WOMEN'S PERSPECTIVES OF SELF-SAMPLING FOR CERVICAL SCREENING IN SOUTH AFRICA

Presented @HPV 2107

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Disclosures

- **National Cancer Institute funded the study**
- **Collaboration between:**
  - **University of Cape Town, South Africa**
  - **Columbia University, New York**
  - **Cepheid**

Introduction

- Molecular testing for HPV has been recommended as an alternative to cytology based screening by the WHO in low resource settings
- HPV tests have been reported to be more sensitive than cytology and visual inspection methods in detecting high-grade CIN and cancer
- HPV test is therefore an attractive alternative to cytology based screening in low resource settings

Introduction/Objective

- HPV tests also have the advantage that vaginal sample can be collected by the woman herself, which presumably will increase coverage
- Self-collected vaginal samples for HPV testing have been shown to be as reliable as physician-collected samples in many studies
- We explored women's perceptions, acceptability and willingness to self-collect samples for cervical screening in a low resource setting in South Africa

Methods

- Mixed methods study using exit questionnaires & focus group discussions (FGD) carried out in Khayelitsha, Cape Town
- It was done as part of the NCI funded study: **Optimizing point-of-care HPV testing for cervical cancer prevention in south Africa. UH2 CA189908**
- Women aged 30-65 years were included
- All women collected **self-sample** after verbal explanation of the procedure by a CHW.
- All had **clinician-collected samples**, then visual inspection with acetic acid, colposcopy, and histology sample collection

Methods: Exit questionnaire

- The exit questionnaire examined the level of embarrassment, discomfort, confidence to carry out self-sampling, whether they felt ignored, on a 5-point scale from 1 = “Extremely” to 5 = “Not at all”.
- There were also questions on preference of collection method, and whether they would be willing to collect a self-sample at home.

Methods: FGD

- Six FGDs were conducted at Khayelitsha study site
- Each group consisted of 6 to 7 participants
- All FGDs took place once participants had completed all clinical assessments
- Discussions lasted between 45 and 60 minutes.
- Using an interview guide, discussions were conducted in Xhosa and were digitally recorded, translated and transcribed verbatim.
- Data was entered into QRS Nvivo10, a software package designed for systematic management and analysis of qualitative data.

Results

- A total of 822 women participated in the exit interviews
- 41 women took part in in the FGDs.
  - Average age is 41 yrs (ranges btw 30-46)
  - The majority of women lived in houses (21/41) and shacks (16/41)
  - lived in homes with an average of 2.6 adults (including the participant)
  - Most of them had education level of grade 9-11 (26/41)

Participant demographic/clinical characteristics

Age (mean)	42.5 ± 8.9
Parity (mean)	2.6 ± 1.5
=<Grade 9 education Grade 10 Grade 11 =>Grade 12	276 (33.6%) 144 (17.5%) 191 (23.2%) 211 (25.7%)
Non-smokers Current smokers Former smokers	646 (78.6%) 125 (15.2%) 51 (6.2%)
Unemployed Full time employment Part time employment	474 (57.6%) 258 (31.4%) 90 (11%)

HIV status Pos Neg	 403 (49%) 419 (51%)
Contraception Yes No	 444 (54%) 378 (46%)
Previous pap Yes No	 659 (80%) 183 (20%)

Women's perception to self-sample

	Self-collected	Clinician-collected
Embarrassed		
Extremely	3 (0.4%)	15 (1.8%)
Very	3 (0.4%)	6 (0.7%)
Moderately	8 (1.0%)	15 (1.8%)
Slightly	39 (4.7%)	60 (7.3%)
Not at all	769 (93.6%)	726 (88.3%)
Discomfort		
Extremely	2 (0.2%)	14 (1.7%)
Very	9 (1.1%)	11 (1.3%)
Moderately	16 (2.0%)	50 (6.1%)
Slightly	60 (7.3%)	287 (34.9%)
Not at all	**735 (89.4%)**	460 (56.0%)

	Self-collected	Clinician-collected
Ignored		
Extremely	13 (1.6%)	15 (1.8%)
Very	1 (0.1%)	0 (0.0%)
Moderately	0 (0.0%)	1 (0.1%)
Slightly	6 (0.7%)	2 (0.2%)
Not at all	802 (97.6%)	804 (97.8%)
Confident		
Extremely	489 (59.5%)	**532 (64.7%)**
Very	112 (13.6%)	134 (16.3%)
Moderately	110 (13.4%)	77 (9.4%)
Slightly	39 (4.7%)	32 (3. 9%)
Not at all	72 (8.8%)	47 (5.7%)

Women's perception to self-sample: FGD

- FGD participants were asked how they felt when first asked to provide a self- sample.

