



# Experiences, Beliefs, and Attitudes About Cervical Cancer Screening Among Women in Pietermaritzburg, KwaZulu- Natal, in South Africa: A Qualitative Study

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## **Experiences, Beliefs, and Attitudes about Cervical Cancer Screening among women in Pietermaritzburg, KwaZulu-Natal, in South Africa: A Qualitative Study**

Tracy Makuvire,<sup>1</sup> Lisa M. Butler,\*<sup>2</sup> S'the Ngubane, Duncan Andrew, Ingrid T. KATZ,\*<sup>1,3,4</sup>

<sup>1</sup> Harvard Medical School, Boston, MA, United States

<sup>2</sup> Institute for Collaboration on Health, Intervention, and Policy, University of Connecticut, Storrs, CT, United States

<sup>3</sup> Department of Medicine, Brigham and Women's Hospital, Boston, MS, United States

<sup>4</sup> Massachusetts General Hospital Center for Global Health, Boston, MA, United States

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**Corresponding author information:** Tracy Makuvire, Address: 46 Park Vale Ave, Allston, USA 02134. Tel: 650-814-0124 Email: ttm4@hms.harvard.edu

## ABSTRACT

**Objective:** The aim of this study was to understand women's experiences, beliefs, and attitudes about cervical cancer screening and the influence of living with Human Immunodeficiency Virus (HIV) on preventive Papanicolaou (Pap) smears in South Africa.

**Design and Setting:** Semi-structured interviews were conducted with participants in a private office at Thandanani Children's Foundation (TCF) in Pietermaritzburg, KwaZulu Natal during July 2015. Data from transcripts was coded for themes using NVivo qualitative research software to identify meaningful patterns for analysis using both content and thematic analysis.

**Participants:** 30 women participated in semi-structured interviews

**Results:** The median age was 48, all participants had some high school education or less, and 77% of participants were unemployed. Seventeen participants were living with HIV, and 70% of participants had received at least one Pap smear at time of interview. Lack of knowledge about Pap smears and fear of the screening procedure were the most common barriers to obtaining Pap smears. Being HIV positive was associated with increased awareness about cervical cancer screening, and a positive facilitator for having had at least one Pap smear in their lifetime. Participants described the role of religion, patient autonomy, financial burdens, healthcare providers, and community awareness as other important factors influencing the decision to obtain a Pap smear.

**Conclusion:** In South Africa, the barriers to cervical cancer screening continue to include lack of education and awareness about Pap smears, financial burdens to attending clinics, lack of connection of HIV negative women to the health care system, and reduced community awareness about cervical cancer and the role of Pap smears in prevention. However, there is improved awareness and utilization of cervical cancer screening among women living with HIV in Pietermaritzburg, Kwa-Zulu Natal. This study highlights that living with HIV in a peri-urban community in South Africa, in clinics with stable integration of HIV care into other health aspects, allows women living with HIV to extend their health care access to other areas of their life, hence improving cervical cancer screening.

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## INTRODUCTION

Cervical cancer is a preventable disease that has a devastating impact on women's health around the world. It is the second most common cause of cancer among women in low and middle-income countries (LMICs), with the majority (~80%) of the global burden of disease due to cervical cancer occurring in these countries (Zvavahera 2001; Globocan 2013; Global AIDS Monitoring 2017). In Sub-Saharan Africa, cervical cancer accounts for 22.2% of all cancers in women, and if left undiagnosed and untreated, age-standardized mortality approaches 22.6/100,000 in Southern Africa (Anorlu 2008). Studies have shown that cervical cancer screening is effective in reducing the annual incidence of cervical cancer (Zvavahera 2001). In high-income countries, cervical cancer screening using Pap smears and Human Papilloma Virus (HPV) testing detects precancerous lesions earlier, and early treatment prevents invasive disease and reduces mortality and morbidity associated with the disease (Smith 2017; Global AIDS Monitoring 2017). However, in LMICs coverage and access to cervical cancer screening are poor, and women are at higher risk of being diagnosed in the later stages of the disease when only palliative options are available (Adepogu 2016).

Cervical cancer screening guidelines in the United States (U.S.) have increased early detection of precancerous lesions, improved treatment, and decreased mortality ((American Cancer Society 2017, National Cancer Institute 2014). In the U.S. between 1975 and 2013, widespread application of screening in the general population led to greater than 50% decline in cervical cancer incidence from 14.8 per 100,000 to 6.5 per 100,000 (American Cancer Society 2017). In addition, the mortality due to cervical cancer declined from 5.6 per 100,000 in 1975 to 2.3 per 100,000 in 2014 due to early detection with Pap tests and decreasing incidence of cervical cancer (American Cancer Society 2017). As a result of the long and slow natural history of progression of CIN to invasive cervical cancer, screening has provided an essential and critical method of detecting and treating pre-invasive cancerous cells (National Cancer Institute 2014). While cervical cancer rates are decreasing in resource-rich countries, this progress has not been observed equally in LMICS. Early seminal studies in the U.S. and internationally have shown that HPV infections and the incidence of CIN and cervical cancer occur at higher rates among women living with HIV compared to risk-matched HIV-negative women (Palefsky 2003, Moodley 2005). In 2013, approximately 6.3 million people were living with HIV in South Africa (Gap Report 2014). Screening practices are critical for the reduction of cervical cancer rates among all women, and routine annual screening is strongly recommended for women with sexually transmitted diseases (Fort 2011; Head 2003).

