Cervical cancer prevention: Perceptions of women attending Knysna primary health care clinics

By Dr Liesl Visser

Thesis presented in partial fulfilment of the requirements for the degree Master of Family Medicine at the University of Stellenbosch

Supervisor: Dr LS Jenkins
Declaration:

I, Liesl Visser, the undersigned, hereby declare that the work contained in this assignment is my original work and that I have not previously submitted it, in its entirety or in part, at any university for a degree. I also declare that the ethical approval for the study was obtained from the Health Research Ethics Committee of Stellenbosch University (Reference number: N11/07/202)

23 June 2012

____________________  __________________
Signature                  Date
Abstract

Background

Cervix cancer is the cancer with the highest prevalence and mortality in Africa. The current screening method is by pap-smear, but other methods of screening and primary prevention against human papillomavirus (HPV) by immunization are currently being investigated. The aim of this study was to explore the experience, knowledge, attitude and beliefs of the clinic attending women attending clinics in the Knysna sub-district regarding the current cervical screening programme and to obtain their opinion on the possible alternatives methods available.

Method

A prospective quantitative and qualitative study was conducted in six primary health care clinics in the Knysna sub-district. Data was collected from 206 completed questionnaires, by sequentially selected women aged 20-65 years. Six focus group discussions were held. Descriptive results were presented as means for continuous/ordinal data, and percentages for categorical data. The Chi-square test was used to test for relationships, Mann-Whitney and Kruskal-Wallis tests were used to compare groups’ mean values and Spearman correlations for comparison between ordinal variables. A 5% significance level (p<0.05) was used as guideline for determining significant results. The qualitative data was analyzed using the framework approach.

Results

One hundred and seventy nine (87%) knew that a pap-smear was to screen for pre-malignant or malignant cells. Seventeen participants (8%) didn’t believe that cervix cancer is preventable by regular pap-smears and 204 (99%) believed that abnormal cells are treatable before it becomes cancer. Hundred and twenty three (60%) didn’t know that different screening programmes exist for HIV positive and negative women.

One hundred and forty one (68%) had undergone pap-smears. The result was collected by 115 (82%) of which 108 (77%) reported understanding the meaning. Fourteen(10%) were referred for further treatment, 47 (33%) were requested to return for another smear the subsequent year. Of this collective group, 31 (62%) complied.

The Visual Inspection with Acetic acid (VIA) method was acceptable to 153 (74%). HPV DNA-testing was acceptable to 171 (83%). HPV vaccination was acceptable to all participants.

The focus groups identified the following themes: knowledge, application, personal esteem, community influence and protection of youth.
Conclusion

Participants had a good basic knowledge of pap smears. Uptake of pap-smears were acceptable but the follow-through was incomplete and influential, externally factors were identified. The influence of the community’s opinion on the women’s ideas should not be disregarded. The participants were serious about protecting the youth and felt unable to do so with the current system. Alternative methods of cervix cancer prevention are acceptable to the community in Knysna and should be explored further.

Background

Cervix cancer is the most common cancer in women in Africa according to the most recent World Health Organization (WHO) report.\(^1\) Yet it is the most preventable cancer through regular screening.\(^1,2,\) Eighty-three percent occur in developing countries, of which Sub-Saharan Africa has the highest incidence, compared to just 3.6% in developed countries, where there are extensive and established screening programs.\(^3,4,\) In South Africa, the lifetime risk is approximately 1 in 41, and 5700 new cases are reported annually.\(^5,6,\)

Human papillomavirus (HPV) infection is the most common sexually transmitted disease worldwide.\(^7\) HPV genotypes 16 and 18 are associated with about 70% of cervical cancer and are classified as “high-risk” genotypes.\(^7\) Around 90% of HPV infections are cleared by the body within 2 years. If HPV persists beyond 12 months, especially the high risk genotypes, the woman is at risk of developing cervix cancer.\(^7\) Among patients with cervical cancer, HPV was present in 99.7%.\(^8\) In a healthy woman this process takes between 9 and 15 years.\(^9\)

