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Cervical Cancer Care Seeking Journey: A Qualitative Study of Care-seeking Experiences Among Zambian Women Living With and Without HIV

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Abstract

Background

Zambia has the third highest cervical cancer incidence rate globally, which remains the leading cause of cancer related death among women. We explored the experiences of Zambian women who accessed cervical cancer services to understand care seeking behavior and factors influencing access to care in urban, peri-urban and rural settlements in Zambia.

Materials and Methods

We conducted eight focus group discussions with women living with and without Human Immunodeficiency Virus (HIV) who had been screened for cervical cancer, and eighteen in-depth interviews with healthcare workers providing antiretroviral treatment (ART) or cervical cancer screening and treatment services at government health facilities in 2020. We coded and analyzed transcripts using thematic analysis.

Results

The majority of women were knowledgeable about cervical cancer and sought care promptly upon recognizing the need for screening, except for a few women who delayed seeking care until they overcame their fear through encouragement from their social networks. Despite a few reported challenges such as distance to the facility, transport costs, and waiting time, screening experiences were largely positive as women were received well and guided through the screening process by healthcare workers. However, for women who needed histopathology services, laboratory inefficiencies and financial constraints particularly in the rural areas delayed diagnosis and prevented timely access to treatment.

Conclusion

To improve uptake and access to cervical pre-cancer services, interventions should intensify cervical cancer sensitization, capitalize on the positive influence of social networks and healthcare workers, address health system inefficiencies, and allocate resources to counter structural barriers.

Implications for Practice

This paper outlines a cervical cancer care seeking pathway, describing decisions, behaviors, and interactions, from recognition of the need to screen to receipt of care, as well as barriers and facilitators that impact care seeking and access. Findings can inform the development of a public sensitization campaign that provides information on cervical cancer and addresses specific fears and misconceptions. Findings can also prompt key stakeholders to allocate resources to improve access and address the health system inefficiencies in the provision of cervical cancer services.

Introduction

Cervical cancer is the fourth most common cancer and fourth leading cause of cancer-related death among women with an estimated 604,000 new cases and 342,000 deaths worldwide.¹ Low- and middle-income countries (LMICs) are disproportionately affected by the disease, accounting for over 80% of the global cervical cancer burden.² Within Southern Africa, Zambia has the third highest age-standardized cervical cancer incidence and mortality rates of 65.5 and 43.4 per 100,000 women respectively.³ High morbidity and mortality rates are likely due to the high burden of HIV, lack of cervical cancer awareness and knowledge, limited access to preventative measures, late stage presentation and diagnosis, and limited availability of cancer treatment services.⁴⁻⁷

Cervical cancer is preventable by primary and secondary strategies, and can be cured if diagnosed at an early stage and treated promptly.⁶ However, several barriers hinder uptake and access to cervical cancer services. Studies in LMICs have identified barriers to care such as lack of knowledge and awareness of cervical cancer, unsupportive partners and families, negative community perceptions of the health system, poor organization of services and lack of capacity, long distance to health facilities, and travel costs.⁸ Barriers to cervical cancer care can result in delays in diagnosis and initiation of treatment, increasing the severity of illness and mortality.^{7,9} On the other hand, facilitating factors have been found to positively influence uptake and access to screening.¹⁰ These factors include perceived risk of developing cervical cancer, support and encouragement from providers, provision of educational materials, peer to peer education and recruitment, and offering screening in convenient locations in the local community.¹⁰

The objective of this study is to explore how women living with and without HIV access cervical cancer services, and factors that influence their decisions and ability to seek care in urban, peri-urban and rural settlements in Zambia. We describe the cervical cancer care journey for women who accessed cervical cancer services from recognition of need to screen, to screening, diagnosis, and treatment in Zambia, highlighting the influencing factors at each stage.