Cervical cancer is the second most common cause of cancer among women in South Africa; an estimated 5,000 new cases occur annually (Sibiya 2012). The risk of cervical cancer in South Africa is highest among black women who are over 30 and of low socio-economic status (Sibiya 2012), and women infected with human immunodeficiency virus (HIV) (Palefsky 2003; Moodley 2005). Living with HIV increases the risk of co-infection with HPV, a virus that causes cervical cancer (Anorlu 2008; Sibiya 2012; Adibe 2017). Women living with HIV are also more vulnerable to progress from low to high-grade cervical intraepithelial neoplasia (CIN, a precursor to cervical cancer), compared to risk-matched HIV-negative women. In this group, careful screening can reduce the lifetime risk of CIN and up to 80% of cases of cervical cancer in LMICs (Palefsky 2003, Moodley 2005, Global AIDS Monitoring 2017).

In South Africa, the screening guidelines for the general population were adopted in the context of limited resources and based on available evidence of cervical cancer progression (Sibiya 2012; WHO Recommendations 2013). The cervical cancer screening guidelines in South Africa were introduced in 2000 and recommend up to three-lifetime Pap smears for women beginning at the age of 30, with a ten-year interval between tests. This policy aligns with the World Health Organization's (WHO) guidelines for LMICS (Sibiya 2012; WHO Recommendations 2013). While South Africa has introduced a policy for screening, barriers to screening implementation include the shortage of health care workers, a poor system for follow up and referral, and poor attendance of women to health care services (Sibiya 2012). To address the shortage of health care providers, task shifting has occurred in South Africa to delegate the bulk of cervical cancer screenings to nurses in clinics and hospitals. However, only 40% of health care facilities have primary health care qualified nurses to provide screening (Sibiya 2012), and uptake of cervical cancer screening remains low (~20%) (Kawonga 2008).

Task shifting was adopted in an era of an increased global burden of HIV/AIDS and the shortage of doctors in LMICs. To tackle the overwhelming need for HIV care in LMICs, the WHO has recommended task shifting to provide essential health care services to people who need them (WHO Recommendations 2013). Since 2010, South Africa, with the support of the President's Emergency Plan for AIDS Relief (PEPFAR) expanded clinics that provide Antiretroviral Therapy (ART) from about 490 to 3,540. To date, approximately 3.4 million South Africans receive life-saving ART through PEPFAR (PEPFAR 2018), and through the initiative, many clinics can provide HIV testing and counseling up to 10.4 million people (PEPFAR 2018). The ongoing decentralization of HIV care has shifted treatment services away from doctors and hospitals, to nurses at primary care facilities (WHO Recommendations 2013). Multiple studies on the barriers to cervical cancer screening in LMICS have been conducted (Denny 2006; Fort 2011). But, not many studies have focused on women's attitudes and beliefs about

cervical cancer screening in the context of the common barriers to screening, HIV status, and interactions with healthcare workers. This study will examine the barriers to care and cervical cancer screening among women living with HIV in a new era of HIV treatment delivery and care in South Africa.

## **METHODS**

### *Study design*

We conducted a qualitative study using semi-structured interview questions. Our goal was to compare and contrast the experiences, beliefs, and attitudes about cervical cancer screening in South Africa among women living with HIV to women who were HIV-negative. Qualitative research questions allowed us to gain a clear understanding of the factors influencing cervical cancer screening and to create an explanatory model for cervical cancer screening uptake.

### *Study Site*

Thandanani Children's Foundation (TCF) in Pietermaritzburg, Kwa-Zulu Natal in South Africa is a non-profit organization that helps facilitate home-based care and support for orphans and vulnerable children (Thandanani website). Thandanani field worker teams are involved in multiple communities and respond to "basic material, physical, cognitive and emotional needs of orphans and vulnerable children ..." (Thandanani website). They also provide education about HIV and other health matters that affect the community. We chose this study site because it was a site involved in multiple research projects on HIV/AIDS and we had already established community partnership that we believed would help in the recruitment of participants and in strengthening the connection.

### *Sampling and Recruitment*

We identified a list of 245 participants from 6 peri-urban communities (Caluza, Copesville, Dambuza, Slangspruit, Snathing, Willowfountain) who had previously consented to future contact for study opportunities. We identified the field workers associated with the communities. Field workers approached participants to request verbal consent to be contacted for study purposes. We recruited 30 women in this study to reach a saturation point for each community sub-group. The study sample had 17 HIV-positive and 13 HIV-negative women between the age 30- to 65 years old from 6 peri-urban communities in KwaZulu-Natal, South Africa.

### *Eligibility Criteria*

The eligibility criteria for this study were:

- (1) Age > 30 at time of enrollment (Sibiya 2012; WHO Recommendations 2013)

- (2) Age < 65 at time of registration
- (3) HIV status is known
- (4) A Thandanani family member who had previously consented to future contact for studies
- (5) A resident in one of the six urban communities with TCF field workers
- (6) Willing and able to give informed consent.

