

# BMJ Open Women's experiences with cervical cancer screening in a colposcopy referral clinic in Cape Town, South Africa: a qualitative analysis

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## ABSTRACT

**Objective:** The aim of this study was to explore and understand women's experience with cervical cancer screening and with the referral pathways for abnormal Papanicolaou (Pap) smears.

**Design and setting:** Focus group discussions were conducted with first time colposcopy clinic attendees at a tertiary hospital colposcopy clinic in Cape Town, South Africa during November 2014. A thematic analysis was conducted to identify key themes. Initial coding categories were drawn from the interview guide.

**Participants:** 27 women participated in 4 focus group discussions.

**Results:** Participants mean age was 34 years, most did not complete secondary level education and were unemployed. Negative community opinions relating to Pap smears and colposcopy referral might deter women from seeking treatment. Having a gynaecological symptom was the most commonly cited reason for having a Pap smear. Fear of having a HIV test performed at the same time as Pap smear and low encouragement from peers, were factors identified as potential access barriers. Participants commented on insufficient or lack of information from primary providers on referral to the colposcopy clinic and concerns and apprehension during waiting periods between receiving results and the colposcopy appointment were discussed.

**Conclusions:** There is a strong and urgent need to improve current knowledge about cervical cancer and Pap smears and the necessity and benefits of timely access to screening programmes, results and treatment. Strategies such as community health education programmes and mass media interventions could be employed to disseminate cervical cancer information and address negative community perceptions. Better training and support mechanisms to equip healthcare providers with the skills to convey cervical cancer information to women are needed. The use of short message service (SMS) to deliver Pap smear results and provide patients with more information should be considered to improve waiting times for results and alleviate apprehension during waiting periods.

## Strengths and limitations of this study

- This study adds to a limited number of empirical studies seeking to explore the views of women about the cervical screening and colposcopy referral process.
- This study builds on previous empirical research, which found that women in South Africa may have limited knowledge of cervical cancer and Pap smears.
- This study provides greater understanding of women's experiences with cervical cancer screening processes.
- This study was conducted at one colposcopy clinic in the Western Cape Province of South Africa and this limits its generalisability.
- A limitation of this study is that only women who have accessed healthcare were included.

## INTRODUCTION

Cervical cancer is the fourth cause of death in women worldwide.<sup>1</sup> In low income and middle income countries (LMIC) it is a significant public health threat exacerbated by limited access to health services and human and financial resources, high rates of poverty and lack of awareness.<sup>2</sup> These factors in combination with poor medical infrastructure hinder the facilitation of early detection and treatment. In South Africa cervical cancer is the second most common cancer among women and the most common type of cancer among women between the ages 15 to 44 years.<sup>3</sup> Moreover, it is the leading cause of cancer mortality among women.<sup>3</sup>

The successful implementation of cervical screening programmes with well-functioning call and recall systems has resulted in a decline in cervical cancer incidence and mortality in high-income countries.<sup>4,5</sup> In contrast, cervical cancer remains a problem in LMIC, mostly because of ineffective or

absent screening programmes.<sup>5–6</sup> Limited knowledge about cervical cancer and screening programmes have been reported among women in South Africa and other LMICs.<sup>7–11</sup> Furthermore, studies have indicated that a lack of adequate knowledge about cervical cancer and screening programmes can detrimentally influence women's likelihood of accessing such programmes.<sup>9–12</sup>

A Papanicolaou (Pap) smear can screen for precancerous abnormalities, and if clients with abnormalities are further investigated and treated, cervical cancer can be prevented. Further investigation usually includes a colposcopy assessment. A key challenge in the implementation of Pap smear screening programmes in LMIC is poor colposcopy attendance and loss to follow-up of women with abnormal Pap smears.<sup>6–13</sup> In 2000 South Africa introduced its first cervical cancer screening policy. According to the policy women aged 30 years and older attending public sector services are entitled to three free Pap smears in their lifetime.<sup>14</sup> Pap smear screening services are available at the primary healthcare facilities throughout the country. National screening coverage has increased from 18% in 2003 to 55% in 2014.<sup>15</sup>

A recent study conducted in three provinces in South Africa highlighted the challenges in getting women with abnormal Pap smears to attend colposcopy appointments.<sup>16</sup> In this study, although appointments were made for all women with a high-grade squamous intraepithelial lesion, only 50% of the women attended the colposcopy clinic. This poor attendance rate occurred despite efforts to improve interfacility linkages and establish paper-based feedback systems. This study did however not explore reasons for poor attendance.

