cervical abnormalities,[4–6] and this raises the possibility that self-sampling might be introduced into some screening programmes. This has the potential to increase screening uptake in hard-to-reach groups who are currently reluctant to attend for a gynaecological examination, but could also widen existing inequalities in screening coverage if those who embrace the new technology are those women who already attend screening.

Although a number of self-sampling methods have been developed for the detection of HPV DNA,[7–13] most studies investigating the effectiveness of these collection methods have been primarily concerned with assessing the sensitivity, specificity and predictive value of the test. Until very recently, little attention had been paid to assessing the acceptability of the test among users, or women's confidence in the results obtained from self-collected samples, factors that may be particularly important in any test associated with cancer screening.

Studies of HPV self-sampling carried out to date generally report that women who have used it find self-sampling acceptable. However, these studies only report the views of women who have already agreed to participate in trials of self-sampling;[9,10,14–16] who may be more accepting of self-collection methods than those who decline to participate. These studies also take place in medical settings where social desirability effects might make women more likely to express positive views than they would be away from healthcare professionals. The one study investigating women's confidence in the self-sampling method reported that lack of confidence in the accuracy of the test was the main reason for preferring conventional screening over self-sampling.[16]

This paper describes a questionnaire survey designed to investigate women's responses to information about HPV self-sampling. Participants in the study had not taken part in clinical trials of self-sampling, which is analogous to the 'real life' situation that would arise if self-sampling were introduced. There has been little research into possible ethnic differences in acceptability, so we recruited women from ethnic groups that have been shown to differ in their attitudes to and uptake of conventional cervical screening,[17,18] and where religious and cultural beliefs and practices may influence attitudes to self-sampling.

METHODS

Sample

Participants comprised 200 women aged between 20 and 64 years (the age range recommended to attend cervical screening in the UK at the time of the study), self-identified as Indian, Pakistani, African-Caribbean or white British. They were recruited from social and community groups in Manchester in the north of England, by ethnically matched community researchers. Women with a history of cervical abnormalities or who had had a hysterectomy were excluded.

Measures

Willingness to try using the self-test if offered it in the future was measured using two intention items:

(1) 'If you were offered the chance to use the HPV self-test, would you take up the offer? (In the questionnaire, the self-sampling kit was referred to as a 'self-test'. This was deemed to be a more readily understandable term, but participants were aware that the sample would need to be tested for HPV in a laboratory.) and
(2) 'If the HPV self-test was introduced as part of the national screening programme, would you want to use it?'.

Both items were scored on a validated four-point scale: 'yes definitely', 'yes probably', 'probably not', and 'definitely not'.[23–25]

Attitudes towards the test

Two items tapped women's confidence in using the test, and possible cultural barriers:

(1) 'I would worry that I had not done the test properly', and
(2) 'It would go against my religious or cultural beliefs'.

Responses were made on a five-point scale, from 'strongly agree' to 'strongly disagree'. Items were derived from focus groups carried out with women from the same four ethnic groups as those included in the present study, the methodology of which has been published elsewhere.[19]

Demographic variables

Sociodemographic information was collected using simple questions to assess age, marital status, place of birth, years of education, self-identified ethnicity, and previous participation in cervical screening (smear testing). Response options to the closed questions can be seen in Table 1.

Procedure

Face-to-face interviews were used to administer the questionnaire. The questions were translated where appropriate and the interview was conducted in the language of the participant's choice (English, Urdu or Gujarati). Before conducting the questionnaire survey, the researcher provided each participant with basic information about HPV. All women were shown a Digene specimen collection kit (Digene UK Ltd., London, UK) for HPV self-sampling and given clear written and verbal instructions about how it would be used. The kit contains a sterile Dacron swab for insertion into the vagina and a small plastic tube containing specimen transport medium in which to place the swab. It should be noted that women were only asked about their attitudes to self-sampling; they were not asked to do it.

The study was approved by Manchester Local Research Ethics Committees. Statistical analyses were conducted using SPSS v10.1.