### *Informed Consent*

Informed consent forms were prepared to ensure that participants understood the possible risks and benefits involved in the study. Consent forms were designed in English and then translated to Zulu by a native speaker to reduce the effects of language barriers. Participants were taken to a private room at TCF where the research assistant was available to read the consent forms to all participants. Participants were allowed to ask questions and asked to verbalize understanding of the risks and benefits involved in the study. Contact information for the staff included in the study was provided to all participants for further use if they had questions or concerns related to the study. Signed consent forms were collected at the end of the informed consent process and before the semi-structured interview started.

Consent forms were stored in a locked cabinet at TCF. After informed consent was obtained, participants were then classified using numerical values, and all electronic data were de-identified and stored in a locked, secure site. Interviews were conducted in a private area, and all staff involved maintained the confidentiality of participants. The study was approved by the Harvard Medical School Institutional Review Board, in Boston, MA, and the Human Sciences Research Council (HSRC) in Pretoria, South Africa.

### *Data Collection and Preparation*

We conducted semi-structured interviews with 30 participants between June 2015 and July 2015. All participants were willing to travel to TCF, and all meetings were held in a private room in TCF facilities. All interviews were semi-structured; audio-recorded and later transcribed and translated; conducted in isiZulu or English, as preferred by the participant; and lasted approximately 40 minutes. Our goal was to determine if women living with HIV would benefit from a tailored intervention to optimize uptake of cervical cancer screening. More explicitly, the topics explored in the interviews were:

- (1) The experiences, beliefs, and attitudes about cervical cancer screening in South Africa among women living with HIV



- (2) The experiences, beliefs, and attitudes about cervical cancer screening in South Africa among women who are HIV-negative
- (3) Understanding individual behaviors and forces influencing uptake of cervical cancer screening

### *Data Analysis*

The goal of the study was to obtain data to understand women's experiences with cervical cancer screening-uptake in KZN, as well as to inform the development of interventions for cervical cancer screening among women, with increased relevance for testing among women living with HIV. Data from transcripts was coded for words and themes using NVivo qualitative research software to identify meaningful patterns for analysis using both content and thematic analysis. We explored whether women have accurate information about cervical cancer screening through data collected about their beliefs, attitudes, and experiences with the process. Misinformation or lack of knowledge potentially correlates with underuse of screening services due to lack of understanding and fear. Among women living with HIV, we explored the factors that facilitate or inhibit women from engaging in preventive actions (getting a Pap smear). Lastly, we studied how women can efficiently participate in health-promoting behaviors from directly utilizing health support services related to living with HIV to reducing the risks of cervical cancer.

## **RESULTS**

### *Participant profile*

For this qualitative study, we recruited thirty individuals to reach saturation point for qualitative data collection. The individuals agreed to participate and signed consent forms. The research assistant and TM interviewed 30 participants, median age of 48 (interquartile range 40-55), in a private room in TCF. Among the participants, one hundred percent had education up to grade 12 or less, seventy-seven percent (23/30) of the participants were unemployed, and sixty percent (18/30) of the participants received their HIV testing in a local clinic, while a minority were tested in the hospital (7/30) or at home (5/30). Of the 30 participants, seventeen were HIV positive, and thirteen were HIV negative. In the study cohort, twenty-one participants (70%) had received at least one Pap smear at time of the interview, and of those with a history of screening, only three (14%) reported having at least a second Pap smear. 14/17 HIV positive participants (82%) had at least one Pap smear at time of the interview, compared to 7/13 among HIV negatives (53%). Table 1 provides a summary of the characteristics of the participant demographics.

**Table 1: Demographics**

<i>Characteristics</i>	<i>N or Mean</i>	<i>%</i>
Female sex	30	100%
Age (years)	48	
HIV status (positive)	17	57%
HIV testing (clinic)	18	60%
HIV testing (hospital)	7	23%
HIV testing (home)	5	17%
Employed (full-time, part-time)	7	23%
Unemployed	23	77%
Education, some high school or less	30	100%
Education matriculated or higher education	0	0%
Community (Caluza)	5	17%
Community (Copesville)	4	13%
Community (Dambuza)	6	20%
Community (Slangspruit)	6	20%
Community (Snathing)	4	13%
Community (Wiilowfountain)	5	17%

### **Knowledge, attitudes, and beliefs towards screening**

Participants expressed varying levels of education and awareness about cervical cancer screening, and different views and beliefs towards preventive health care. The patterns identified using content and thematic analysis of the transcripts were categorized as follows.

#### **BARRIERS TO SCREENING:**

##### *Lack of knowledge and education*

Participants often cited the lack of knowledge and education about cervical cancer as a critical barrier preventing women from obtaining Pap smears (Table 2, Quote 1). They felt that the lack of knowledge contributed to an increased fear of the procedure or the results after screening. Fear was a crucial overarching factor, with many participants using words like "terrified," "scared," and "ignorance" (Table 2, Quote 2) that prevented women from cervical cancer screening. They perceived that this "fear" spread among women in communities, as some would describe the procedure as "painful" thus dissuading others from seeking it. However, upon obtaining their first Pap smear, many participants felt that the procedure was "not as painful" as they had feared.