Numerous studies have emphasised the need for regular screening and for improving access to information about cervical cancer. However, few studies have been conducted in LMIC where additional challenges such as barriers to access and knowledge may exist. Moreover, there is a deficit of empirical research seeking to explore the views of women about the cervical screening and colposcopy referral process. This study therefore sought to examine women's experiences with cervical cancer screening and to better understand the referral pathways for women with abnormal Pap smears.

## METHODS

### Study design and sample

The study findings reported in this article form part of a larger study on the feasibility of mobile health interventions to improve the management of women with abnormal Pap smears. As part of the study focus group discussions were conducted with first time colposcopy clinic attendees at a tertiary hospital colposcopy clinic in the Western Cape Province, South Africa during November 2014.

In our study area women are typically asked to return to the primary healthcare clinic within 6–8 weeks for their Pap smear result, which is the average waiting

period for the area. Women with abnormal Pap smears that is, either a high-grade squamous intraepithelial lesion or a second low-grade intraepithelial lesion are referred for further assessment to a colposcopy clinic based at the referral tertiary hospital. Colposcopy appointments are made by the primary healthcare provider at the time that clients return for their Pap smear result. Colposcopy services are fee-free and typically women wait between 1 and 8 months for a colposcopy appointment.

Women who met the study eligibility criteria (referred to the colposcopy clinic from a primary health facility; ability to understand and converse in English, Afrikaans or Xhosa and willing to provide informed consent) were approached by the research team to ascertain interest to participate. Twenty-seven women were approached and all were eligible and consented to participate in four focus group discussions conducted in a private room. Informed consent was obtained and a brief sociodemographic survey was administered (age; employment; education; type of housing; home language; mobile phone ownership and usage). Group discussions lasted between 90 and 120 min. Participants received incentives worth ZAR100 for taking part in the study and refreshments during the focus group discussions. Additional cervical cancer or colposcopy information in the form of pamphlets was made available after the focus group discussions. Two female researchers trained in qualitative methods conducted the discussions in English, with Afrikaans and isiXhosa translation provided where necessary. The following broad themes were explored: cervical cancer and Pap smear knowledge; means of obtaining Pap smear results; referral pathway to the colposcopy clinic; expectations and knowledge about the colposcopy appointment; views and opinions about the use of short message service (SMS) to convey results and appointment reminders. Focus group discussions were digitally recorded and field notes were also made.

### Data analysis

All digital recordings and field notes were translated into English and transcribed. Transcripts were reviewed by JM and data collection stopped once data saturation was achieved. Transcripts were not returned to participants for comment. Data were entered and coded into QSR Nvivo V.10 (a qualitative computer software package). Conventional thematic analysis was conducted to identify key themes. Initial coding categories for analysing data were drawn from the interview guide. MM and JM read the transcripts and developed initial coding categories (see online supplementary file 1). MM coded the data and JM reviewed codes and identified sub-themes. Once all the text segments had been given basic codes, the codes were categorised and grouped into similar themes. No additional themes emerged from this process. Selected participant quotations were chosen to illustrate both themes and findings. Each quotation was identified using a unique participant ID. Data presented

was consistent with study findings and all major themes were clearly presented and discussed, while minor themes are described in the findings.

## RESULTS

### Participant profile

Sociodemographic characteristics were collected from all 27 women who participated in the focus group discussions. The mean age was 34 years (range 18–49). A majority of participants (85%) did not complete secondary level education and 48% were unemployed. Participants were mostly Xhosa speakers (71%) and 26% spoke Afrikaans. Majority of participants identified themselves as black African (74%) followed by Cape Coloured (26%). Most participants reportedly lived in houses (59%), 19% lived in informal structures (shacks), 15% in cottages/sheds behind another house and 7% lived in flats.