Materials and Methods

Study setting: To address the high burden of cervical cancer in Zambia, the Cervical Cancer Prevention Program in Zambia (CCPPZ) was established in 2006.¹¹ The “see and treat” program integrated cervical cancer prevention services into existing primary health care facilities and capitalized on infrastructure established by the HIV/AIDS care and treatment program.¹² Nurses were trained to provide free, personalized cervical precancer screening initially targeting women living with HIV before expanding to all women irrespective of HIV status.¹¹ The primary screening method is visual inspection with acetic acid (VIA) aided by digital camera enhancement of the cervix (digital cervicography).¹¹ Women who are found VIA positive are offered treatment immediately if their precancerous lesions are eligible for ablative treatment. Women with large and complex lesions who do not meet the criteria for immediate treatment are referred for histopathological evaluation. Despite the establishment of CCPPZ, cervical cancer incidence and mortality remain high indicating the need to explore factors that promote or inhibit access to cervical cancer services.

We conducted an exploratory qualitative study across three districts – Lusaka, Chipata, and Lundazi – respectively representing urban, peri-urban, and rural settings in Zambia. Between September and November 2020, we conducted eight focus group discussions (FGDs) with women aged 18 and above who had previously been screened for cervical precancer; four discussions (n=7, n=5, n=6, and n=7) with those found with cervical lesions and four (n=7, n=5, n=9, and n=8) with those without lesions. Additionally, we conducted 18 in-depth interviews (IDIs) with healthcare workers (HCWs) in antiretroviral therapy (ART) and cervical cancer clinics (**Table 1**). We sought a convenience sample of women found with or without cervical lesions to understand their care journey and a purposive sample of HCWs to gather their experiences in promoting or providing cervical cancer services.

Trained Qualitative Research Assistants (QRA) collected the data after receiving informed consent to audio-tape proceedings and transcribed them directly into English. Thematic analysis was conducted using excel to code the data first deductively using the questioning frame, and then inductively to capture new codes that emerged from the data.¹⁵ The themes and subthemes were categorized into chronological stages to form a cervical cancer care seeking pathway guided by Kohler's breast cancer help-seeking pathway.¹⁴ The study was approved by the University of Zambia Biomedical Research Ethics Committee (Ref No.387-2019), and the National Health Research Authority under the Zambian Ministry of Health.

Results

Cervical Cancer Care Seeking Pathway

The pathway comprises five stages that emerged from the FGDs with women with lesions (WL) and women without lesions (WWL), supplemented by IDIs with HCWs. Women and HCW experiences illustrate a complex set of factors that influence care-seeking behavior and access to care, and sometimes lead to delays between stages from recognition of need to screen, to hesitation and consultation, to screening, result interpretation, and treatment.

Stage 1: Recognition of Need to Screen

In the first stage, women promptly recognized that they needed to screen for cervical cancer because they were experiencing symptoms, perceived themselves to be at risk of developing cervical cancer, and had been sensitized on the importance of screening.

1.1 Experiencing symptoms

Women with and without lesions reported experiencing “stomach ache”, “back pain”, “pain when urinating”, “itchy private parts”, “warts”, “vaginal bleeding”, “white discharge”, “painful period pains ... like someone who has just aborted”, “pain during sex”, “prolonged period”, “swelling in the vagina”, and “sores on the private parts.” Due to the discomfort caused by these symptoms and the perception that their symptoms could be cervical cancer, women recognized the need to go for screening. A woman in Lusaka (WWL, Lusaka) explained that “the main reason that made me ... screen ... “I feel pain in the stomach, I have pain even it’s not the monthly periods. Then I had a lot of white mucus being discharged.” Symptom-driven health seeking was also

observed by HCWs at the cervical cancer clinic, with one saying that “others would come because they feel some abdominal pains because they know that it’s one of the signs. Others may come because they have prolonged PV [per vaginam] bleeding.”