##### *High financial burdens*

Difficulties with healthcare access were associated with economic hardships such as having access to transportation to facilities, stable financial income to support health care costs, and steady employment. Most participants noted that they could easily access the local clinic for non-urgent issues

and could walk-in with no problems. However, if they needed a higher level of care or referral to local hospitals, transport and financing became a considerable burden, with one saying, “We walk to the clinic. What becomes a challenge is when I have to go to the hospital. So I borrow money ...” (Table 2, Quote 12, 13). Participants would turn to other family members or neighbors in the community to finance transport costs to the hospitals, or to provide the needed health care supplies “one can try and borrow from neighbors. You won’t suffer and die when you have neighbors and relatives.” Others cited delaying obtaining necessary medical care due to the financial burden of traveling to the nearest hospital. (I’d feel pain in my leg because I had a fracture. If I don’t have transport money ... I’d take painkillers until I get bus fare to go there).

#### *Lack of community awareness*

Lack of community awareness about cervical cancer screening was critical in influencing health decision making among women. Following the HIV epidemic, most participants felt that knowledge about HIV was now prevalent and most people in the community were willing to get tested to know their status. However, awareness about cervical cancer screening is still low, most people in the neighborhood do not communicate about cervical cancer either due to lack of knowledge or education about the disease and thus, most women have neither had a Pap smear nor heard about cervical cancer screening. Therefore, there was fear of stigma and discrimination due to lack of knowledge about the disease and risk factors.

#### *Lack of urgency for screening*

Participants identified lack of urgency about one’s health as a factor limiting cervical cancer screening in the community, “...when you care about your health you check and get tested.” They often juxtaposed the HIV epidemic with exposure to other healthcare conditions such as cervical cancer. Related to their HIV status, women felt that they had to get tested to know their status and maintain their health, and they believed that all women should have a similar approach to cervical cancer screening. However, they cited ignorance about risk factors for cervical cancer and Pap smears as the main factor reducing women's urgency to get screening (Table 2, Quote 3). If more women had the urgency to prevent cervical cancer, the majority of participants believed that more people in their communities would obtain cervical cancer screening “Screening for cervical cancer is for one to know their health status, knowing how much risk your life is faced with.” (Table 2, Quote 4)

### **FACILITATORS TO SCREENING:**

#### *Role of religion*

Religion plays a vital role in women's health care decisions. Several participants cited being part of a church as a critical factor in obtaining health knowledge, such as having a dedicated women's group consisting of doctors and nurses that "take time and gather women to educate them." Also, many cited their beliefs in God as augmenting their choice to visit hospitals when sick as they "do believe that God will heal us but there are things that one needs to get screened and tested for" (Table 2, Quote 6). However, one participant chose not to seek help from clinics, precisely because they believed that God would provide healing (Table 2, Quote 5).

#### *Role of traditional healers*

For participants who felt that they had a "mystery" diagnosis or who did not improve after going to the hospital, they turned to traditional healers for "portions" to "get" the illness out of their systems. They believed that certain illnesses could be "hiding" and only through traditional healers did they get better. Most participants do turn to modern practice and hospitals when they are sick; however, when their prognosis does not improve, they return to traditional customs. On the contrary, some participants who did not believe in traditional medicines cited religious beliefs that do not allow them to go to traditional healers, as "traditional medicines don't help, only God helps people." Others cited financial burdens associated with "traditional medication ... are expensive, and one would not even be guaranteed [they] will work ...". Hence, most participants advised that the health of the community could improve if more people accessed modern medicines instead of traditional practices, as they are not always guaranteed to work (Table 2, Quote 8).

#### *Influence of living with HIV*

Among participants, women living with HIV had increased awareness about cervical cancer screening, the majority had at least one Pap smear in their lifetime (82%), and they had increased face-to-face time with healthcare providers. One participant reported that to "anyone who has a disease like HIV, diabetes or TB... it is essential that they get a Pap smear test done". Women living with HIV noted that they had to visit local clinics monthly to receive their antiretroviral (ART) medications, and while there, the nurses encouraged them to receive Pap smears among other preventive health screening (Table 2, Quote 10). HIV positive participants also tended to have increased knowledge about cervical cancer screening and cited that the nurses would encourage all women visiting the clinics on certain days to obtain cervical cancer screening. One participant said nurses told them to "get their Pap smears done" and also educated them on the "dangers of cervical cancer, that if you don't have a Pap smear test done and it gets discovered late that you have cervical cancer, there are dangers towards that. She'd explain that if it is detected early, it could be cured."

### *Role of healthcare providers*

The relationship of trust built over time between participants and health care providers was vital in obtaining cervical cancer screening. HIV positive women receiving ART therapy are more likely to have longitudinal relationships with their care providers, who consistently encourage and teach them about preventive disease screening. Since HIV positive participants spend more time interacting with the health care system, they are also more likely to report being influenced by a health care provider to seek Pap smears. Among HIV negative women, they were more likely to be affected by community groups, churches, or friends as they visit the clinic or the hospitals less often (Table 2, Quote 14, 15).

### *Courage to get screening*

Participants cited that obtaining cervical cancer screening was a way of showing “braveness,” “courage” as one would not only know their risk factors but also receive assistance early if diagnosed with cervical cancer. Obtaining a Pap smears was expressed similarly to getting tested for HIV, as knowing one's health status was a way to take better care of oneself (Table 2, Quote 18, 19).