### Community views on Pap smears and cervical cancer

When asked whether cervical cancer and Pap smears in particular were topics that were discussed among peers, most women admitted to rarely hearing others talking about it in their respective communities. Negative community opinions relating to Pap smears and colposcopy referral in particular, were discussed by some as factors which deter women from seeking screening and further assessment.

When you have gone for a Pap smear and maybe you tell others about, they will tell you that: 'Oh! When you go there they will find this and that, it's better not to go at all.' It is worse when you tell them that you are referred to [colposcopy clinic]. Then they say: 'you see, you should not have gone there. Now you must go to [colposcopy clinic] and they are now going to tell you that they must burn something underneath there. Maybe they will tell you that something is growing in your womb and they must take it out.' People in the community say you must leave this Pap smear 'cause it make you very worried. (FGD21)

Nobody accepts that she has cervical cancer; it is like being HIV positive. It's something that is not acceptable in the community. You tend to keep it to yourself because if you tell someone about it she will go around making a laughing stock in the streets about that. (FGD22)

Some women commented on cervical cancer being less stigmatised in their respective communities than it had been previously. However, others felt it was still heavily stigmatised and many discussed the negative association of being seen at the clinic and being assumed by the community to be HIV positive.

Others are afraid of stigma of being seen at the clinic, they think that if you see them there you are going to talk about her in the community. Another thing once they see you there they think that everyone there is HIV positive. If you tell someone that you are going or you

have done a Pap smear immediately they say you are [HIV] positive. (FGD31)

There is a perception in the community that if you do a Pap smear you are HIV positive. So people tend to shy away from doing a Pap smear. Even if you do it while you are pregnant you do not tell anyone because there is that perception. (FGD41)

### Reasons for having a Pap smear

Having a gynaecological symptom was the main reason reported for having a Pap smear. However, the symptoms that prompted women to have a Pap smear performed varied greatly and included abdominal pain, heavy periods, spotting between periods, pain on urination and vaginal discharge and itching. Other participants were encouraged by health professionals to have a Pap smear performed and a few were encouraged by their peers.

Many referred to wanting their *womb cleaned* in order to conceive. Having a Pap smear was frequently seen as diagnostic rather than preventative measure of cancer. Moreover, some women thought that the *cleaning of the womb* procedure enabled health providers to identify whether it was *damaged* and subsequently remove it.

People say that if you do a Pap smear they will tell you that you have cancer or find out that your womb has a green discolouration and that will lead to them taking out your womb. (FGD23)

They [health providers] clean the uterus and if they find out that it is damaged, they take it out. (FGD11)

### Reasons for not having a Pap smear

Some participants mentioned fear of having a HIV test performed at the same time as a Pap smear is a potential barrier to women accessing screening procedures.

The reason they [women in community] are scared of having a pap smear is because they are worried that they will also be checked for HIV. (FGD32)

As discussed under the previous heading 'community views', low encouragement by their peers also deterred women from having a Pap smear.

### Healthcare provider interaction and communication (receiving results and referral to colposcopy clinic)

Most women were asked to return to the clinic within 6–8 weeks following their Pap smear to discuss their results, while some were notified by post to return to the clinic. Participants, who were HIV positive and already attending the clinic regularly for treatment, incorporated getting their results into these visits, while some reported challenges in receiving their results;

...Sometimes you do not get your letters. My letter was delivered two doors from my house and those people brought it to me. [Neighbours had also opened letter] (FGD13)

There's a lot of airtime that you are using [trying to obtain Pap smear results], because they put on hold, it's expensive. (FGD34)

The main concern appeared to relate to anxieties during the waiting period and uncertainty about the safety of the procedure. Many participants commented on the lack of information received from the primary provider on referral to the colposcopy clinic.

They [primary referring clinic] did not say anything. I was given a letter and a date to come here [colposcopy clinic]. (FGD11)

I'm here today and I really do not know why I'm here [at colposcopy clinic]. They [primary referring clinic] never explained to me what the results say. They [primary referring clinic] just told me that they have made an appointment for me here [colposcopy clinic] but I do not know for what. (FGD21)

Some women, who had their Pap smear results explained, admitted to not understanding the explanation. However, they did not ask for clarification.