Cervix cancer is labelled as an AIDS-defining illness. The HIV positive woman has an increased risk of persistent HPV infection and is 4.5 times more likely to develop biopsy confirmed dysplasia, have significantly more advanced disease at presentation and presents on average 15 years earlier.\(^9-11\)

Well organized population screening is cost–effective relative to the treatment of invasive cancer.\(^12,13\) Screening is recommended to start by the age of 21 years or within 3 years of the onset of sexual debut, if earlier than 21 years.\(^5\) Risk reduction is directly related to more frequent screening.\(^5\)

The gold standard in screening is the Papanicolaou smear (Pap-smears), identifying precancerous cells, which allows early, fertility-sparing, less-radical procedures, which may also be curative.\(^14\) Pap-smears have a sensitivity of 50-75% and specificity of 98-99%.\(^13\) Adenocarcinoma, which comprises 15% of cervix cancers, may go undetected despite screening. Approximately 8% of Pap-smears can’t be interpreted due to poor sampling or preparation. Liquid-based screening (LBS) techniques reduces the repeat rate to around 2%, with improved efficiency.\(^6\)

Previously, opportunistic screening was performed on woman who attended family planning and antenatal clinics. After implementation of the South African screening policy, which offers asymptomatic HIV negative women 3 free cervical smears in their lifetime, with 10 year intervals starting at the age of 30 years, a marked reduction in the total number of smears performed occurred.\(^5,9,15\) No national policy on revised screening among HIV positive women is available. The Western Cape provincial government has compiled a different screening policy which calls for pap-smears every 3 years among the HIV positive women, starting at the age of 20 years.\(^16\) In the general population, uptake of screening varied among women with regards to parity, level of
education, smokers, marital status and demographics.\textsuperscript{5,12} Primary, as well as follow-up attendance decreases significantly without the involvement of community health workers (CHW) or other forms of reminders. Just two home visits by CHW increased the appointment attendees to at least 95%.\textsuperscript{9,17}

There are many personal and logistical obstacles to accessing screening services. Anxiety, lack of understanding of the need for screening and personal factors play important roles.\textsuperscript{12,18,19} A significant number of women who did not participate in routine screening programs were agreeable to performing a self-sampling HPV test.\textsuperscript{19,20} This could become a very relevant method of screening, as demonstrated in the Netherlands.\textsuperscript{19-21}

HPV DNA-testing has proved to be more sensitive than conventional cytology to detect any cervical intra-epithelial neoplasia and HPV infection. The specificity is similar to that of a pap-smear but the sensitivity is more than 10\% higher than for cytology.\textsuperscript{13} A negative predictive value of 97\% may allow for longer screening intervals (6 years - 10 years).\textsuperscript{11,13,22} A variety of products are available, some to be obtained by health professionals and others self-obtainable samplers, which renders similar results as confirm by molecular testing.\textsuperscript{23} The self-test would relief pressure on the primary health care (PHC) clinics, is experienced as less invasive and has a built in control mechanism to ensure adequate sampling.\textsuperscript{13}

Visual inspection with acetic acid (VIA) is an alternative to routine cytology. The immediate availability of the result, high accuracy as well as the benefits of no loss to follow-up makes this a desirable alternative to pap-smears. It will also decrease the amount of referrals for colposcopy and large loop excision of the transformation zone (LLETZ) when combined with immediate cryotherapy which renders this to be a potentially viable alternative in resource restricted settings.\textsuperscript{10} It’s sensitivity range between 66-96\% and has a negative predictive value of between 92-97\%. Unfortunately it has a specificity mean of 82\% which can lead to over-treatment and over-investigation. Strengthening of existing infrastructure and training of staff would be crucial for the implementation of this method.\textsuperscript{13}