### *Interventions at community level*

The majority of participants were interested in community interventions to raise awareness about cervical cancer screening in their communities. For those with a prior history of testing, they believed that including the community in education initiatives would provide the necessary knowledge needed to encourage cervical cancer screening. Some cited that while they had received screening, they did not feel similar motivation for Pap smears at the community level. For those with no history of testing, they also believed that providing the necessary information at a community level would educate more women about cervical cancer screening, and encourage behavior change. Community interventions suggested by participants included approaching community councilors to arrange education sessions to provide information through schools, community halls, churches, and distribution of pamphlets door to doors in smaller neighborhoods.

## **The Explanatory Model for Decision-Making**

Using thematic analysis of the women's experiences, beliefs, and attitudes, we developed an explanatory model for understanding cervical cancer screening among women in Pietermaritzburg, South Africa. The positive facilitators to cervical cancer screening include beliefs in health outcomes such as knowing one's status, and detecting cancer early, courage to get screening, and the role of religion, traditional healers, and health care providers in health decision making. However, information and

knowledge about perceived health outcomes alone is insufficient to support cervical cancer screening uptake. Women faced multiple barriers to cervical cancer screening that limited the ability to obtain screening such as ease of access to a clinic, financial costs of transport, lack of community awareness, and the ability to follow up on Pap smear results.

Using the explanatory model, the main facilitator to obtaining cervical cancer screening was living with HIV. Women living with HIV in South Africa are more likely to interface with the health care system on a frequent basis. Most HIV participants reported that they visited local clinics to receive their ART medications every month. While in the clinics, they were more likely to receive preventive health information from the nurses. They had increased knowledge about Pap smears and their role in detecting cervical cancer. Expanded information about cervical cancer screening was also related to improved knowledge about the procedure itself. Fear was one of the significant barriers noted as decreasing motivation for testing. However, after their first Pap smear, women reported that their concerns might have been unfounded. However, only 14% had at least a second Pap smear. Therefore, even though they were less afraid to have the procedure, barriers to obtaining another Pap smear were still prevalent.

Being HIV positive was noted as a positive facilitator to maintain one's health. One participant reported that after they discovered their HIV status, they were more motivated to ensure that their other health aspects were up to date. Having necessary information about cervical cancer screening, and the motivation about one's health contributes to an urgency to obtain the resources required to achieve the essential behavioral skills for changing behavior. Therefore, living with HIV in a peri-urban community in South Africa, in clinics with stable integration of HIV care into other health aspects, allows women living with HIV to extend their health care access to other areas of their life, hence improving cervical cancer screening. Conversely, HIV negative women felt that they were a burden to the healthcare system as they overall felt healthier and did not interact with the care system as often. These findings support a broader understanding of barriers to cervical cancer screening based on one's HIV status and the community of support that improves participants' ability to change behavior.

## **DISCUSSION**

Research in LMICs has identified a myriad of factors that influence cervical cancer screening among women including: lack of access to health facilities; increased financial burdens; fear of the procedure (Momberg 2017); lack of community sensitization; lack of decentralized clinics in rural areas (Adepoju 2016); and lack of knowledge about cervical cancer, Pap smears, and HPV infections (Francis 2011; Adibe 2017). However, challenges exist even when free cervical cancer screening is made available

for women. In a recent study in Nigeria, the authors found that barriers to free cervical cancer screening were still prevalent, and included the lack of mobile clinics and screening centers in rural areas. Most people who obtained free Pap smears were from urban centers with ease of access to facility centers. They found that community sensitization was essential as neighbors had a strong influence on women's health decision making. They found that even in urban centers and among highly educated women where awareness about Pap smears was high, uptake of cervical cancer screening was low (Adepoju 2016). Hence, providing free cervical cancer screening is important but insufficient to increase the number of women who access the test.

Using qualitative research methods for this study allowed us to study the key factors that influence cervical cancer screening among women living with HIV in South Africa compared to women who are HIV negative. This study builds the potential for a new approach to cervical cancer screening that would maximize on well-developed HIV care. In the Limpopo province in South Africa, studies have demonstrated successful testing when cervical cancer screening using visual inspection with acetic acid (VIA) is integrated into HIV care among migrant farm workers and sex workers (Afzal 2017). HIV clinics are equipped with resources to take care of a large number of patients living with HIV, and this study demonstrated that utilization of available resources for preventive screening allowed for more patients (91.6%) to receive prompt treatment with cryotherapy (Afzal 2017).

Systemic reviews have shown that community-based HIV testing, including door-to-door, mobile clinics, index testing, church and school-based testing are effective in increasing universal HIV testing (Suthar 2013). Community-based testing increased HIV testing uptake in difficult to reach communities compared to facility-based testing (Suthar 2013). Therefore, people living with HIV are more likely to receive linkage to healthcare either through community-based testing and outreach efforts surrounding HIV education and counseling, as well as in clinics when they receive ART. In South Africa, PEPFAR efforts allow the healthcare system to reach up to 10.4 million people for HIV testing and counseling (PEPFAR 2018). However, women who are HIV negative are less likely to be reached by outreach efforts solely focused on HIV care. They need be introduced to the health care system through contact with field workers providing HIV testing and counseling in communities. Hence, if cervical cancer screening and education are integrated into the HIV care model, it will likely increase awareness about cervical cancer and improve uptake of Pap smears. Also, it includes the potential to extend the screening model to reach HIV negative women and enhance their interaction with the health care system by increasing community outreach efforts to include healthy women.