1.2 Perceived risk and threat

Some women considered themselves “at risk” of cervical cancer due to HIV-infection expressed by one woman (WWL, Lusaka) as “us who are on ARVs [Antiretrovirals]”; having multiple sexual partners, and in one case, using herbs for vaginal tightening “because the herbs might have affected my cervix” (WWL, Lusaka). One woman felt at risk because “cancer is prevalent in women” (WWL, Lundazi), while another recognized her increased risk of acquiring HPV because her husband was uncircumcised. Additionally, women perceived cervical cancer to be life threatening especially if care seeking was delayed. They emphasized the urgency and importance of undergoing screening giving the example of relatives or friends who had succumbed to cervical cancer: “I saw my neighbor died, she was bleeding a lot, so I decided to go” (WL, Lundazi). Another woman, aware of the impact of delay, disclosed: “I heard that a lot of women are dying, so that’s what made me to go for screening...if they go for screening late, women die” (WL, Lusaka).

1.3 Sensitization

Many women were knowledgeable about the risks and the symptoms of cervical cancer and of the importance of screening due to health education given at health facilities, during community outreach, and via television, radio, and social media, with one woman explaining that: “I just decided on my own with all my heart because I used to hear about the lesson that screening is important” (WL, Lundazi). HCWs

attested to the positive impact of social media on screening: “the ‘Teal sisters’; this is a group on social media – Facebook, it’s a group consisting of women only. It’s meant for women to give each other support, motivation to go and get screened. It helps in boosting the numbers.”

Women living with HIV (WLHIV) in all three locations were prompted to screen primarily due to health education provided at the ART department, with a woman accessing ART explaining: “I saw from the lessons that we get at the ART clinic ...Cervical cancer usually affects women that are positive, who are weakened and are susceptible to many infections” (WWL, Lundazi). In some cases, WLHIV were mandated to get screened when accessing ART, as explained by a HCW at the ART clinic: “In the women living with HIV ... It’s like it has become mandatory for them to be screened ... Because of this linkage which was introduced between ART and cervical cancer.” For women who were not accessing ART, other mediums such as radio prompted them to screen: “I was listening on the radio, they were talking about cancer. Just like that I decided that I would also have to go and get tested” (WL, Chipata).

Stage 2: Hesitation and Consultation

All women who participated in the FGDs had been screened, however, a few women admitted that they delayed seeking care due to fear instigated by rumors in their communities. Women overcame their fears and doubts with the support of their social networks. HCWs encountered women who delayed seeking biomedical care because they sought traditional intervention first.

2.1 Fear and doubt

Some women feared going for screening due to negative rumors circulating in the community about the painful insertion of the metal speculum, screening outcomes, the biopsy procedure, male HCWs, and fatalism associated with a cancer diagnosis. The following quote illustrates the negative impact of the rumors: “They were saying that ... the machine [speculum] is painful ... and then they cut a piece of your skin, and a scar will remain ... I’m going to have a sore and ... male doctors are the ones who do the screening...” (WL, Lusaka). Another woman explained: “I was told that the metal [speculum] for testing for the cancer is what brings the cancer ... I refused at that time, I did not get tested ...” (WL, Chipata). HCWs confirmed that fear was a delaying factor for women as “a lot of them will tell you that they were very scared, and you will even see them shiver ... Fear of having the disease and because of what they have heard ... That once ... you have cancer, it means you are going to die.”

2.2 Consultation with social network

Some women shared their hesitations with their spouses, family, neighbors, peers, and healthcare workers who eased their fears and encouraged them to get screened. A woman narrates how her mother helped her overcome her fears: “She told me that it was a lie [that the speculum hurts] and that she did not feel any kind of pain and that I was wasting time. She said that I had to go to the clinic and go and get tested for cancer” (WWL, Lundazi). Another woman was encouraged by a peer who had received early diagnosis and successful treatment: “She is the first person that encouraged me and made me strong to say that I should go to the hospital also to go and get tested for cervical cancer” (WL, Chipata). Many women reported that they

were supported by their husbands: “He tells me not to be scared, we will know what to do if I have it ...” (WWL, Lusaka).

2.3 Seeking traditional intervention

Though no women in our study reported seeking traditional interventions, HCWs across all locations reported suspecting that women presented with late-stage cervical cancer due to delays in seeking care. They thought that women only resorted to biomedical care when they realized that traditional interventions were ineffective. One HCW in Lundazi explained: “The people who usually come when it’s late ... They have tried taking different herbs ... They have tried and they have failed, and that’s when they will come [to clinic]....”

