



South African women's perspectives on self-sampling for cervical cancer screening: A mixed-methods study

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Background. Self-sampling as a method of screening for cervical cancer and its precursors is an attractive option for low-resource settings. However, to allow successful integration of self-sampling into national screening programmes, it is necessary to understand women's perceptions and beliefs surrounding this method of sampling the cervix.

Objectives. To explore women's attitudes to self-collection of samples for cervical screening in a low-resource setting in South Africa (SA).

Methods. Mixed methods were used to meet the study objectives. We recruited women aged 30 - 65 years into a study in Cape Town, SA, to participate in a cross-sectional survey. All women collected a vaginal self-sample, and underwent visual inspection with acetic acid, colposcopy, and collection of cervical samples and appropriate histology specimens by a doctor. Women had a quantitative questionnaire-based exit interview. A subset of these women participated in focus group discussions (FGDs).

Results. A total of 822 women answered the exit survey questionnaire and 41 women participated in the FGDs. Most women from the survey had a positive perception of self-sampling, with 93.6% of the women reporting not feeling embarrassed and 89.4% reporting experiencing no discomfort at all when taking a self-sample. This was corroborated by the FGD participants, who found self-sampling easier, more comfortable and less embarrassing than clinician sampling. However, many women (64.7%) felt more confident when the sample was taken by a clinician, despite having a positive attitude towards self-sampling. In most cases this was because they thought that the clinician would take a better sample, as explained by the FGD participants. Although 93.9% of the women were willing to collect a self-sample, the women in the FGDs expressed a preference for doing so at the health facility rather than at home. There were many reasons for this, including the cost of returning to the clinic with the sample.

Conclusions. Attitudes regarding self-sample collection were positive in this study population. Participants were willing to perform self-sampling, but expressed concerns regarding the quality of the specimen and the financial implications of returning to the clinic with it. Pilot implementation studies will be useful before this method of sampling is adopted and integrated into screening programmes.

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There are marked global disparities in the incidence of cervical cancer, with most cases occurring in low- and middle-income countries (LMICs). In high-income countries (HICs), the implementation of organised cytology-based cervical screening programmes has resulted in a decline in cervical cancer incidence and mortality rates. Unfortunately, cervical cancer continues to be a significant public health problem in LMICs owing to the lack of high-quality screening programmes and poor screening coverage in those regions.^[1,2] Effective cytology-based screening requires a relatively robust healthcare infrastructure with functional laboratory services, well-trained healthcare providers and technicians, good referral systems, and linkage to accessible treatment facilities and follow-up after

treatment for women with abnormal screening tests. This approach requires resources typically not available in LMICs, hampering the initiation and maintenance of screening programmes.^[3]

The World Health Organization has recommended molecular testing for human papillomavirus (HPV) as an alternative to cytology-based screening in low-resource settings, given that these tests are more sensitive than cytology and visual inspection methods in detecting high-grade cervical intraepithelial neoplasia and cancer.^[2,4-6] A randomised controlled trial in India showed that in low-resource settings, a single round of HPV testing was associated with a significant reduction in cervical cancer mortality.^[5] HPV tests also have the advantage that vaginal samples can be collected by the

woman herself, which may increase coverage.^[3,7] HPV DNA testing is therefore an attractive alternative to cytology-based screening in low-resource settings.

HPV testing on self-collected vaginal samples has been shown to be as accurate as testing on samples collected by a doctor and can potentially increase coverage for cervical cancer screening in low-resource settings.^[7-12] Several studies done across the world in various settings suggest that self-sampling is an acceptable method of collecting a sample for HPV typing for most women.^[3,13-16]

Objectives

To explore women's perceptions and acceptance of self-collection of samples for cervical screening and their willingness to do so, in a low-resource setting in South Africa (SA).

Methods

This mixed-methods study was part of a National Cancer Institute (NCI)-funded collaborative project carried out by the University of Cape Town, Columbia University and Cepheid Inc. (Sunnyvale, Calif, USA), utilising a new point-of-care CE-IVD test, Xpert HPV. A convergent parallel design was used in which quantitative and qualitative data were collected and analysed separately and then merged. Approval for the study was obtained from the Faculty of Health Sciences Human Research Ethics Committee, University of Cape Town (ref. no. 703/2014) and the Human Research Protection Office, Institutional Review Board, Columbia University (ref. no. AAAO3652). The subjects provided written informed consent for participation.