In a recent qualitative study in Cape Town, South Africa to understand women's experiences with

cervical cancer screening and referral for colposcopy, the authors found that only 50% of all women referred for colposcopy after an abnormal Pap smears attended the clinic. Barriers to participating in referral clinics included lack of explanation about Pap smear results and need for colposcopy, which increased fear, anxiety, and uncertainty among women. However, they found that women referred by a primary antiretroviral clinic reported having received information and counseling about the Pap smear results, and need for colposcopy (Momberg 2017). Data from such studies in communities continue to show that women living with HIV in South Africa are more likely to be exposed to better healthcare infrastructure and resources that are lacking among women who are HIV negative.

Conversely, other studies in LMICs still show poor awareness and knowledge about cervical cancer among women who are HIV positive (Adibe 2017). Among the respondents in the study, only 10% had ever had a Pap smear, and the most commonly cited reason (61.8%) for not having a Pap smear was that they did "not know about it." Less often, they mentioned the fear of procedure, bad attitudes of nurses, and discouragement from sexual partners as other reasons for not obtaining a Pap smear. The most common sources of information about cervical cancer among respondents came from the media (23%) and health professionals (19.9%). Also, there was a strong positive association between having a positive attitude towards Pap smears and visiting gynecologist. This study was done in Nigeria at a University Hospital where cervical cancer screening counseling is not routinely included in the post-HIV testing counseling (Adibe 2017). Therefore, while knowledge, awareness, and uptake of Pap smears were still low, likely due to lack of integration of HIV care with cervical cancer screening, the study supports the strong influence of health care professionals in the primary and secondary prevention of cervical cancer.

Our study provides a new understanding of the influence of HIV status on preventive cervical cancer screening among women in a peri-urban setting in South Africa. In our thematic analysis, the decision to obtain a Pap smear is influenced by one's HIV status, information and knowledge about Pap smears, and being in an environment that increases the facilitators for behavioral change, and reduce the barriers to screening. Women living with HIV started a cohesive relationship with the health care system to obtain ART medication and treatment for HIV. Developing this good contact with the health care system ensured that women would frequent the clinic to get medications and receive peripheral benefits of interacting with the health care system. Among these benefits was receiving knowledge and education about Pap smears, developing communities of trust among other women in clinics, and encouraging each other to acquire other preventive health efforts. While fear, financial burdens, lack of knowledge, and lack of patient urgency were identified as a critical barrier to cervical cancer screening, interacting with the health care system was a key in overcoming the obstacles to testing. HIV positivity necessitates that



patient frequent local clinics or hospitals for necessary medical treatment. This model has been extended to include other aspects of health care, such that overall, HIV positive women are frequently visiting the health care system, and are more likely to have ever had a Pap smear in their lifetime.

This study was designed to understand women's experiences, beliefs, and attitudes about cervical cancer screening in South Africa, and to specifically focus on women living with HIV. Our qualitative findings support that women living with HIV do benefit from an established HIV care integration model, and thus are more likely to have ever heard of a Pap smear. However, only fourteen percent of participants with prior history of screening had a repeat Pap test, showing that information alone is insufficient to increase screening uptake. A major limitation to our study is that only women who had already engaged in prior studies were included. It is more likely that this population contained women with increased urgency about their health and who were more likely to follow up on their monthly ART treatment and obtain Pap smears. The study contained only thirty women to reach saturation, however, the study sample was skewed towards more women living with HIV. Nonetheless, our findings support that when women are integrated with the healthcare system and feel empowered to visit clinics and doctors for all aspects of their health, not just for HIV care, they are more likely to also utilize healthcare resources such as screening for detection and prevention of cervical cancer. Preventive strategies should target communities with education and awareness about cervical cancer screening, encourage all women to utilize the health care system, even when they are HIV negative, and include cervical cancer screening education as part of routine care for all women who qualify for Pap smears, or when they interact with the healthcare system.

## **FUTURE DIRECTIONS**

This research highlights the effectiveness of integrating cervical cancer screening with HIV health care services in a peri-urban community with low resources in South Africa. The study shows that reducing balkanization of care and integrating health care services can improve access to preventive services in LMICs. While there was no standardized method to provide cervical cancer screening among all women visiting clinics, the qualitative data shows that there is a "one-stop shop" for health care for women presenting for ART in local clinics. Future studies should focus on integration of primary care services in HIV clinics to increase essential and preventive screening for women. In resource poor settings, different methods of cervical cancer screening integration into HIV care should be studied to reduce the burden of care for health care providers, nurses, and community health workers. Recent studies by Cohen et al. on integration of family planning services into HIV care clinics showed sustained use of contraceptives among participants and overall reduction in unintended pregnancy rates among the cohort

over 24 months (Cohen 2017). Currently in South Africa, nurses in primary care facilities provide the bulk of cervical cancer screening. If HIV clinics could formally include specific training to increase the capacity for nursing and health care providers at all levels to provide cervical cancer screening, we could improve access to women in a peri-urban community. By harnessing the established systems of HIV care, HIV clinics can expand to not only support women living with HIV, but also to extend preventive primary care services to the local communities they serve.