Stage 3: Arrival at the Health Facility and Screening

To access screening, women had to find money for transport and cover the distance to the health facility. Upon arrival, HCWs welcomed and counselled them before conducting a guided screening process which elicited varying emotions and sensations.

3.1 Distance and transport

Women in urban areas could walk to health facilities or were able to find money to take a bus. Additionally, a few women in Lusaka reported that HCWs “gave me money for transport” (WWL, Lusaka) after screening. In comparison, some women in peri-urban and rural areas were unable to traverse the long distance from their homes saying, “we want a place which is near us because I know the distance is the reason why many of us women have fear ...” (WL, Chipata). HCWs in the rural areas echoed

women's distance and transport challenges when asked about delayed care seeking: "Others, it's the distance I can say, others they come from very far areas, they don't have transport money..."

3.2 Positive interaction with healthcare workers

At the health facility, most women in all locations experienced a positive interaction with HCWs which put them at ease during the procedure and enhanced their trust in the healthcare system. They felt "welcomed", "encouraged", "cared for" and "well received" as explained by a woman with lesions from Lusaka: "They just welcomed me very well ... I asked them if I won't have a problem with conceiving? ... They told me that I will just be ok, we were even chatting while laughing." Similarly, a woman without lesions from Lundazi appreciated that all clients were given the same unbiased care: "I was received quite well, and everyone is treated well. They don't look at how clean you are or anything." HCWs recognized the importance of fostering a welcoming environment for women: "You greet, create that rapport and then someone would be comfortable, and they will feel that the nurse or the doctor has a good heart."

3.3 Care procedures

Women in Lusaka and Lundazi noted that that they were quickly seen by a HCW, and that the actual screening procedure "didn't take long" (WL, Lusaka). However, some women in Chipata complained about waiting a long time because HCWs were busy on the phone or prioritized women who they knew. One woman stated: "if you had the thought that you have come here early in the morning, and you will leave early, then that is a lie ..." (WWL, Chipata).

A few women with lesions appreciated the guided screening process where they were told to remove their underwear, lie down, put their legs up, and shown and explained the images of their cervix during the procedure. One woman narrated: "... They ask you ... to lie on the bed ... They tell you what to do to open the legs. Then they just insert the machine [speculum] ... When the cervix pops up then they capture ... [the] image. They will show you where that cervix is infected or it's just okay..." (WL, Lundazi). HCWs confirmed that women appreciated being able to view images of their cervix.

Women without lesions in Lusaka also described a similar screening process; they inferred procedures from the sounds, sensations, and TV camera, and replaced their concerns with their trust in the HCW. In contrast, few women without lesions in Lundazi and Chipata described the process and only a few in Chipata mentioned "being shown" or "watching by myself on TV." None reported being told when the speculum was being inserted or where the camera was placed.

3.4 Mixed emotions and sensations

The screening procedure elicited mixed emotions and sensations in the women. A few women felt "shy" or "bad that they were going to see my private parts" (WWL, Lusaka) when asked to undress for the screening. HCWs confirmed that women felt embarrassed saying, "the most difficult part is to make them undress." Some women expressed fear and having to gather courage to enter the screening room, whereas others said they were fearless and did not hesitate. Women described the vaginal speculum as "the metal", "the instrument", "that thing", "small thing that is cold." Many women reported initially feeling scared due to rumors that insertion of the "metal" is

painful, but after screening, they realized that they had been misinformed: “Other women that got tested earlier were scaring us and saying that it hurts when they are testing you. After I ... tested, I realized that there was nothing that was painful” (WWL, Chipata).

Stage 4: Interpretation of Results

Result turnaround time and interpretation differed for women with lesions versus women without lesions. All women without lesions received results immediately and were scheduled for their next screening, whereas women with lesions underwent additional diagnostic procedures and/or treatment. As a result of the laboratory inefficiencies associated with sending cervical biopsy samples to the central lab in Lusaka, women with lesions in Lundazi experienced delays in receiving further care.