In the limited resource environment, we need to look at more radical solutions like primary prevention with HPV vaccination. Preliminary investigation has shown this to potentially be cost-effective, according to the WHO.\textsuperscript{7} This would entail immunizing girls before they are exposed to HPV. Both vaccines available shows >90\% protection against persistent HPV and 100\% efficacy against moderate precancerous lesions.\textsuperscript{7} The administration could be linked to the educational system or the current immunization program and this approach would be more effective and easier to implement. Yet the benefit of this will not be seen for many years but over time (estimated at 20 years), this will lower the logistical demands on the health system.\textsuperscript{3,4,7} In comparison to the 3 pap-smears per lifetime approach which has a 26\% mean risk reduction, vaccination alone has a 43\% mean risk reduction and a combination of vaccination and pap-smear has a 61\% cancer risk reduction.\textsuperscript{7}

The aim of this study was to explore the experience, knowledge, attitude and beliefs of women attending clinics in the Knysna sub-district regarding the current cervical screening programme and to obtain their opinion on the possible alternatives methods available. The objectives included: To assess women’s experience, knowledge, attitude and beliefs about precancerous disease, Pap-smears and their relevance in health care and the screening programmes available. To further also assess the women’s participation in the screening programmes, for any factors that may influence the uptake of screening and to gather their opinions on other possible screening methods and preventative initiatives.
Methods

Setting

The study was conducted at the 6 permanent primary health care clinics in the Knysna sub-district. This includes Knysna and Sedgefield, both semi-rural towns along the Garden Route of the Western Cape Province of South Africa. This area has an estimated population of 60,000 people which is increasing rapidly, partly due to the immigration of people from the Eastern Cape. The clinics are nurse-driven with visiting doctors from the local hospital some days of the week. Referrals are made to either the visiting doctor or directly to the hospital. The patient population is ethnically, literacy and social-economically diverse with mostly the non-medical aid patients utilizing the clinics for care.

Study design and sampling

This was a prospective, mixed quantitative and qualitative study. The quantitative method collected specific background information on the clinic attending women whereas the qualitative method provided in-depth opinions and explanations. Inclusion criteria were: any women who attended the clinic (as patient, mother, companion etc.), aged between 20 to 65 years, able to speak Afrikaans, English or Xhosa and who consented to the completion of the survey. Prior to conducting the study, ethical approval was obtained from the University of Stellenbosch Health Research Ethics Committee and the Department of Health’s Provincial Strategy & Health support directorate.

Quantitative data collection: sampling and analysis

The sample size needed to estimate a proportion with a 95% Confidence Interval (CI) and a precision of 5% (Cp = 5%), was determined to be 200 participants. The sample required from each clinic was stratified according to the percentage of the total population served by that clinic. A customized questionnaire was compiled with fixed response answers and space for additional comments for 3 questions. The data was collected during a 2 week period in January 2012. Sequentially selected women who gave informed consent, completed the questionnaire with the researcher or the research assistant privately in an allocated consultation room.

The data was manually captured on a customized Excel spread sheet and statistically analysed by the Centre for Statistical Studies, University of Stellenbosch.

Descriptive results were presented as means for continuous/ordinal data, and percentages for categorical data. The Chi-square test was used to test relationships between categorical variables. Differences in mean values of continuous/ordinal variables between groups were tested using non-parametric Mann-Whitney and Kruskal-Wallis tests. Comparisons between ordinal variables were done using non-parametric Spearman correlations. A 5% significance level (p<0.05) was used as guideline for determining significant results.

Qualitative data collection: sampling and analysis
Six focus group discussions were held, one per clinic, which consisted of women who already completed the questionnaire and were willing to participate in a discussion. The groups consisted of 4 to 9 women, aged between 20 and 65 years, and was conducted in a consultation room at the clinic. Each was conducted in the language of their choice with verification of information given in Xhosa by means of immediate translation into English by the research assistant and then checking the translation with the participants. The focus group discussions were based on the exploratory question: What do you think about cervical cancer prevention? The discussion was further facilitated with visual aids to explain alternative screening or prevention methods and was based on the literature. The discussions were digitally recorded and after transcription, the data was analysed using the framework approach. After familiarization with the data, a thematic framework was identified by the researcher and the study supervisor. The thematic framework was then used to systematically index the data before the charting process was done. Lastly, the charts were used to define concepts and find associations between themes.
**Results**