RESULTS

Sample characteristics

A total of 50 African-Caribbean, 50 Indian, 51 Pakistani and 49 white British women were interviewed (mean age: 38.5 years, [standard deviation 10.6]). Sociodemographic characteristics of the groups are presented in Table 1.Most women (85.5%) had previously had a smear test. There were significant differences between the ethnic groups for a number of the variables; chi-squared (Chi^2) tests for between-group differences are shown in Table 1. African-Caribbean women were younger and less likely to be married; Indian women were more highly educated than other groups; and previous experience of smear testing was much lower in the African-Caribbean and Indian groups than the other two groups.

Intention to use the self-test

Women seemed willing to try using the self-test. Just over half the sample (56%) stated that they would 'definitely' use the test if they were offered it in the future (see Table 2). This varied from 71% of the white British group to around 46% of the Indian and Pakistani groups. Almost none of the women said that they would 'definitely not' use the test. When asked about their intention to use self-sampling if it were offered as part of the national cervical screening programme, 65% of women said that they would 'definitely' take up the offer. Chi^2 tests showed that there were no statistically significant differences in intention between ethnic groups.

Attitudes towards the self-test

Over half of the respondents (55%) agreed with the statement 'I would worry that I had not done the test properly', and a further 19% were unsure. Indian and African-Caribbean women were more likely to be worried about doing the test properly (66% and 70%, respectively) than

Table 1 Demographic characteristics of the sample

	All	White (n=49)	Indian (n=50)	Pakistani (n=51)	Africa-Caribbean (n=50)	Chi^2 (p)
Age [mean (SD)]	38.5 (10.6)	40.2 (10.5)	41.1 (12.2)	35.1 (9.3)	37.5 (9.4)	F(3,196) = 3.43, p = 0.02
Marital status [n (%)]						
Single	40 (20.0)	9 (18.4)	10 (20.0)	1 (2.0)	20 (40.0)	31.7 (<0.0001)
Married/cohabiting	139 (69.5)	35 (71.4)	36 (72.0)	47 (92.2)	21 (42.0)	
Separated/divorced/widowed	21 (10.5)	5 (10.2)	4 (8.0)	3 (5.9)	9 (18.0)	
Age left education [n (%)]						43.7 (<0.0001)
15 years and under	25 (12.5)	7 (14.3)	4 (8.0)	8 (15.7)	6 (12.2)	
16	65 (32.5)	29 (59.2)	9 (18.0)	15 (29.4)	12 (24.5)	
17–18	47 (23.5)	12 (24.5)	8 (16.0)	14 (27.5)	13 (26.5)	
19 and over	62 (31.0)	1 (2.0)	29 (58.0)	14 (27.5)	18 (36.7)	
Born in UK [n (%)]	94 (47.0)	46 (93.9)	8 (16.0)	14 (27.5)	26 (52.0)	7.84 (<0.0001)
Previous smear test [n (%)]	171 (85.5)	48 (98.0)	39 (78.0)	46 (90.2)	38 (76.0)	13.1 (0.005)

SD, standard deviation

Table 2 Attitudes to self-sampling and intentions to use the test by ethnic group [% (n)]