## **CONCLUSION**

Cervical cancer continues to be a significant contributor to the burden of disease in LMICs. Cervical cancer screening has been associated with reduced mortality in high resource settings; however, uptake of cervical cancer screening in LMICs is still very low. In South Africa, the barriers to cervical cancer screening continue to include lack of education and awareness about Pap smears, financial burdens to attending clinics, lack of connection for HIV negative women to the health care system, and reduced community awareness about cervical cancer and the role of Pap smears in prevention. However, while barriers to screening exist among women in South Africa, women living with HIV were more likely to have heard of a Pap smear, received a Pap smear in their lifetime, and are more likely to be encouraged to get screened more often than HIV negative women. There is increased awareness and utilization of cervical cancer screening among women living with HIV in Pietermaritzburg, Kwa-Zulu Natal.

This study highlights that living with HIV in an LMIC has a tremendous impact on beliefs related to the health care system in general, and the experiences with cervical cancer screening among women living with HIV. Women living with HIV benefit from an integrated treatment model for HIV, which increases women's interaction with, and linkage to the health care system, and optimizes uptake of cervical cancer screening. However, while Pap smears are offered at most clinics in Pietermaritzburg, women who access them still have little knowledge about their role in cervical cancer prevention, which is associated with decreased likelihood of repeat Pap tests (only 14 % had at least a second Pap smear test).

According to the qualitative themes identified in this study, women living with HIV feel empowered to live positively, and that includes being able to overcome any barriers to obtaining their monthly ART from clinics and as well undergoing Pap smear tests. Women report the importance of health care providers in encouraging them to get preventive screening during their face time in clinics and hospitals. The relationship with healthcare workers is a critical factor that highlights that even in low resource communities when women have access to clinics and have strong relationships with health care

providers, they are also better equipped to modulate their behaviors and improve health outcomes. Studies have shown the link between HIV and HPV infections, and thus, we are encouraged that women living with HIV were more likely to receive Pap smears than women who are HIV negative. However, this study highlights the urgent need for care integration to not only include women living with HIV but also to extend to the rest of the community where most women feel neglected by the healthcare system. In an era where preventive screening with Pap smears has been shown to have mortality benefits, lessons learned from HIV care in low resource settings should be extended to include preventive care such as Pap smears to help reduce the burden of disease due to cervical cancer in LMICs.

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**Table 2:** Themes identified by participants regarding the knowledge, attitudes, and beliefs towards Pap smears

Categories	Age	HIV status	Pap smear history	Representative quotation
Barriers to screening	43	Negative	2	<b>QUOTE 1:</b> “There are a lot of factors that would make people not to get screened. Sometimes it would be the lack of knowledge; people are not informed. Others are scared. Some might be scared of the treatment they get at the clinic from the health workers. It sometimes happens that one would go there only to be told that they are attending the sickly and no one would attend to them. So I think a lot of people end up not going because they'd think they'd be ill-treated. So people just stay at home when they could have received help.”
	63	Positive	1	<b>QUOTE 2:</b> "Others would have knowledge others wouldn't. Others would be aware but would be ignorant, even when there'd be an invitation to certain health education they wouldn't care. That's ignorance. [...] Sometimes that I would desire to go for check-ups but would not be able to because I wouldn't have money. [...] I went to the clinic to get tested for TB. They told me to go back and come again because they are not handing out spitting bottles [...] They said I'll have to come to the clinic early I'll have to do it there. I just saw it burdening me, I was there, and I had to back to come back again. I just decided to wait for my medication collection date."
Lack of urgency for screening	34	Negative	0	<b>QUOTE 3:</b> “It is a problem, they would hear about it. However, most women are ignorant, like myself, I've never had a Pap smear done even when I've heard that cervical cancer is dangerous. [...] The reason why others don't have it done is the lack of knowledge as to why a Pap smear is done, how cervical cancer occurs in a woman.”
	58	Positive	1	<b>QUOTE 4:</b> “I think other people get it done to know their status (health status). Like myself, I tested because I wanted to know how much risk my life is at. So the same with them too, they'd want to know their status. It's better to die knowing rather than living carelessly when you already have this disease. Screening for cervical cancer is for one to know their health status, knowing how much risk your life faced with.”
Role of religion	44	Positive	0	<b>QUOTE 5:</b> “[...] I don't go out seeking help from people. I'd ask myself ‘why I should seek help from people when God is there. I must pray, he will help me and give strength'. If I say that, all get better.”
	43	Negative	2	<b>QUOTE 6:</b> “I am a saved child of God. I pray, and other church members would come over and pray for me, but one needs to go to the hospital. We do believe that God will heal us, but there are things that one needs to get screened and tested for. Not that God fails to heal us. We don't go to the hospital believing that healing is found in hospitals but we'd want to know exactly what wrong so that when we pray, we'd know what we are praying for, knowing what's exactly wrong in Jesus Name.”
Role of traditional healers or beliefs	63	Positive	1	<b>QUOTE 7:</b> “[...] the last time I got seriously ill is when I was HIV positive and had not been diagnosed with it. [...] I was moved to [Hospital Name], and that's where I got diagnosed with it (HIV). When I

