

# “It was not normal, and I had to find a doctor and tell him.” Kenyan Women’s Response to Cervical Cancer Symptoms

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## Abstract

This study aimed to characterize the cervical cancer diagnosis experience of Kenyan women undergoing treatment for cervical cancer. We analyzed qualitative interviews with 29 women living in rural Kenya who were currently undergoing cervical cancer treatment at Machakos Cancer Care and Research Centre at Machakos Level 5 Referral Hospital in eastern Kenya. Semistructured qualitative interviews were conducted in Kiswahili and English and then de-identified and translated to English during transcription. The main themes generated were identified through an inductive approach to determine how women experienced cervical cancer symptoms and their process of navigating healthcare. Three themes emerged from the qualitative interviews: (1) delaying seeking care, (2) misinterpreting or misdiagnoses, and (3) grappling with the costly diagnosis process. Women misattributed early signs of cervical cancer to benign conditions. Women sought care only after experiencing severe symptoms. When they sought care, women reported facing lengthy and costly screening processes before receiving a cervical cancer diagnosis. There is a need to educate women on the early symptoms of cervical cancer and to increase the institutional capacity and availability of cervical cancer screening resources in healthcare facilities.

## Keywords

Kenya, cervical cancer, symptom, diagnosis, screening, treatment, discharge, pain

## Introduction

Cervical cancer is preventable and curable if detected early.<sup>1</sup> However, it is a common cause of cancer-related death in low- and middle-income countries, including Kenya, among women.<sup>2-5</sup> Cervical cancer screening is an essential first step to identifying women with cervical precancer or early cancer, both of which can be treated and cured.<sup>6</sup> However, only 13% of Kenyan women between the ages of 30 and 45 years have received cervical cancer screening<sup>7</sup> in the last 5 years. Low screening rates in Kenya exist despite women having awareness about cervical cancer screening.<sup>8-10</sup>

Despite knowledge and awareness of cervical cancer in Kenya, low screening rates can be explained using the Commission on Social Determinants of Health framework.<sup>11,12</sup> Cultural and societal values, specifically stigma

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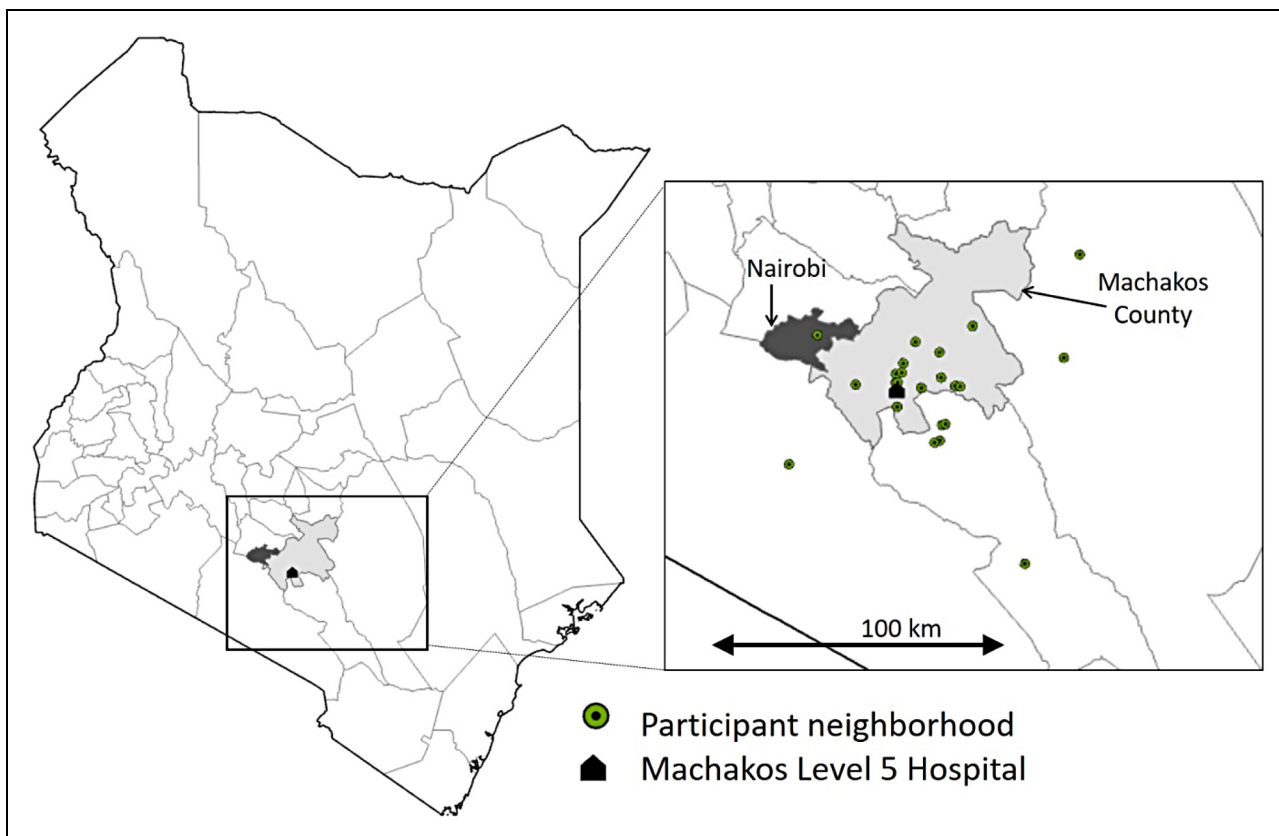
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and religious beliefs, have been shown to contribute to low screening rates in Kenya.<sup>13,14</sup> Women report a lack of knowledge about human papillomavirus (HPV) or cervical cancer, fear of pain, or fear of pelvic exams causing infertility.<sup>13,15–18</sup> Embarrassment, spousal approval, and discomfort with male providers are well-documented barriers to screening in Kenya.<sup>13,15–18</sup> Low socioeconomic status and residential location, particularly for women living in rural areas, also influence which women in Kenya can receive screening.<sup>13,15–18</sup> At the institutional level, health system service delivery barriers, including the shortage of health-care staff, lack of specialized training on cervical cancer, and insufficient resources are barriers to providing cervical cancer screening.<sup>15,19,20</sup>