4.1 Turnaround time and diagnosis

Aside for one exception in Lusaka, women without lesions received their results immediately, some while watching the screen and some after the screening while being shown the “photo.” Due to their personal experiences and post-screening counseling, women without lesions thought that the purpose of screening was to determine the presence or absence of cancer: “It will show on the cervix if it is clean or dirty, infected or it is just ok ... (WWL, Lusaka). They described their results as “just okay,” “negative,” “just clear,” “clean” “no problem,” and “no cancer.” The women “felt good” and “very happy” knowing their results, with one woman declaring: “I felt good because I was told the way I was, and also the way I should take care of myself” (WWL, Lundazi). After screening, women reported appointments ranging from 1-5 years for their next screening.

Women with lesions felt anxious or scared as they waited for their results. Two women explicitly stated that “they diagnosed me with cancer” and “I was told that my cancer was in the early stages,” while others were found with “sores”, “a problem/small problem” on the cervix or told that their cervix was “not okay” or “had not yet developed to becoming cancer.” As a result, they were told that they had to undergo cervical biopsy – “a piece had to be cut so that they test it for cancer” or treatment – “they had to burn it.” A few women were still waiting for their results, and one received a paper copy of results without any explanation of their implications. Some women described feeling “good”, “happy”, and “free” that they had been screened and would be treated, with one woman saying: “I just felt good, my heart was free because they worked on me” (WL, Lusaka).

Due to the lack of histopathology services at the government labs, the Eastern Province (Chipata and Lundazi) health facilities sent cervical biopsy samples to the central lab in Lusaka. Consequently, many women in Lundazi and Chipata stated that their histopathology results were either delayed or lost: “It is not known when the results will come, other results are lost” (WL, Lundazi). HCWs in Chipata concurred with these reports with one saying: “Sometimes we just take those samples, and they go for good ... We usually don’t get results.” These delays could prevent access to treatment as reported by one woman who said, “I’m still waiting for the doctor to remove the uterus because they said that they need the results first ...” (WL, Lundazi), and another woman declaring that “others, they die before those results come in” (WL, Lundazi).

4.2 Financial barriers

Due to the inefficiencies at the government lab, HCWs advised women to pay out of pocket for histopathology testing of their cervical biopsy samples at a private lab: “Most of them we tell them if they can afford, they can pay because it’s better to know than not to know.” However, many women reported that they could not find the funds to do so: “I was told that my cervix was not okay, ... that a piece had to be cut so that they test it at cancer, so I don’t have money” (WL, Chipata). Women reported that if they did not find the funds, their samples were not tested: “When they get the sample, the sample stays that side unless you find the money” (WL, Lundazi).

Stage 5: Treatment

Women found with precancerous lesions that did not require additional diagnostic testing were either treated the same day or referred to see a doctor on another day.

5.1 Treatment procedures

A few women with precancerous lesions in Lusaka believed that cancer is treatable if diagnosed early: “They give pills to take if it’s in its early stages, and I will be ok if I just adhere to the treatment” (WL, Lusaka). Women who were eligible for same day treatment described procedures such as “spraying,” “laser beams,” “burning,” and “pills.” One woman explained: “I was told that there was something on my cervix that we are going to need to burn off, but it was done the same day” (WL, Chipata). Aside for one woman in Lusaka who felt “cold and pain inside” during treatment, no other women reported feeling any pain, disproving contrary rumors.

After treatment, women felt “good”, “restored”, “cured” and believed that the procedure was successful and helpful in relieving symptoms: “I felt good, the pain that I had in the stomach was no more and my body was even restored” (WL, Lusaka). Except for one woman in Lusaka, no other women faced challenges from their husbands regarding abstaining from sexual intercourse following treatment.

Discussion

Our study found that many women were prompted to screen because they perceived themselves to be at risk of developing cervical cancer, associated their symptoms with those indicative of cervical cancer, were aware of the importance of screening, and understood the potential consequences of delayed care seeking. Our study revealed a predominantly proactive approach among women toward screening for cervical precancer. While fear initially hindered some women, the supportive influence of social networks facilitated their eventual care-seeking. Regardless of the structural challenges such as distance, transportation costs, and waiting times, women’s screening experience was largely positive with healthcare workers playing a key role in guiding women through the process. However, delays in diagnosis and treatment were reported in rural areas primarily due to laboratory inefficiencies and financial constraints.