	60	Negative	0	<p>came back from the hospital my children... they were still alive then, got me traditional medicines. I used the medicines and got worse. I stopped using them and continued with using tablets. I use tablets and church stuff.”</p> <p><b>QUOTE 8:</b> “It would be to cease going to traditional healers but go to clinics and hospitals. I promote going to hospitals because hospitals have resources that can quickly detect the sickness and how far it has gone so that they can overcome it or have the uterus removed while there is still time. That’s what I think will help us.”</p>
Influence of living with HIV	42	Positive	1	<b>QUOTE 9:</b> “They told me I have I had to have it done because I am already sick. They say all of us who are sick (HIV+) must and have a right to have it.”
	49	Positive	1	<b>QUOTE 10:</b> “They were doing tests on us as I explained to you earlier that I got tested and was found (HIV) positive, now they were checking to see what other diseases we have in our bodies.”
	31	Positive	1	<b>QUOTE 11:</b> “I learned when they told us at the clinic that if you are HIV positive and you are above.... well they didn't tell us the age group, but before you start taking treatment, it is a must that you do a Pap smear. I think these diseases (cancer) are related to HIV.”
High financial burdens	57	Negative	1	<b>QUOTE 12:</b> “I would end up going to the neighbors to borrow money to go to the doctors, or I'd go to the clinic because services at the clinics are free, but I'd borrow transport money. Another thing that makes it worse for us who wouldn't have money to go to private doctors/ surgeons is when we'd go to the clinic, and the doctor at the clinic would write a referral letter referring you to the hospital. At the hospital, I'd spend the whole day being sick. After spending the whole day at the hospital, then the hospital doctor would issue me with __ (painkillers). How did I get help there? There's no way I was helped! This is one of the problems that we people who don't have money encounter. People who have the money go to private hospitals and get help. [...]”
	47	Positive	1	<b>QUOTE 13:</b> “Going to the clinic in [Community Name] is just across from where we stay. We walk to the clinic. What becomes a challenge is when I have to go to the hospital. So I borrow money as a result [...]”
Role of healthcare providers	63	Positive	1	<b>QUOTE 14:</b> “I started hearing about it when I started taking ART.. The doctor told me I should have a Pap smear done. Every year I should have Pap smears done.”
	58	Positive	1	<b>QUOTE 15:</b> “One day I spoke with a nurse who was issuing my medication. I told her I have a problem; I feel pain in certain parts (of my body). She then encouraged me and told me about this disease (cervical cancer). I didn't know anything about it then. She said there is something called a Pap smear used to diagnose cervical cancer. As I was complaining about these symptoms, I might have just thought it was just the pain because of this disease I have (HIV) whereas it could not be it. I had to have a Pap smear test done and be screened for cervical cancer. [...] She felt it was important for me to have it done because I'd keep feeling the pain thinking it's the treatment (that causes it) only to find out otherwise at the end.”

Lack of community awareness	42	Negative	2	<b>QUOTE 16:</b> “I think they need to get educated on the importance of having it done. They need to be encouraged to have it early while they are still feeling healthy not when they'd be sick. In fact, one should get screened for everything while still healthy. One shouldn't wait until they are sick for the virus to be detected. It should be done early. When I tested for HIV, I did it early, and I wasn't sick I was well. It had to do it because I knew that I had been through certain things. Even though I am no longer doing those things but I had to get tested while I still had time.”
	49	Positive	1	<b>QUOTE 17:</b> “Things (diseases) like HIV, cancer, etc., people don't like discussing them and sit you down to disclose? No. They just go to facilities and get their problems sorted. [...] Most of the time when you disclose to people they walk around talking about your issue. So I think there are (people with cervical cancer problem) but I wouldn't know who they are. It's not easy for people to open up and disclose.
Courage to get screening	47	Positive	1	<b>QUOTE 18:</b> “It's braveness/courage. Getting tested/screened needs courage, and convincing yourself that if you are diagnosed positive, you will accept and get the assistance that will be available to you...”
	54	Negative	1	<b>QUOTE 19:</b> “I think I am prepared to deal with it if they say I have it, I'll have to look for a way forward. If they say I don't have it, I'll take care of myself and behave well not to get it because negative changes someday but positive never change. So I'll try to keep my negative not to change someday. But if diagnosed positive, I'll look after myself the way they'll tell me to look after myself so that I don't die early." So that's what I'd tell them. One would say I am just terrified of knowing. So there are those who are scared of just knowing. I went for it just because I wanted to know not because something was pushing me into doing it.”
Interventions at community level	51	Positive	1	<b>QUOTE 20:</b> “We will be joyful if someone came into our community to talk about these issues. If you arrived and approached a school and asked about raising awareness, you set a date for when you will arrive to talk about Pap smears and cervical cancer, and I am sure that many people may be seeking this information and concerned about their life. People worry about their life and would come to such an event.”
	58	Positive	1	<b>QUOTE 21:</b> “[...] They can announce that on a certain day there will be a meeting in the certain area, and you come and share information. We as people would appreciate. It shouldn't be only us who have this knowledge when there are people who want this knowledge but don't have it. Some people are HIV positive and have cervical cancer but are not aware of it because no one has given them this kind of information. If no one has ever told you/ warned you of certain things you never seem to care or take it seriously but if this is announced and awareness is raised, others who didn't know about it would get help.”
Commonly asked questions	43	Negative	2	<b>QUOTE 22:</b> “How would you help a person who suspects that she might have cervical cancer? Someone who hasn't gone to the clinic and is seeking to counsel.”
	30	Positive	1	<b>QUOTE 23:</b> “What I'd like to ask is; what causes cancer?”
	34	Negative	0	<b>QUOTE 24:</b> “How does one certainly know they have cervical cancer?”