In Kenya, the majority of the women who overcome the barriers and receive a screening test are found to have advanced-stage cervical cancer.<sup>21,22</sup> Little research in Kenya has been conducted to examine experiences with cervical cancer symptoms and the cervical cancer diagnosis process among cervical cancer survivors. This research study characterizes cervical cancer survivors' diagnosis experience to highlight factors that may contribute to delayed diagnoses and subsequent late-stage cervical cancer diagnoses among women living in rural Kenya.

## Methods

We recruited 30 women over the age of 18 years living in rural Kenya receiving treatment for cervical cancer at Machakos Cancer Care and Research Centre at Machakos Level 5 Referral Hospital in eastern Kenya. Figure 1 illustrates the geographic location where participants reside. We recruited patients using purposive convenience sampling.<sup>23</sup> A nurse recruited cervical cancer patients from a list of patients receiving treatment through a phone call. To ensure that patients did not feel coerced to participate,<sup>24</sup> the nurse informed patients that participation in the study was completely voluntary and would not affect the care they received. Patients who agreed to be interviewed consented and were provided with 2 choices to participate: either an in-person interview before or after the patient's next appointment at the hospital or traveling to the hospital for the interview at a separate hospital visit. Patients were compensated financially for their time and travel expenses. Each survey lasted ~ 30 to 45 min. Participants were issued participant numbers 1 to 30 in order of their participation. However, due to issues related to audio transcription, the transcript of Participant 22 was excluded from the study, ultimately reducing the sample size to 29 participants. Subsequently, data analysis was conducted on the remaining participants to draw meaningful conclusions from the study.



**Figure 1.** A map depicting rural neighborhoods of women undergoing cervical cancer treatment at Machakos Cancer Care and Research Centre at Machakos Level 5 Referral Hospital in eastern Kenya.

Surveys were conducted in both English and Kiswahili. Kiswahili surveys were later translated during transcription. We began with quantitative demographic questions (eg, age, level of education, marital status, working status, occupation, and health insurance status). Then, followed with in-depth interviews that explored participant experiences with cervical cancer screening and treatment initiation. All surveys were transcribed verbatim and analyzed using an inductive structured coding approach. For this study, we focused on understanding how women experienced cervical cancer symptoms and navigated the process of seeking healthcare.

Descriptive analysis for quantitative variables was conducted using SPSS. Structured coding was used to analyze the qualitative interviews following guidance from Saldana, 2013.<sup>25</sup> Two coders were involved in the process of manually coding the data. First, the coders each read 2 transcripts and labeled text by using either a word or phrase that summarized the essence of the statement. Then, the coders met to discuss the codes identified and created a codebook that included codes and their definitions. The codebook was structured to align with the thematic topics of the qualitative interview questionnaire. After creating the codebook, the 2 coders conducted the first cycle of the coding process, which involved analyzing 2 more transcripts independently. Then, they met to compare codes and discuss discrepancies in coding. Meetings were held every 2 weeks to review coding and discrepancies. The codebook was updated by adding or removing codes and clarifying definitions of some codes. The rest of the transcripts were coded, and the team met weekly to discuss the coding. Once all transcripts were coded, the team met to identify which codes were the most represented by examining the frequency of the number of participants associated with having text for the codes. Codes with the largest number of participants were grouped into categories that could be summarized with similar meanings. The segregated groups of codes were then identified as the themes.