No, I did not [ask for further clarification/explanation]. I was just given the letter to come here [colposcopy clinic]. Sometimes when they are telling you, you are also shocked and worried so you do hear some of the things they tell you. (FGD23)

No, [I did not ask for further clarification/explanation] I didn't want to worry myself. (FGD35)

Differences were reported in terms of the quality of information received depending on the type of primary referring clinic. Women who were referred from anti-retroviral (ARV) clinics reported receiving counselling and information about their Pap smear results whereas those referred from non-ARV facilities reported receiving little or no information. Participants framed this in terms of ARV facilities generally having better resources, in terms of staff and infrastructure.

Waiting periods between receiving results and the colposcopy appointment varied greatly, with some women waiting a month and others waiting up to 6 months. Many raised concerns and apprehension during the long waiting period between obtaining results and the colposcopy appointment. These trepidations were compounded by not knowing how to interpret the results or what to expect at the colposcopy appointment. Many informants talked about expectation that 'something' in their 'womb' will be burned and most expressed concerns about the colposcopy procedure.

I'm expecting anything could be said. Being a woman we are prone to have many things. (FGD15)

For me what is worrying if the fact that they [primary referring clinic] don't tell you your results. They tell you

that you must go to [colposcopy clinic] because there is something wrong. Now you are worried for the more than one and half months, wondering what is actually wrong with you. I would feel better if they did explain to me what the results of my Pap smear are saying and be prepared for what I'm going to do [at colposcopy clinic]. It's big problem for me because you are sitting with this letter which you don't know what it says. (FGD21)

... I just became depressed and very worried because I had told myself that this is the end. I don't even function well at work and I've since lost a lot of weight. It has been a very hard time for me. (FGD34)

## DISCUSSION

The use of qualitative methods in formative research is gaining increasing acceptance as a mode of scientific inquiry and may be an essential foundation for successful interventions. Women's voices become more audible through qualitative research, which emphasises the importance of providing a safe space for women to express their unique experiences while gaining support from other women with a common cultural background.<sup>17 18</sup>

Research from LMICs has identified a variety of factors which influence women's screening practices for cervical cancer, including: financial implications; accessibility; waiting periods and the quality of services;<sup>19 20</sup> discomfort associated with the procedure; and mistrust of the medical system;<sup>7 8 20 21</sup> the influence of husband and/or family and the use of traditional medicine.<sup>22</sup> These potential barriers to routine screening services were explored during the discussions but were insignificant for our study participants.

Our findings build on previous empirical research, which found that women in South Africa and more broadly in LMICs may have limited knowledge of cervical cancer and Pap smears.<sup>7-11</sup> While all participants used words such as Pap smear and colposcopy, many were not able to distinguish the differences between the two procedures. Studies conducted in LMICs revealed that a lack of knowledge on the topic can severely deter women's likelihood of accessing cervical screening programmes.<sup>9 12</sup> Although the availability and accessibility of screening services are vital, this alone does not guarantee uptake. A study conducted in a rural district of KwaZulu-Natal, found although 49% of the women who participated in the study knew about Pap smears, more than half did not undertake the test—most commonly because of a perceived fear of the procedure.<sup>21</sup> Study participants frequently referred to having their 'womb cleaned'. This finding is consistent with other studies that South African women often construct cervical cancer in non-medical terms and rarely use the term cervix in reference to cervical cancer.<sup>23</sup>

Our findings echo previous research that identified a general perception that the Pap smears are frequently seen as diagnostic of cervical cancer, rather than a

preventative or intervention measure.<sup>23–24</sup> However, this finding might be influenced by the fact that our study only included women with abnormal Pap smear results. The reluctance many of the study participants spoke of to have a Pap smear for fear that they would be diagnosed with cervical cancer and a general consensus that it is better not to know than know you have cancer also needs to be addressed. A strong and urgent need therefore exists to improve women's knowledge about cervical cancer and the necessity and benefits of timely access to screening.