As a qualitative study, our findings cannot be generalized to larger populations of women and other districts within Zambia. Additionally, we did not separate women on ART from other women in FGDs. Nonetheless, the inclusion of diverse geographic contexts—urban, peri-urban, and rural areas; spontaneous sharing by women living

with HIV and healthcare workers provide a rich context regarding cervical cancer care in Zambia.

Knowledge and awareness of cervical cancer (demonstrating that extensive sensitization may facilitate uptake of screening), high risk perception due to HIV infection, and experiencing symptoms have also been cited as facilitators to uptake of screening in studies in Zambia¹⁵ and other African countries.^{16,17} While many women sought care promptly, a few delayed care seeking due to fears instigated by community misconceptions about the screening process and outcomes as found by other studies conducted in LMICs including Zambia.^{8,15,18,19} Even though no women in our study reported seeking traditional interventions, HCW reports suggest that women may delay seeking biomedical care and seek traditional interventions first. Cultural beliefs such as witchcraft causing cervical cancer²⁰ and a preference for alternative treatment from traditional healers²¹⁻²³ that may delay care seeking have been reported in cancer studies across sub-Saharan Africa.^{24,25} Consistent with other studies from Zambia, women who initially hesitated to undergo screening ultimately opted to seek care because of encouragement from their social network, often prompted by peers and family members.^{15,26,27} A few women in peri-urban and rural areas cited long distance to health facilities, lack of money for transport, and long wait time as barriers to accessing and receiving care. These findings align with studies conducted in Malawi, Peru, and Uganda which identified similar barriers to accessibility of cervical cancer services.^{28,29}

Our findings suggest that healthcare workers recognized the impact of their attitude and interaction on women's screening experience, therefore, they made deliberate

efforts throughout the counseling and screening process to ensure that women had a positive experience of care. These positive interactions and a guided screening process alleviated concerns such as feeling shy about their “nakedness,” anticipated pain and beliefs that the speculum caused cancer, feelings also identified in other studies in Africa.^{26,30,31}

Delays in diagnosis impact initiation of treatment which can negatively impact patient survival and worsen cervical cancer morbidity and mortality.³² As found in Rwanda and Uganda, diagnostic delays occurred due to long wait time for laboratory results, loss of biopsy samples or results, inadequate health infrastructure and lack of pathologists.^{31,33,34} Additionally, though cervical cancer services are free for women in Zambia; HCWs often advised women in peri-urban and rural areas to seek histopathology testing at a private lab due to inefficiencies at the central government-run laboratory, which many could not afford given the high poverty levels in Zambia.

Our study highlights the need to design stage specific interventions to address individual, health system, and structural barriers to improve the cervical cancer program to ultimately reduce cervical cancer incidence and mortality in Zambia. Strategies to improve screening uptake should include awareness campaigns that address specific fears and misconceptions and encourage women to prioritize seeking biomedical care. Given evidence of partner support increasing uptake of screening¹⁵ and studies from other African countries indicating the influence of husbands on decision making,^{35,36} sensitization campaigns should create targeted messaging for men.^{26,35-38} Increasing screening sites with adequate number and mix of trained providers can reduce the wait time,²⁸ along with mobile community outreach could

make screening more accessible by reducing need for and cost of transportation. Additionally, women's screening experiences should be monitored to identify and address any areas of concern to encourage women to return for a follow-up screening and share only positive messages about cervical cancer services within their social network. It is crucial that the health system provides efficient diagnostic services to ensure that women receive timely and appropriate care, minimizing delays in diagnosis and facilitating prompt initiation of treatment.

Conclusion

To improve uptake and access to cervical pre-cancer services, interventions should intensify cervical cancer sensitization, capitalize on the positive influence of social networks and healthcare workers, address health system inefficiencies, and allocate resources to counter structural barriers.

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