**Quantitative data**
Two hundred and six questionnaires were completed. Two women declined participation. The mean age of participants was 36.6 years and the mean age of sexual debut 17.9 years. Eleven participants (5%) had not yet undergone HIV testing. More than a quarter of the group (n=53, 27%) were HIV infected. The average age of women who did not undergo a HIV test was significantly higher (52.2 years) than those who had been tested (35.7 years) (p<0.01). There was a significant relationship between the age of sexual debut and the women’s HIV status. The mean age of sexual debut among the HIV infected group were 17 years in comparison to the HIV negative group with a mean age of 18.1 years (p<0.01).

The basic knowledge of cervix cancer prevention was assessed by four closed questions with fixed responses in the questionnaire (Table I). One hundred and eighty (87%) of the women had heard about a pap-smear. Eighty seven (42%) knew that a pap-smear was to screen for pre-malignant cells and a further 92 (45%) thought it to be for cancer screening. One hundred and eight participants (52%) believed that an abnormal pap-smear does not signify that the woman has cancer. Almost all the participant (n=204, 99%) believed that abnormal cells are treatable before it becomes cancer. Yet 17 (8%) participants did not believe that cervix cancer can be prevented by regular pap-smears.

All questions and answers scored equally and the participants’ score on the number they had correct was compared to factors that could potentially influence their knowledge. The women with the lowest knowledge scores were single, smoking and who were not fulltime employed. The women’s schooling played a statistically significant role (Spearman r=0.3, p=0.04), as did their age of sexual debut, also but to a smaller degree (Spearman r=0.15 , p=0.03). The number of children and their HIV status did not influence their knowledge scores.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
</table>
| **1 Do you think a pap smear is to:** (Just mark the one you think is most correct) | • Treat infection on the female organs  
• To help you fall pregnant  
• To look for cancer on the mouth of the womb  
• To treat cancer on the mouth of the womb  
• To look for any abnormal cells on the mouth of the womb  
• I have no idea at all |
| **2 Do you think that an abnormal pap smear result means that you have cancer of the cervix?** | • Yes  
• No |
| **3 If there is an area with abnormal cells, do you think that it is possible to treat the area with abnormal cells before it becomes cancer?** | • Yes  
• No |
| **4 Do you think that cervix cancer can be prevented if you go for regular pap smears?** | • Yes  
• No |

Table I: Questions and answers from questionnaire to assess knowledge on cervix cancer prevention
One hundred and twenty three (60%) of the participants did not know that different screening programmes are implemented in the Western Cape for HIV positive and negative women and only five participants (2%) knew the detail of the programmes.

Just less than a third (n=65, 32%) of participants had never been for a pap-smear. Figure 1 provides a graphic display of the participation in the cervical cancer screening programme.

![Figure 1: Cervical cancer screening participation](https://scholar.sun.ac.za)

Of the 141 that underwent pap-smears, 115 (82%) reported collecting their results, of which 108 (77%) believed they understood the meaning of the results. Of the original 141 who underwent a
pap-smear and who went back to collect their results, 50 (35.5%) were referred for further treatment or asked to come back to repeat their pap-smear within a year. Of this group, 19 (38%) participants reported to not have complied with this request. This demonstrated 52 missed opportunities in the prevention of cervix cancer. Missed opportunities are categorized as:

1) the failure to ensure that the woman receive her pap smear result and thus ensure that the result was reviewed (n=26),
2) the failure to effectively communicate the result to the woman, optimize health education and counsel on the recommended follow-up (n=7) and
3) as the failure to ensure that the women attend the recommended follow-up (n=19).

All of these categories influence the quality and outcome of cervical cancer screening. There was no statistically significant difference in uptake of pap-smears among the HIV infected (71.7%), and uninfected participants (66.9%, p=0.51). Eight participants (4%) had undergone a hysterectomy.