Women aged 30 - 65 years were recruited from a referral colposcopy clinic and a primary care site in Cape Town, SA, from February 2015 to May 2016. Equal numbers of HIV-positive and HIV-negative women were recruited. All the participants self-collected a vaginal sample (a Dacron swab placed into 4 mL of PreservCyt transport medium in a polypropylene tube) in a private room following a verbal explanation on how to collect the sample by a community health worker (CHW). All the women also underwent collection of cervical samples by colposcopy, followed by visual inspection of the cervix after application of acetic acid and collection of histology samples by a doctor. The study aimed to recruit roughly equal numbers of HIV-positive and HIV-negative women.

Cross-sectional survey

All participants answered an exit questionnaire that examined the woman's level of embarrassment, discomfort, confidence to carry out self-sampling, and feelings of being ignored by the health worker and of intrigue with the procedure. The response options for these questions were coded on a 5-point scale: 1 = 'extremely', 2 = 'very', 3 = 'moderately', 4 = 'slightly', 5 = 'not at all'. The responses to the questions regarding 'confidence to carry out self-sampling' and 'whether they felt intrigued' were reverse-coded (1 = 'not at all', 2 = 'slightly', 3 = 'moderately', 4 = 'very', 5 = 'extremely') for accurate interpretation. Questions on collection method preference (whether they preferred self-sampling, clinician sampling or had no preference for either method) and whether they were willing to take a self-sample at home were also included in the questionnaire.

Descriptive statistics were used to describe the respondents' demographic profile and response to the exit questionnaire. The χ^2 test was used to compare categorical variables and the Kruskal-Wallis test for continuous variables. Variables that were significant in the bivariate analysis were included in a multinomial logistic regression model to investigate independent predictors of sampling preference.

The differences were statistically significant at $p < 0.05$ (two-sided). The data analysis was performed using SPSS 23 (IBM, USA)

Focus group discussions

Six focus group discussions (FGDs) were conducted at the primary healthcare study site. Each group consisted of 6 - 7 participants, considered the minimum number required to elicit meaningful dialogue and discussion. All FGDs took place once participants had completed all the clinical assessments. Written informed consent for the FGD was obtained from all participants. Discussions lasted between 45 and 60 minutes. An interview guide was used for the FGDs, which were facilitated by a female trained qualitative researcher with the assistance of a translator (discussions were conducted in isiXhosa and were digitally recorded, translated and transcribed verbatim).

The health belief model (HBM) theory^[17] was employed to construct exploratory themes for the FGDs. The themes explored included individual and community understanding of cervical cancer; perceived risk of and susceptibility to cervical cancer; perceived individual and community barriers to and benefits of Pap smears; women's experience with self-sampling (including preceding anxiety/fears/concerns, ease or difficulty of the procedure, associated pain and/or discomfort, confidence in collecting sample, perceived individual and community barriers, and benefits of self-sampling); self-sample collection preference (i.e. provider or self-collected); site preference (at home or at the clinic) and reasons for preference; and suggestions on how to facilitate self-sampling.

The transcripts were reviewed, and data were entered on QSR Nvivo10,^[18] a software package designed for systematic management and analysis of qualitative data. Initial coding categories were based on the interview guides and from the theoretical concepts of the HBM. Once all the text segments had been given basic codes, the codes were categorised into basic themes by placing similar codes together. For this study, only themes related to self-sampling were analysed.

Results

Results from the quantitative and qualitative research were reviewed to seek corroboration, to clarify results from the quantitative research and vice versa, and to extend the breadth of our understanding.

Sociodemographic characteristics

The cross-sectional survey included 822 women, with a median age of 41 years (interquartile range (IQR) 35 - 49) and median parity of 2 (IQR 2 - 3). Most of the women had a secondary education (78.4%), 80.0% had had a previous Pap smear, and 78.6% were non-smokers. More than half of the participants (54.1%) used some form of contraception, and 42.3% tested positive for HIV. Forty-one women were enrolled and participated in the FGDs (mean age 41 years, range 30 - 62).

Acceptability of self-sampling

Table 1 reports on participant perceptions of self- and clinician sampling elicited during the cross-sectional survey. A higher proportion of women reported that they did not feel embarrassed at all taking the self-sample (93.6%) compared with those reporting no embarrassment having the doctor collect the sample (88.2%) ($p = 0.0002$). Mean Likert scores for embarrassment (Table 2) also showed that women were significantly less embarrassed to self-sample compared with sampling by a doctor. The proportion who reported feeling no discomfort at all was greater for the self-collected (89.4%) v. the doctor-collected sample (56.0%) ($p < 0.001$), with

Table 1. Frequency of perceptions of self-sampling and clinician sampling among 822 women who completed the exit interview, scored on a Likert scale