"I was shocked because I came to get tested and now I am told to do it myself so it was surprising"

- Some were curious and excited at the prospect of taking a self-sample.

"I was first happy because I was given an opportunity to do it myself, so when I did it I had no worries and I felt good"

"What came to mind was that the reason they gave me that stick is because I have a right with my body to do self-sampling on my own"

"I thought it was a cool idea to be able to do it myself"

Women's perception to self-sample: FGD

- The majority of participants found the self-sample procedure easy to perform, and less painful than having the doctor take a sample.

"I prefer doing it [self-sample] myself; to me it was easier than having someone else doing it to me"

"It was [more] comfortable to do the self-sampling myself than to be done by the doctor"

"It was painful after the doctor took the sample and I could not walk properly"

Women's perception to self-sample: FGD

- Some women were not confident about performing the procedure correctly and afraid they could cause themselves undue harm or pain.

"I was worried about doing the method correctly"

"I could feel that I was not doing it correctly because when I did the sample it did not come so I had doubts that I got what the doctor want"

"The pain, I thought of how painful it will be"

"I thought I was going to hurt myself"

Women's perception to self-sample: FGD

- We asked whether the use of diagrams and pictures would be useful.
- Most of them did not like the idea of diagrams:

"When you see a picture you ask yourself "Is that how I look inside?" so it does shock you so I would rather not see the picture"

"The explanation was clear enough for me and if there were pictures it was going to scare me"

"Those pictures of cervix and wombs are scary"