The influence of different factors on the uptake of pap-smears is summarized in table II. Statistically significant factors were: relationship status, age of sexual debut, number of children they had and schooling. Schooling was significant as a negative contributor (p=0.01), but in practice there is little difference in the schooling completed. HIV status did not make a statistically significant contribution to the uptake of pap-smears.

### Table II: Cervical cancer screening participation and the influence of external factors

<table>
<thead>
<tr>
<th>Schooling</th>
<th>Average within Gr 8</th>
<th>Completed Gr 10</th>
<th>Relationship Status</th>
<th>Widow (n=10, 90%)</th>
<th>Married (n=79, 81%)</th>
<th>Divorced (n=12, 75%)</th>
<th>Living with partner (n=49, 63%)</th>
<th>Single (n=56, 50%)</th>
<th>No children (n=15, 53%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
<td>5 or more (n=16, 94%)</td>
<td>3 to 4 (n=59, 80%)</td>
<td>1 to 2 (n=116, 61%)</td>
<td>18.19 yrs</td>
<td>Fulltime (n=68, 74%)</td>
<td>Not (n=117, 63%)</td>
<td>Still smoking (n=64, 67%)</td>
<td>Negative (n=142, 67%)</td>
<td></td>
</tr>
<tr>
<td>Sexual debut</td>
<td>18.19 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
</tr>
<tr>
<td>Employment</td>
<td>Some days (n=21, 81%)</td>
<td>Fulltime (n=68, 74%)</td>
<td>Not (n=117, 63%)</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
</tr>
<tr>
<td>Smoking</td>
<td>Smoked but stopped (n=17, 71%)</td>
<td>Never smoked (n=125, 69%)</td>
<td>Still smoking (n=64, 67%)</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
</tr>
<tr>
<td>HIV</td>
<td>Positive (n=53, 72%)</td>
<td>Negative (n=142, 67%)</td>
<td></td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
<td>17.18 yrs</td>
</tr>
</tbody>
</table>

Regarding the alternative modes of prevention, 153 (74%) participants were satisfied with the suggestion of the VIA as a primary screening method. A further 37 (18%) expressed a fear of the test and 16 (8%) participants did not trust this screening method. The average age of the women willing to participate in VIA screening was 36 years, which was significantly less than the mean age of 41.7 years (p=0.04) for those who rejected the suggestion of this as the primary screening method. The women willing to undergo VIA screening were also more educated than those declining this method (p=0.02).

The HPV DNA-test was acceptable as a screening test to 171 (83%) participants, but 62 (30%) expressed a degree of apprehension towards performing the test on themselves. The women completely comfortable to participate in such a program are significantly younger (35 years) than those who are apprehensive about it(>42 years, p<0.01).
All the participants (100%) were in favour of HPV vaccination and would take their daughters for such an immunization.