Perception	Method	1 (extremely)	2 (very)	3 (moderately)	4 (slightly)	5 (not at all)
Embarrassed	Self-sample	3 (0.4)	3 (0.4)	8 (1.0)	39 (4.7)	769 (93.6)
	Clinician sample	15 (1.8)	6 (0.7)	15 (1.8)	60 (7.3)	726 (88.3)
Confident	Self-sample	489 (59.5)	112 (13.6)	110 (13.4)	39 (4.7)	72 (8.8)
	Clinician sample	532 (64.7)	134 (16.3)	77 (9.4)	32 (3.9)	47 (5.7)
Discomfort	Self-sample	2 (0.2)	9 (1.1)	16 (2.0)	60 (7.3)	735 (89.4)
	Clinician sample	14 (1.7)	11 (1.3)	50 (6.1)	287 (34.9)	460 (56.0)
Ignored	Self-sample	13 (1.6)	1 (0.1)	0	6 (0.7)	802 (97.6)
	Clinician sample	15 (1.8)	0	1 (0.1)	2 (0.2)	804 (97.8)
Intrigued	Self-sample	709 (86.3)	67 (8.2)	27 (3.3)	9 (1.1)	10 (1.2)
	Clinician sample	705 (85.8)	68 (8.3)	22 (2.7)	7 (0.8)	20 (2.4)

Table 2. Mean Likert scale scores for perceptions of self-sampling and clinician sampling among 822 women who completed the exit interview

Acceptability measure on a scale of 1 - 5	Self-sample, mean (SD)	Clinician sample, mean (SD)	p-value
Embarrassed	4.91 (0.41)	4.79 (0.68)	0.0005
Discomfort	4.84 (0.52)	4.42 (0.81)	0.0005
Ignored	4.93 (0.52)	4.92 (0.54)	0.89
Confident*	4.10 (1.3)	4.92 (0.54)	0.0005
Intrigued*	4.77 (0.68)	4.74 (0.79)	0.41

SD = standard deviation.
*Reverse-coded for purposes of analysis.

significant differences in the mean Likert scores (Table 2). Women were more confident when the sample was taken by a clinician (64.7%) rather than by self-sampling (59.5%) ($p=0.03$), also with significant differences in the mean Likert score. These findings were corroborated during the FGDs, as illustrated by the quotes below.

‘I prefer doing it [self-sample] myself; to me, it was easier than having someone else doing it to me.’ (FGD1)

‘It was [more] comfortable to do the self-sampling myself than to be done by the doctor.’ (FGD6)

‘I would choose to do it [sample] myself because I get embarrassed to expose myself to the doctor.’ (FGD2)

Instructions on self-sampling procedure

This was explored in the FGDs only. All the women thought that the CHWs’ verbal explanation of how to perform the self-sample procedure was sufficient and could not think of ways in which the description of the procedure could be improved. When asked whether diagrams or illustrations would be useful, mixed views were expressed. Most women did not think it would be beneficial to include diagrams and preferred a verbal explanation only. Some felt that pictures would be disturbing.

‘Those pictures of cervix and wombs are scary.’ (FGD 6)

Some women, however, did think the use of diagrams and illustrations would be helpful.

‘I would prefer an explanation and a diagram because the doctor will explain and at the same time show you on the picture how to do it [self-sample].’ (FGD 4)

All participants noted the importance of using simple and easy-to-understand expressions when explaining how to perform the self-

sampling. While some thought that an explanation in English would be acceptable, the majority would prefer the explanation to be given in their mother tongue.

Sampling method preference

In the cross-sectional survey, more women (45.1%) preferred their cervical sample to be taken by the clinician, while 33.8% preferred self-sampling and 21.0% did not have a preference for one method over the other. FGD participants gave more insight into why the participants preferred the health worker to take the sample rather than to self-sample. Those who preferred the sample to be taken by a health worker justified their choice by stating that the doctor is a trained professional and therefore more capable of taking the sample. Furthermore, he or she could also investigate, identify and treat any other abnormalities that the patient might not be able to see.

‘I would rather have a doctor do it [sample]. When she opens down there, she can examine and see other things inside down there, which I would not be able to notice myself.’ (FGD 5)

However, some of the women who preferred taking the sample themselves stated that when the health worker collected the sample they found it painful and were embarrassed.

We further analysed the cross-sectional data to see the relationship between sampling method preference and the demographic variables of the respondents. On bivariate analysis, women with a tertiary level of education and HIV-negative women were significantly more likely to prefer self-sampling to clinician sampling, while women who were not on any form of contraception and those who lived in informal settlements were significantly more likely to prefer clinician sampling (Table 3).