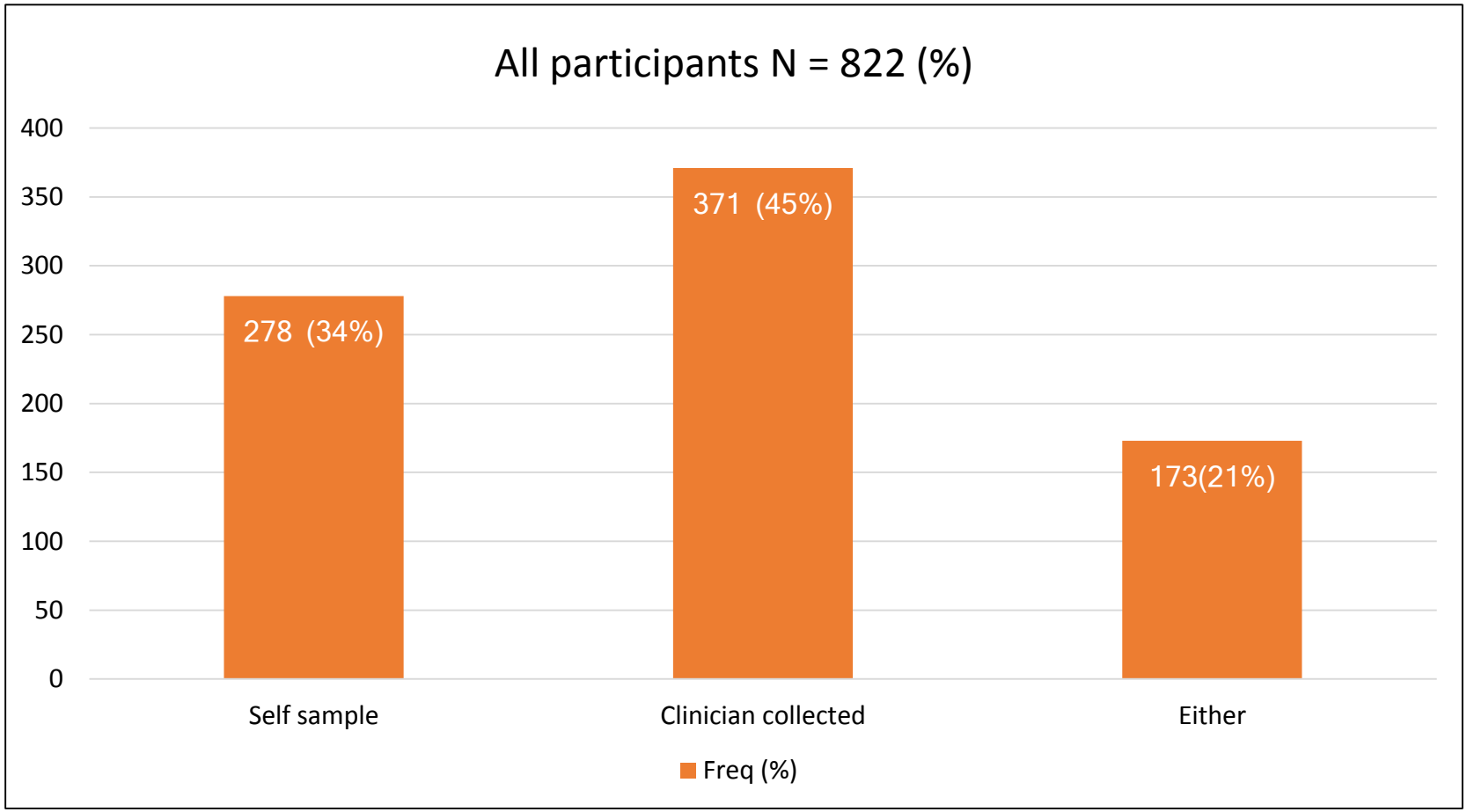
Women's perception to self-sample: FGD

- Some women did however 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]"

"It should be done the same as the female condom instruction leaflet. If there could be an instruction leaflet wrapping, on the stick that has instructions on how to do it [self- sample], that could help"

Preferred method for sample collection for cervical cancer screening



Preferred method for sample collection

- Univariate analysis to look at the relationship between participants' demographics and preferred sampling method
  - level of education ($p = 0.005$)
  - type of housing ($p = 0.02$)
  - HIV status ($p = 0.001$)
  - use of contraceptives ($p = 0.005$)
- A logistic regression model, women with HIV positive status ($p=0.009$) and not on contraception ($p=0.004$) are more likely to prefer clinician-sampling than self-sampling.

Preferred method for sample collection: FGD

- While SS is a widely acceptable method, most participants preferred the sample to be taken by a trained professional who would be able to detect and investigate any abnormalities they themselves might be unable to identify.

"I would rather have a doctor do it [sample]. When she open down there, she can examine and see other things inside down there, which I would be able to notice myself"

"I would choose the doctor because they know what to do, I'm scared to do it [take sample] myself"