**Qualitative data**

The main themes identified were knowledge, application, personal esteem, community influence and protection of the youth. Table III contains more information regarding the individual themes and Figure 2 illustrates how the themes relate to each other.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
<th>Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge</strong></td>
<td><strong>GENERAL</strong></td>
<td>“Many of my friends have cervix cancer”</td>
</tr>
<tr>
<td></td>
<td>• More awareness around cervix cancer</td>
<td>“Like world AIDS day and breast cancer month. We all hear about that. But not this”</td>
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<tr>
<td></td>
<td>• Need for campaigns: awareness day and month</td>
<td>“Not just a poster”</td>
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<td></td>
<td>• Insufficient health education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Reasons for screening needs to be explained more</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Modern world: more open and information should be more accessible</td>
<td></td>
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<tr>
<td></td>
<td>• Need to teach youth about safe sex</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• No easily available information about National/Provincial screening policies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Methods (including new ones) needs to be explained well</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Need information about preventative outcomes of immunization</td>
<td></td>
</tr>
<tr>
<td><strong>Application</strong></td>
<td><strong>PAP-SMEAR</strong></td>
<td>“10 years are too long. A lot can happen in that time”</td>
</tr>
<tr>
<td></td>
<td>o Pap-smear 10 year intervals too long</td>
<td>“Prevention is better than cure”</td>
</tr>
<tr>
<td></td>
<td>o Should be available on demand</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Pap-smear results take too long</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>VIA</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Good to receive result immediately</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o With cryotherapy means need not go anywhere else: immediate treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Scared of para-cervical block for cryotherapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>HPV DNA self-test</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Good to do it at home: no need to come to clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Those not willing to perform self-test can have it done at clinic</td>
<td></td>
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<tr>
<td></td>
<td><strong>IMMUNIZATION</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Immunization: earlier rather than later.</td>
<td></td>
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<tr>
<td></td>
<td>o Add immunizations to already existing child immunizations programmes</td>
<td></td>
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<tr>
<td><strong>Personal esteem</strong></td>
<td><strong>GENERAL</strong></td>
<td>“I don’t like these injections down there”</td>
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<td>--------------------</td>
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<tr>
<td></td>
<td>- Screening important for personal reassurance and</td>
<td>“We all use tampons these days. And if you can use a tampon you will be comfortable doing this (HPV-DNA testing)”</td>
</tr>
<tr>
<td></td>
<td>- Happy and relieved when receiving result</td>
<td>“It looks easy (HPV-DNA testing)”</td>
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<tr>
<td></td>
<td>- Shy of vaginal examination</td>
<td></td>
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<tr>
<td><strong>VIA</strong></td>
<td>- More scared of VIA than of pap-smear : going for screening but might also get cryotherapy. Emotional barrier to overcome</td>
<td></td>
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<tr>
<td></td>
<td>- More scared of procedure : para-cervical block for cryotherapy</td>
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<tr>
<td><strong>HPV DNA self-test</strong></td>
<td>- Better to perform test in private</td>
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<td></td>
<td>- Scare of performing test wrong but willing to try</td>
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<tr>
<td></td>
<td>- Good that test has indicator for ‘control’ of doing it correctly</td>
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</tbody>
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<table>
<thead>
<tr>
<th><strong>Community Influence</strong></th>
<th><strong>GENERAL</strong></th>
<th>“They say a lot about pap-smears. But I had one and it’s not so painful. But that’s not what everyone say”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- Should encourage, educate and support each other</td>
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<tr>
<td><strong>PAP-SMEAR</strong></td>
<td>- A lot of rumours about pap-smear method : painful/bleeding</td>
<td></td>
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<tr>
<td></td>
<td>- Rumours about VIA will be even worse and scare people off as this is a more painful procedure</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Protection of Youth</strong></th>
<th><strong>GENERAL</strong></th>
<th>“We are different from America. We don’t know what happen (to our children) when we are not there”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- Youth should be warned about cancer as about HIV.</td>
<td>“You don’t know what is happening before they admit about being sexually active”</td>
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<tr>
<td></td>
<td>- Health promotion should be started at younger age : could focus on those using family planning</td>
<td></td>
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<tr>
<td></td>
<td>- Important to protect our children</td>
<td></td>
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<tr>
<td></td>
<td>- RSA social circumstances very different : logistical : single room houses</td>
<td></td>
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<td></td>
<td>- High incidence of abuse of women and children</td>
<td></td>
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<tr>
<td></td>
<td>- Communication and teaching about safe sexual practices</td>
<td></td>
</tr>
<tr>
<td><strong>IMMUNIZATION</strong></td>
<td>- Best way to protect them</td>
<td></td>
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<tr>
<td></td>
<td>- Prevent infection from occurring</td>
<td></td>
</tr>
</tbody>
</table>

Table III: Summary of themes, sub-themes and quotations compiled from the qualitative data
Figure 2: Schematic representation of interrelationship of themes