A multinomial logistic regression analysis that included age categories, education level, type of housing, HIV status, smoking and contraceptive use was performed to determine the predictive factors of sampling preference (self-sampling, clinician sampling or no preference for method). The reference group was those women with preference for the clinician sampling method. Accordingly, each predictive factor has two parameters, one for predicting preference for self-sampling rather than clinician sampling and one for predicting no preference for either method. Women who used contraception and those who smoked were ~1.5 times more likely and those living in houses they owned twice as likely to prefer self-sampling to clinician sampling. Women with primary education and above were ~3 times and HIV-positive women ~1.5 times more likely to prefer clinician sampling to self-sampling or to have no preference for either method (Table 4).

Table 3. Associations between women's reported sampling preference and demographic and clinical characteristics

Variable	Prefer self-sampling (N=278)	Prefer clinician sampling (N=371)	No preference (N=173)	p-value
Age group (years), n (%)				0.99
30 - 39	123 (44.2)	167 (45.0)	78 (45.1)	
40 - 49	86 (30.9)	117 (31.5)	57 (32.9)	
50 - 59	55 (19.8)	71 (19.1)	30 (17.3)	
≥60	14 (5.0)	16 (4.3)	8 (4.6)	
Education, n (%)				0.045
None	3 (1.1)	5 (1.3)	3 (1.7)	
Primary	37 (13.3)	47 (12.7)	22 (12.7)	
Secondary	207 (74.5)	304 (81.9)	133 (76.9)	
Tertiary	31 (11.2)	15 (4.0)	15 (8.7)	
House, n (%)				0.02
Informal	71 (25.5)	132 (35.6)	45 (26.2)	
Formal	155 (55.8)	196 (52.8)	101 (58.7)	
Owns house	33 (11.9)	21 (5.7)	15 (8.7)	
Other	19 (6.8)	21 (5.7)	12 (7.0)	
Smoking, n (%)				0.02
Never smoked	204 (73.4)	306 (82.5)	136 (78.6)	
Current/former	74 (26.6)	65 (17.5)	37 (21.4)	
HIV, n (%)				0.001
Positive	93 (33.5)	173 (46.6)	82 (47.4)	
Negative	185 (66.5)	198 (53.6)	91 (52.6)	
Contraceptives, n (%)				0.005
Yes	145 (52.2)	148 (39.9)	85 (49.1)	
No	133 (47.8)	223 (60.1)	88 (50.9)	
Previous Pap smear, n (%)				0.31
Yes	231 (83.1)	292 (79.0)	135 (78.0)	
No	47 (16.9)	78 (21.0)	38 (22.0)	

In multivariable analysis, educational status, contraceptive use and HIV status remained significant. Type of housing was no longer significant in the multivariable model.

Willingness to self-sample at home

The majority (93.9%) of the women who participated in the cross-sectional survey said that they would be willing to self-sample at home. Going deeper into this discussion during the FGDs, many women mentioned that the idea of collecting the self-sample at home was appealing, because of home comfort. Even those who lived in crowded homes said that they would be able to find a space to take the sample. When asked how they would feel if somebody saw them taking the self-sample or found the self-sample at home, most felt confident that they would be able to explain what they were doing and why they were taking the sample.

'It's like the same as putting a tampon, if someone sees you putting it they have the same reaction, and you explain.' (FGD 5)

However, during the FGDs when women were told that the self-sample collected at home would need to be returned to the health facility, most suggested that they would then prefer to collect the self-sample at the clinic instead. Reasons for choosing to do so included costs associated with having to come to the clinic twice, while having a health professional at hand who could give reassurance if needed was also important for some. Some women also raised concerns about specimen contamination and the possibility of forgetting or being unable to return it to the clinic in time.

'It's waste of time and money coming here and going home and coming back here again whereas I could have done everything here all at once.' (FGD 5)

'It will also depend on having money to come back to the clinic, if I have money then I will come.' (FGD 5)

'I would be worried about something getting into the sample and contaminating it.' (FGD 3)

'I would worry about it getting dry before bringing it back.' (FGD 5)

Discussion

In this study, we integrated questionnaire-based interviews, which were used to determine individual experiences of the patients of both self-sampling and clinician-collected sampling, with FGDs, which were used to obtain an in-depth discussion to understand their beliefs and opinions with regards to self-sampling.