	All (n=200)	White (n=49)	Indian (n=50)	Pakistani (n=51)	African-Caribbean (n=50)
Intention					
Intention to use the HPV self-test if offered					
Yes definitely	56.0 (112)	71.4 (35)	46.0 (23)	47.1 (24)	60.0 (30)
Yes probably	37.5 (75)	26.5 (13)	41.2 (24)	41.2 (21)	34.0 (17)
Probably not	5.5 (11)	2.0 (1)	6.0 (3)	9.8 (5)	4.0 (2)
Definitely not	1.0 (2)	0	0	2.0 (1)	2.0 (1)
Intention to use the self-test as part of the national screening programme					
Yes definitely	65.0 (130)	75.5 (37)	64.0 (32)	60.8 (31)	60.0 (30)
Yes probably	30.5 (61)	24.5 (12)	32.0 (16)	31.4 (16)	34.0 (17)
Probably not	3.0 (6)	0	2.0 (1)	5.9 (3)	4.0 (2)
Definitely not	1.5 (3)	0	2.0 (1)	2.0 (1)	2.0 (1)
Attitudes towards the test					
I would worry that I had not done the test properly					
Strongly disagree/disagree	27.0 (54)	42.9 (21)	22.0 (11)	29.4 (15)	14.0 (7)
Unsure	18.5 (37)	24.5 (12)	12.0 (6)	21.6 (11)	16.0 (8)
Agree/strongly agree	54.5 (109)	32.7 (16)	66.0 (33)	49.0 (25)	70.0 (35)
It would go against my religious/cultural beliefs					
Strongly disagree/disagree	96.5 (193)	98.0 (48)	98.0 (49)	98.0 (50)	92.0 (46)
Unsure	2.0 (4)	2.0 (1)	2.0 (1)	2.0 (1)	2.0 (1)
Agree/strongly agree	1.5 (3)	0	0	0	6.0 (3)

white or Pakistani women (33% and 49%, respectively), and differences between ethnic groups were significant (χ^2 [6]=18.8, p=0.005). Very few women reported that using the self-test would go against their cultural or religious beliefs (2%), and there were no differences between ethnic groups on this item.

DISCUSSION

The study takes place in the context of increasing interest in the use of self-collected sampling in screening. Self-sampling methods for HPV testing have the potential to overcome important procedural and cultural barriers to attendance for cervical screening but there has been very little research on perceptions of self-sampling among potential users, and no previous research on women from contrasting ethnic groups in the UK. If uptake is to be high and concerns among users minimised, it will be vital that the test is well received among the target populations. It is therefore important to assess acceptability not only among participants in clinical trials of self-sampling, as has been the tendency in the past, but also among potential users with no prior experience of self-sampling.

Encouragingly, the majority of women in the study expressed willingness to try the self-test if they were offered it; however, the study also found that over 70% expressed concern or uncertainty about carrying out the test properly. This level of concern about self-sampling has not been identified in the literature to date and was consistent with the qualitative data collected in our focus groups. Women expressed concern about self-sampling within cancer screening and were worried that if the test result were negative they would not feel confident that they had carried out the test adequately, and hence would not be reassured by a negative result. This lack of confidence was highest in the Indian and African-Caribbean groups; however very few women reported religious or cultural barriers to self-testing.

The design of the study was strengthened by the inclusion of women from different ethnic groups, varying in age, marital status and socioeconomic position, some of whom had never had a smear test. However, limitations in the sampling should be borne in mind when interpreting the results. Differences between ethnic groups on a number of demographic factors means that observed differences in attitudes to self-sampling between the groups should be treated with some caution. The findings should be replicated using larger and more representative samples.

Notwithstanding the study limitations, our findings suggest that attitudes towards self-sampling for HPV testing are positive and that women are likely to be willing to try the test if it were offered to them within the UK national screening programme. Wherever HPV self-sampling is introduced, women will have to decide whether to take part on the basis of the kind of information provided in our study, so the responses of our participants provide an important indication of potential acceptability and uptake. Women in the four ethnic groups included did not seem to regard cultural or religious beliefs as a barrier to participation, but there was concern about doing the test properly. This has implications for women's confidence in test results from all self-sampling tests, and must be addressed if women are to feel comfortable using self-collection methods.