- Knowledge
  - Reason for screening
  - Procedures
  - Importance of follow up

- Application
  - (+): Immediate treatment
  - (-): Para-cervical block

- Pap-smear
- VIA
- HPV DNA self-test

- Personal Esteem
  - (-)
  - Community Health Workers

- Community Influence
  - (-)

- Protection of Youth
  - Less invasive future screening

- Immunization
  - As part of immunization schedule

- (+) Private

- (-) Negative rumours

- (+/-) Pap-smear
  - (+/-) VIA
  - (+/-) HPV DNA self-test

Figure 2: Schematic representation of interrelationship of themes
In figure 2, the screening and preventative initiatives were placed in the centre of the figure (blue). The themes were placed around it (red) and the weight of the influence of the theme depicted by the width of the arrow. Each theme has a dedicated colour for its arrows. The positive or negative influences are depicted by the (+) or (-) next to the arrows and some of the key influential factors are recorded as short text notes on the figure.

Knowledge about reason for screening, procedures and the importance of follow up are important sub-themes. The participants also had clear opinions on the application of the programmes: performing cryotherapy with VIA screening if indicated, the HPV DNA self-test at home rather than a clinic based test and to incorporate the HPV vaccine into current child immunization schedule would all improve the acceptance of the screening or prevention programmes and the positive experience of the participants. Community influence on screening uptake, spreading rumours and supporting each other were raised. Personal esteem is a strong theme with sub-themes of privacy, fear of pain or performing the test incorrectly, but also having the advantage of performing the self-test personally. Lastly, a very strong theme is the protection of the youth: preventing illness, not inflicting unnecessary pain and further protection of the indirect impact on other unfortunate events, like sexual abuse.

Discussion

Key findings

Participants knew about the preventative nature of screening. However, they believed there is insufficient awareness around preventing cervix cancer.

Knowledge of the details of the provincial programmes are lacking. The uptake of pap-smears were acceptable but the follow-through from results onwards was incomplete, with many missed opportunities. There are Influential, external factors that impact on screening participation.

The participants were interested in the alternative screening methods and vaccination and this was largely acceptable to them. The influence of the community’s opinion on women’s ideas should not be disregarded. The participants were serious about protecting the youth and felt unable to do so with the current system.
Comparison with the literature

The results suggest that not enough is being done about screening for cervix cancer. This is supported in the literature.\textsuperscript{5} Women are more willing to be screened if they understand the indications and method upfront.\textsuperscript{10} There is a need for clear, unambiguous information on the screening programs, the timing, the intervals and special recommendations.\textsuperscript{10}

Some participants believed that little can be done to prevent cervix cancer or that screening is to look for already existing cancer, as also described in the literature.\textsuperscript{25} Screening inappropriate patients, at inappropriate times or having a poor screening programme can actually be detrimental for women. This increases their anxiety and plays a role in the non-compliance with referral or follow-up appointments as also reported by the participants.\textsuperscript{25} There is currently no routine tracing being done in South Africa for non-compliant women who made use of cervical screening services. There is evidence that the use of CHWs dramatically improved adherence to the screening programmes.\textsuperscript{10,17}

Other methods of recall, a more systematic system, or incorporation into, for example the treatment plan for HIV positive women, will also improve the participation and adherence to the screening program.\textsuperscript{3,10,26} Uptake of screening was significantly influenced by the women’s marital status, the number of children she had and the age of her sexual debut. This is supported by previous research.\textsuperscript{27,28} In contrast, the level of education and smoking habits did not significantly influence the uptake of cervical cancer screening, as has been found in other countries.\textsuperscript{5} The uptake was also not significantly influenced by the HIV status which clearly contrasts with the provincial screening policy.\textsuperscript{10,16} Personal and emotional factors also played a role in the participation in screening programs. The screening guidelines were correctly followed for age but incorrectly for HIV status.

The success with LBS could alleviate some of the pressure on the PHC system with the average consultation being shorter, less possibility of poor preparation or poor sampling and thus a much lower need-for-repeat rate.\textsuperscript{6} On implementation, this will replace the pap-smear but not the need for a well-planned, equipped, maintained and supported screening programme. Closer attention should be paid to the infrastructure surrounding screening.