As described in Table 1, and corroborated by the findings in the FGDs, even though there was initial surprise when women were asked to take the sample, they had more positive perceptions about self-sampling than clinician sampling, most notably regarding less embarrassment and discomfort when self-collecting the sample. Previous studies have noted similar findings from both HICs and LMICs.^[3,12-15] However, women were significantly less confident about the quality of the self-collected sample compared with the clinician-collected sample. This lack of confidence in self-sampling has been reported in previous studies.^[19,20] Incorporating additional information to assure women that self-sampling does not compromise the quality of the sample and that many studies have found self-

Table 4. Parameter estimates from multinomial logistic regression models describing associations between women’s reported sampling preference* and demographic and clinical characteristics

Predictor variable	Prefer self-sampling (n=371)			No preference (n=173)		
	p-value	OR†	95% CI	p-value	OR†	95% CI
Age (years)						
30 - 39	0.646	0.825	0.36 - 1.86	0.643	0.798	0.31 - 2.07
40 - 49	0.745	0.874	0.38 - 1.97	0.785	0.876	0.34 - 2.26
50 - 59	0.954	0.976	0.43 - 2.23	0.696	0.824	0.31 - 2.17
≥60 (ref)	-	-	-	-	-	-
Education						
None	0.146	0.308	0.06 - 1.51	0.636	0.673	0.13 - 3.47
Primary	0.013	0.370	0.17 - 0.81	0.090	0.458	0.19 - 1.13
Secondary	0.001	0.328	0.17 - 0.63	0.029	0.432	0.20 - 0.92
Tertiary (ref)	-	-	-	-	-	-
Type of housing						
Informal	0.182	1.649	0.79 - 3.43	0.786	0.896	0.41 - 1.98
Formal	0.333	1.420	0.70 - 2.89	0.615	1.211	0.58 - 2.55
Owens house	0.026	2.719	1.13 - 6.57	0.140	2.037	0.79 - 5.28
Other (ref)	-	-	-	-	-	-
Smoking						
Current/former	0.026	1.559	1.06 - 2.30	0.388	1.224	0.77 - 1.94
Never smoked (ref)	-	-	-	-	-	-
HIV status						
Positive	0.009	0.639	0.46 - 0.90	0.619	1.101	0.75 - 1.61
Negative (ref)	-	-	-	-	-	-
Contraceptive						
Yes	0.003	1.670	1.19 - 2.35	0.030	1.537	1.04 - 2.27
No (ref)	-	-	-	-	-	-

OR = odds ratio; CI = confidence interval.
 *Preference for clinician sampling is the reference category.
 †OR >1 indicates an increased preference for self-sampling (or no preference) compared with clinician sampling. OR <1 indicates decreased preference for self-sampling (or no preference) compared with clinician sampling.

sampling to be as reliable as clinician sampling may help boost their confidence to obtain a self-sample.^[7,8,10,11]

Despite acceptability of the self-sampling method, about half of the women overall (45.1%) preferred the samples to be collected by the clinician. Anhang *et al.*^[21] reported similar findings in 2005 among Hispanic women in New York City, where there was an overwhelming acceptance of self-sampling, but more preference for clinician sampling. In the FGDs, some participants expressed concern about their ability to take a high-quality sample and would therefore prefer a clinician to obtain it. Others were worried about performing the procedure incorrectly and causing harm. Still others expressed that they would prefer the sample to be collected by a health worker, who apart from taking a good-quality sample would also be able to detect and investigate any abnormalities the patient might be unable to identify. Previous studies have found similar concerns in various groups of women.^[12-14,16,19] In the present study, HIV-negative women and women using contraception were more likely to prefer self-sampling, while HIV-positive women were more likely to prefer clinician sampling. Many HIV-positive women in SA have access to reproductive healthcare services integrated into the antiretroviral (ARV) programmes and trust their caregivers, and may therefore feel safer and more confident if a health worker takes the sample.

Many women from both the survey and the FGDs found the idea of performing the self-sampling procedure at home appealing despite sometimes having unfavourable home settings. However, the realisation during FGDs that they would need to return the specimen to the clinic was a deterrent to home self-sampling. Women raised

concerns about specimen contamination, being unable to return the sample to the health centre in time, the cost of making two clinic visits, having to take additional time off work, and not having a health professional at hand to help and give reassurance if needed. It is worth noting that self-sampling in the health facility has the potential to reduce patient load on the limited number of health personnel in poorly staffed clinics and reduce patient waiting times in overcrowded clinics.

Conclusion

This study has highlighted positive perceptions of self-sampling for cervical cancer screening in this low-resource setting. Concerns raised by the women could be addressed by appropriate health education and counselling on self-sampling. The study highlighted some limitations to collecting self-samples at home in this environment. However, many health centres in developing countries have insufficient human resources to collect cervical samples from all women who require screening. In this situation, self-sampling in the health facility may contribute significantly to reducing long waiting times and congestion in health centres. Pilot implementation studies are needed to determine how best to incorporate this approach in national screening programmes

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