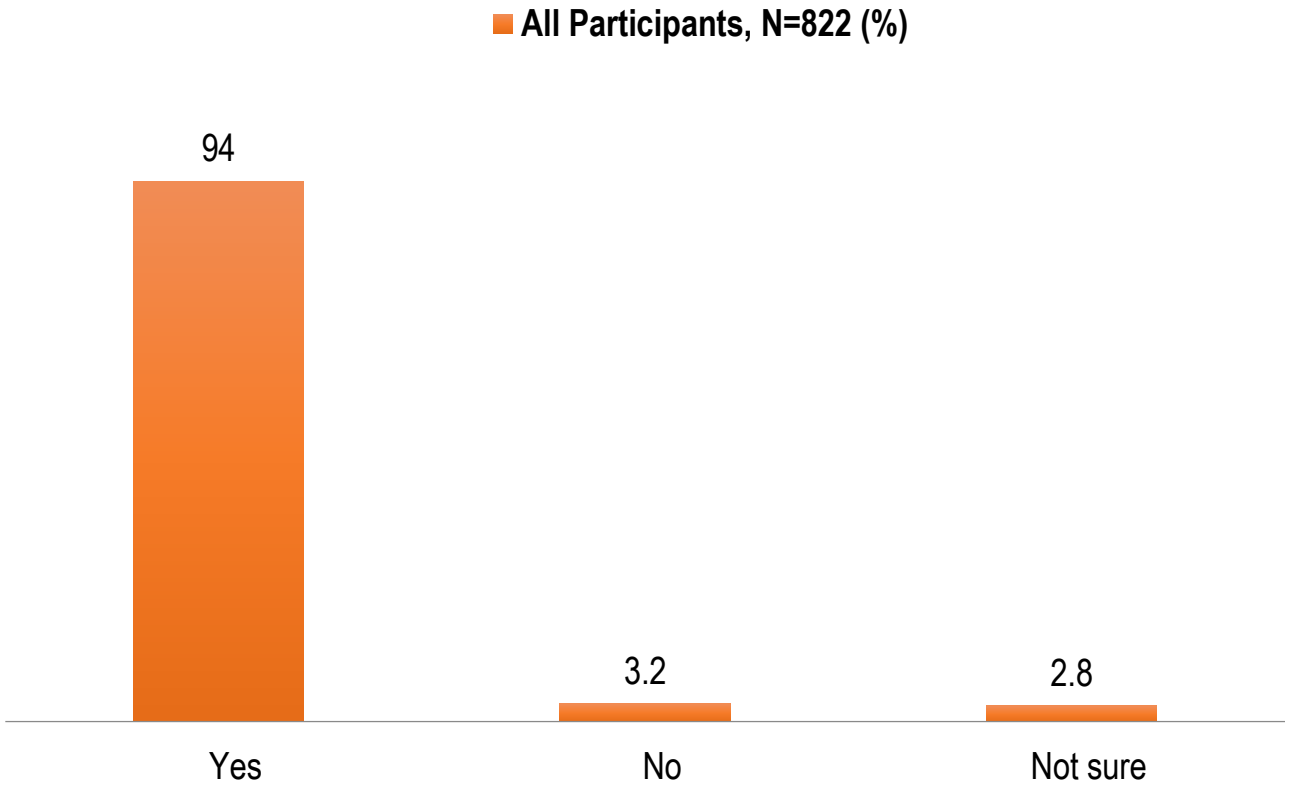
Preferred method for sample collection: FGD

- Those who preferred taking the sample themselves stating that they found it less painful and were embarrassed by having it done by the doctor.

“It was more comfortable to do the self-sampling myself than to be done by the doctor”

“I would choose to do it [sample] myself because I get embarrassed to expose myself to the doctor”

Willingness to perform self-sample at home for cervical cancer screening



Willingness to perform self-sample at home: FGD

- Most women found the idea of performing the self-sample at home appealing, in terms of the comfort of their own homes.
- Even living in crowded homes was not seen as a barrier to SS at home and in case a family member saw them taking the sample, 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"

Willingness to perform self-sample at home: FGD

- However, the fact that the sample would need to be returned to the clinic caused most to prefer the self-sample to be taken at the clinic instead.
- Women raised concerns about:
  - specimen contamination;
  - being unable to return the sample to the clinic in time;
  - costs of making two clinic visits;
  - having to take additional time off work and
  - not having a health professional at hand to provide assistance and assurance if needed

Willingness to perform self-sample at home: FGD

"I would be worried about something getting into the sample and contaminating it"

"I would worry about it getting dry before bringing it back"

"It's waste of time and money coming here and going home and coming back here again were as I could have done everything here all at once"

"It will also depend on having money to come back to the clinic, if I have money then I will come"

Summary/Conclusions

- Attitudes regarding self-sample collection were exceedingly positive in this study population based in Cape Town, South Africa.
- However, a substantial portion preferred collection by a healthcare worker due to concerns about the quality of the self-collected samples, fear of hurting themselves and the desire to get a pelvic examination, therefore preferring clinician sample.
- Of note is the difference in the preferred method of sample collection (self-sample vs. physician-collected) by HIV status

Summary/Conclusions

- While participants were almost universally willing to perform self-sampling at home, there are major concerns about logistical requirements of taking the sample at home and then returning the specimen to a health facility.
- Implementation studies are needed to determine how to best incorporate this approach in national screening programs given these concerns raised by the women.

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