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REFERENCES

1 Wiesenfeld HC, Lowry DL, Heine RP, *et al*. Self-collection of vaginal swabs for the detection of chlamydia, gonorrhea, and trichomoniasis: opportunity to encourage sexually transmitted disease testing among adolescents. *Sex Transm Dis* 2001;**28**:321–5.
2 Holland-Hall CM, Wiesenfeld HC, Murray PJ. Self-collected vaginal swabs for the detection of multiple sexually transmitted infections in adolescent girls. *J Pediatr Adolesc Gynecol* 2002;**15**:307–13.
3 Bosch FX, Lorincz A, Munoz N, *et al*. The causal relation between human papillomavirus and cervical cancer. *J Clin Pathol* 2002;**55**:244–65.
4 Wright TC Jr, Cox JT, Massad LS, *et al.* 2001 consensus guidelines for the management of women with cervical cytological abnormalities. *JAMA* 2002;**287**:2120–9.
5 Food and Drug Administration. FDA approves expanded use of HPV test [monograph online]. Available from http://www.fda.gov/bbs/topics/NEWS/2003/NEW00890.html (last accessed 14 January 2004).
6 Cuzick PJ, Szarewski A, Cubie H, *et al.* Management of women who test positive for high-risk types of human papillomavirus: the HART study. *Lancet* 2003;**362**:1871–6.
7 Wright TC Jr, Denny L, Kuhn L, *et al*. HPV DNA testing of self-collected vaginal samples compared with cytologic screening to detect cervical cancer. *JAMA* 2000;**283**:81–6.
8 Gravitt PE, Lacey JV Jr, Brinton LA, *et al.* Evaluation of self-collected cervicovaginal cell samples for human papillomavirus testing by polymerase chain reaction. *Cancer Epidemiol Biomarkers Prev* 2001;**10**:95–100.
9 Harper DM, Noll WW, Belloni DR, Cole BF. Randomized clinical trial of PCR-determined human papillomavirus detection methods: self-sampling versus clinician-directed biologic concordance and women's preferences. *Am J Obstet Gynecol* 2002;**186**:365–73.
10 Nobbenhuis MA, Helmerhorst TJ, van den Brule AJ, *et al*. Primary screening for high risk HPV by home obtained cervicovaginal lavage is an alternative screening tool for unscreened women. *J Clin Pathol* 2002;**55**:435–9.
11 Morrison EA, Goldberg GL, Hagan RJ, *et al*. Self-administered home cervicovaginal lavage: a novel tool for the clinical-epidemiologic investigation of genital human papillomavirus infections. *Am J Obstet Gynecol* 1992;**167**:104–7.
12 Coutlee F, Hankins C, Lapointe N. Comparison between vaginal tampon and cervicovaginal lavage specimen collection for detection of human papillomavirus DNA by the polymerase chain reaction. The Canadian Women's HIV Study Group. *J Med Virol* 1997;**51**:42–7.
13 Hillemanns P, Kimmig R, Huttemann U, *et al*. Screening for cervical neoplasia by self-assessment for human papillomavirus DNA. *Lancet* 1999;**354**:1970. [AQ7]
14 Rompalo AM, Gaydos CA, Shah N, *et al*. Evaluation of use of a single intravaginal swab to detect multiple sexually transmitted infections in active-duty military women. *Clin Infect Dis* 2001;**33**:1455–61.
15 Serwadda D, Wawer MJ, Shah KV, *et al*. Use of a hybrid capture assay of self-collected vaginal swabs in rural Uganda for detection of human papillomavirus. *J Infect Dis* 1999;**180**:1316–9.
16 Dzuba IG, Diaz EY, Allen B, Leonard YF, *et al*. The acceptability of self-collected samples for HPV testing vs. the pap test as alternatives in cervical cancer screening. *J Women's Health Gend Based Med* 2002;**11**:265–75.
17 Luke K. Cervical cancer screening: meeting the needs of minority ethnic women. *Br J Cancer* (Suppl) 1996;**29**:S47–50.
18 Health Education Authority. *Black and Minority Ethnic Groups in England: Health and Lifestyles*. London: Health Education Authority, 1994.
19 McCaffery KJ, Forrest S, Waller J, *et al*. Attitudes towards HPV testing: a qualitative study of beliefs among Indian, Pakistani, African Caribbean and white British women in the UK. *Br J Cancer* 2003;**88**:42–6.