The VIA method decreases the waiting time for results and the anxiety associated with that. It also allows for improved logistics with no need to return for the result or, with the implementation of immediate cryotherapy, even no need for referral for treatment.\textsuperscript{13} The data reflects that this method is fairly acceptable to the majority of women who appreciate these characteristics of the procedure. The women not trusting and not willing to go for such a procedure are mostly older. There is a concern from the women regarding a painful para-cervical block as part of the provision of the immediate treatment. A lot of community education and spread of information will be necessary to make such a system a success. The variable outcomes depending on the operator’s skills, the ongoing training and evaluation of operators and the improvement of infrastructure are some of the biggest concerns from a pilot and programme maintenance point of view.\textsuperscript{11}

The HPV DNA test was well received by the participants with extra focus placed on the acceptance of the self-test. It was mostly older women who were reluctant to perform the self-test, with the
possible solution that those can be performed by the PHC nursing sister. The younger women commented that they commonly use tampons and, they are comfortable and willing to perform the self-test. The possibility of performing this in the privacy of their own house, with a CHW collecting it, could make this a very attractive alternative. As pointed out by previous research, a single round of HPV DNA screening of the community has more preventative value than a single round of VIA or cytology. This would alleviate the pressure on the clinics regarding pap-smears by only performing pap-smears on women that are HPV positive. With a negative predictive value of >97% and the potential of prolonging the screening intervals, this method has, as mentioned, several new and unique attributes. The acceptability of this test by women, including those not willing to go for cytology screening, does present the potential to utilize it in the meantime.

The unanimous approval (100%) of the HPV vaccination by the participants urges us to look into this as the preferred mode of prevention. This is in-line with the WHO’s recommendations, which also points out that, if administered well, it can be a cost-effective venture. The focus group discussions raised the point that we need to protect our youth and while we can’t shield them from domestic violence and abuse, we should aim to at least protect them from further insults due to that. The WHO recommends that it should be combined with already existing vaccination schedules to ease the implementation.

In our limited resource environment we need to look at more radical solutions to reduce cervix cancer, like primary prevention with HPV vaccination which preliminary investigation has been shown to potentially be cost-effective, according to the WHO. The benefit of this will not be seen for many years but over time (estimated at 20 years), this will lower the logistical demands on the health system. In comparison to the 3 pap-smears per lifetime approach, which has a 26% mean risk reduction, vaccination alone has a 43% mean risk reduction and a combination of vaccination and pap-smear has a 61% cancer risk reduction. The combination of immunization with follow-up HPV screening could even further revolutionize screening. HPV vaccination urges us to rethink cytology based screening. The feasibility, upscale-ability, and sustainability of these alternative methods of cervix cancer needs further exploration.

Study limitation

The sequential (not random) sampling may have created bias if the clinics had specific patients or internal speciality clinics booked for specific times of the day as the researcher was unaware of such arrangements during the data collection process. Language and culture issues as confounding factors could not be totally controlled, and was addressed with the help of a Xhosa speaking research assistant during the completion of the questionnaires and the focus group discussions. Interviewer bias during the focus group discussions was kept to a minimum with triangulation in the literature, a semi-structured discussion sheet around an exploratory question, and discussions with a second researcher (the supervisor).
Conclusion

The aim of this study was to explore the experience, knowledge, attitude and beliefs of the clinic attending women in the Knysna sub-district regarding the current cervical screening programme and to obtain their opinion on the possible alternatives methods available. Participants had a good basic knowledge of pap smears. Uptake of pap-smears was acceptable, but the follow-through was incomplete and influential, external factors were identified. Alternative screening methods and vaccination are acceptable to women who attend PHC clinics in the Knysna sub-district. The influence of the community’s opinion on the women’s ideas should not be disregarded. The participants were serious about protecting the youth and felt unable to do so with the current system. Alternative methods of cervix cancer prevention should be explored further.

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