Our study speaks of deep-rooted misconceptions and stigma about cervical cancer at a community level. The use of community outreach workers to promote cervical cancer knowledge and to improve screening uptake has yielded positive results in some settings.<sup>25–27</sup> Previous well-organised cervical screening programmes have failed to be effective without the incorporation of community health education programmes.<sup>6, 28</sup> Similarly, planned mass media interventions (including radio, television, newspapers, magazines, leaflets, posters and pamphlets) to improve cancer screening programmes had a positive effect on healthcare usage.<sup>29</sup> The use of such strategies to disseminate cervical cancer information at grass root level using locally understood messages could therefore facilitate greater, more accurate understanding.

Healthcare providers appear to be providing insufficient or inappropriate information at the time of referral, causing unnecessary concern and anxiety in the period leading to the colposcopy appointment. Previous studies have reported inadequacies in training of health professionals and the management of patients with cervical cancer.<sup>9, 30, 31</sup> Healthcare providers play a pivotal role in improving quality of care and improving knowledge and are in a unique position to potentially modify structural and process factors that impact health outcomes.<sup>32, 33</sup> Informed decision-making (IDM), is said to occur when an individual understands the disease being addressed and comprehends what the clinical management entails; including the benefits, risks, limitations and alternatives. The individual has also considered their unique preferences and believe they have participated in the decision-making process.<sup>34</sup> The usage of IDM strategies by providers to enhance patient knowledge, beliefs and risk perceptions in cancer screening interventions have proven successful in some settings, but insufficient research has been carried out to assess its effectiveness in LMIC settings.<sup>35, 36</sup> Better training and support mechanisms are required to equip staff with the necessary skills to convey information in a manner that can be better understood by the populations they serve. The potential benefits of employing IDM strategies in a South African setting should be investigated. A growing body of research have proven the effectiveness of SMS/text messages in support of behavioural change and disease management.<sup>37, 38</sup> Such interventions could enhance the current standard of care with information provided through mobile phones could help improve health outcomes and processes.<sup>38</sup> The use

of SMS to deliver Pap smear results and provide patients with more information should be considered to improve waiting times for results and alleviate apprehension during waiting periods.

Owing to the explorative methodology employed in this study, findings are descriptive in nature. Although only 27 women participated in four focus group discussions, we believe that saturation was reached as no new themes emerged. As is usual in focus group discussions, some women were more willing to contribute to the discussions than others. We acknowledge that more vocal participants in the group may have influenced less forthcoming participants' responses. However, probing techniques were employed to encourage quieter participants to actively contribute to the discussions. A major limitation of this study is that only women who have accessed healthcare were included.

This study was designed to examine women's experiences with cervical cancer screening and the referral pathways for women with abnormal Pap smears. Significant concerns were identified among the women we interviewed, despite their ability to access cervical screening services. Women who do not access cervical screening programmes are likely to experience additional barriers which were not explored in this study. Awareness of cervical cancer and factors influencing women's willingness to undergo screening procedures among women that have not accessed care needs to be explored. However, our findings do provide greater understanding of women's knowledge of cervical cancer and experiences with screening and referral processes.

## CONCLUSION

This study highlights significant gaps in women's knowledge about cervical cancer and Pap smears and, importantly, also the further management in case an abnormality is identified which can have a negative effect on healthcare usage. A strong and urgent need therefore exists to improve current knowledge on the topic and the necessity and benefits of timely access to screening programmes. Strategies such as community health education programmes and mass media interventions should be employed to disseminate cervical cancer information and address negative community perceptions. Better training and support mechanisms to equip healthcare providers with the skills to convey cervical cancer information to women are needed. The use of IDM strategies to enhance patient knowledge and participation in the decision-making process should be investigated. Strategies should aim to better inform women about cervical cancer, the benefit of early screening and what to expect if referred to a Colposcopy clinic thus potentially alleviating any unnecessary stress and concern women have about cervical screening and treatment programmes. The use of SMS to deliver Pap smear results and provide patients with more information should be considered to improve waiting times for results and alleviate apprehension during waiting periods.

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**Contributors** JM initiated the study and developed the study protocol. MHB and FHvdM reviewed the protocol and provided clinical oversight throughout the project. MM and JM read through the transcripts and developed initial coding categories. MM coded, and MM and JM analysed the data. MM prepared the first draft, incorporated revisions and prepared the final draft. All the authors reviewed drafts and approved the manuscript.

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