## Results

### Demographic Characteristics

The descriptive characteristics of the participants are outlined in Table 1. The average age of participants was 56 years. Most participants had at least a primary education ( $n = 27$ ). Most participants were married ( $n = 21$ ), and almost half reported currently working ( $n = 12$ ). Farming was the most common activity for profit and subsistence ( $n = 21$ ). Most participants did not have health insurance before diagnosis; however, at diagnosis ( $n = 23$ ), those who were not previously enrolled in health insurance enrolled for the National Health Insurance Fund (NHIF).

Three themes emerged from the qualitative interviews (Table 2): (1) delaying seeking care, (2) misinterpreting or misdiagnoses, and (3) grappling with the costly diagnosis process.

### Theme 1: Delaying Seeking Care

Participants reported experiencing symptoms including pain, discharge including bleeding, cold, bad smells, and

**Table 1.** Participant Demographics and Characteristics.

	Participants (n = 29)
Age, mean $\pm$ SD (range)	56 $\pm$ 9.3 (32-70 years)
Education, n (%)	-
None	2 (7)
Some schooling to primary education	22 (76)
Secondary school or more	5 (17)
Marital status, n (%)	
Single	2 (7)
Married	21 (72)
Widowed	5 (17)
Divorced	1 (4)
Working status previous to diagnosis, n (%)	
Working	18 (62)
Not working	11 (38)
Current working status, n (%)	
Working	12 (41)
Not working	17 (59)
Current occupation, n (%)	
Business	3 (10)
Farming for profit	9 (31)
Volunteering	1 (4)
Personal farming/housewife/homestead	13 (45)
Not reported	3 (10) n
National Health Insurance Fund Status at diagnosis, n (%)	
Active	8 (28)
Not active	14 (48)
Unclear/not reported	7 (24)

backaches. More severe bleeding, abnormal discharge including sustained offensive odors, and intense pain or experiencing multiple symptoms prompted participants to seek care. Participants also shared experiencing bleeding during and after intercourse. Participants waited until their symptoms were abnormal or more severe to seek care.

*Subtheme 1a.* Participants sought care after experiencing severe pain ( $n = 15$ ).

Participants shared that they experienced back pain, stomach ache, and headaches. The pain would intermittently appear and disappear. However, they sought care when the pain became chronic or severe. One participant shared:

I have stomach aches and I have back pain (...) It started with a headache, bleeding went on for one month and stopped for three months then started again. (Participant 13)

*Subtheme 1b.* Participants sought care after experiencing severe discharge ( $n = 26$ ).

Participants shared that they experienced discharge. The discharge was reported as a symptom that occurred with pain for some participants. Participants waited until their bleeding was severe to seek care. One participant shared

**Table 2.** Thematic Findings.

Themes	Example Quotes
1. Delaying seeking care Subtheme 1a. Participants sought care after experiencing severe pain (n = 15) Subtheme 1b. Participants sought care after experiencing severe discharge (n = 26)	<i>"I felt very severe pain in the stomach which I did not know what it was, so when I came and tested I was diagnosed with cancer. Then I knew all the issues I have had related to cancer. I was told that the cancer had stayed for long."</i> Participant 30
2. Misinterpreting or misdiagnosing symptoms Subtheme 2a. Participants misinterpreted their symptoms as side effects of family planning (n = 10) Subtheme 2b. Participants misattributed their symptoms to other chronic health problems (n = 13). Subtheme 2c. Some healthcare providers initially misdiagnosed cervical cancer symptoms as being indicative of other conditions (n = 7).	<i>"I checked myself and found I had a discharge and I thought it was a kidney problem. I took a while before going to the hospital."</i> Participant 5 <i>"I came here at the hospital for the first time. He who saw me first told me it is pregnancy. I was losing my pregnancy. I went, stayed and felt that it was not pregnancy. I went to the other hospital."</i> Participant 30
3. Grappling with costly and/or long diagnosis process Subtheme 3a. Participants reported that the diagnostic examinations were expensive (n = 9). Subtheme 3b. Participants reported having to go to multiple places for diagnosis confirmation (n = 7). Subtheme 3c. Participants opted for private hospitals to avoid delays in the diagnostic process (n = 6).	<i>"When I came here I got tested and they discovered I got cancer. They told me I had to be scanned. They sent me to Kenyatta. There I was scanned 25 times but as they continued they had to add another five. So, 30. They sent me from Kenyatta to Nairobi Hospital."</i> Participant 7

that their bleeding became life-threatening, necessitating urgent medical attention:

I felt blood flowing out. I could not even stand ... I told them I am dying ... It just continued flowing. An uncle of mine has a car ... They went and got him because I could not walk. He was told to hurry up and take me to the hospital. He did not ignore it ... He took me to Bamako. (Participant 8)

## Theme 2: Misinterpreting or Misdiagnosing Symptoms

Participants reported that they did not seek immediate care for their symptoms because they attributed their symptoms to conditions other than cancer. Women said that they initially attributed their symptoms to different causes, such as overworking, malaria, failed family planning methods, or kidney problems.

**Subtheme 2a.** Participants misinterpreted their symptoms as side effects of family planning (n = 10).

Some participants shared that they thought that discharge or bleeding symptoms were side effects of family planning medications (eg, birth control). One participant shared:

Sometimes, when I meet [sexual encounter] with my husband, blood comes out. I thought it might be the family planning medicines since I have used them for 17 years continuously, and I was not getting any periods. I did not take it seriously. (Participant 18)

**Subtheme 2b.** Participants misattributed their symptoms to other chronic health problems (n = 13).

Participants shared that they associated their symptoms with other conditions such as kidney disease, malaria, infections, stomach issues, or others. Cancer wasn't initially considered as the cause of their symptoms. One participant shared:

I started feeling sick in my stomach. I wanted to know what is the problem. I first bought medicines thinking it is just a normal stomach ache. (Participant 10)

**Subtheme 2c.** Some healthcare providers initially misdiagnosed cervical cancer symptoms as being indicative of other conditions (n = 7).

Some participants reported that providers misdiagnosed them with having other conditions, including having a urinary tract infection (ie, UTI), sexually transmitted infection, or other conditions.

The first time I was told it is UTI. The second time I was told the same. The third one, I was told by the doctor to go take a picture [X-ray] so as to see what's the problem. (Participant 25)

## Theme 3: Grappling With Costly and/or Long Diagnosis Process

Participants reported that when they presented to their providers with advanced-stage symptoms such as severe bleeding, physicians referred them to other facilities with resources to perform X-rays or biopsies.

**Subtheme 3a.** Participants reported that the diagnostic examinations were expensive (n = 9).

Participants shared that the diagnosis confirmation process was delayed due to a lack of finances, as they were expected to pay out of pocket for screening.

It was a challenge getting those pictures. It was outside, and it was expensive. We did not do all immediately. We contributed a certain amount to do one first. We then look for money then do a CT for the abdomen. Another [time] we do MRI, and they are expensive. There it took us around two months before we did the staging. On doing staging, we brought all the pictures and we were told that she is in stage two. Stage 2B. Of which if we did it earlier, it would have been discovered earlier. (Participant 9)

Participants also shared that the NHIF did not cover screening. The out-of-pocket costs delayed their diagnosis confirmation and subsequent initiation of treatment.

**Subtheme 3b.** Participants reported having to go to multiple places for diagnosis confirmation ( $n = 7$ ).

Several participants shared frustrations about prolonged waiting periods for their test results. Additionally, some participants still needed to receive their test results.

I had to go for an X-ray and get a biopsy removed and taken to Kenyatta, we waited on the results but they never returned. I went, and they took another biopsy and took me to another place and the result turned out to be cancer. (Participant 30)

**Subtheme 3c.** Participants opted for private hospitals to avoid delays in the diagnostic process ( $n = 6$ ).

Patients shared that limited testing resources contribute to the long waiting periods at public hospitals. Some participants experiencing long waiting periods due to limited availability for testing at public referral hospitals who could afford private hospitals opted for testing at private hospitals. One participant shared:

Biopsy here is a challenge. Like here, in General [Machakos Level 5 Referral Hospital], if it [the appointment] was on February, you are told to come in September. We went privately [paid for a biopsy at a private hospital, due to the long waiting period] and did a biopsy then, it brought the results. (Participant 9)

## Discussion

The majority of studies that have examined the perceptions and experiences of cervical cancer screening in Kenya have focused on accounts from community members,<sup>9,13,16</sup> patients living with HIV,<sup>26</sup> or healthcare providers,<sup>13,15,19</sup> not women cancer survivors. We report firsthand accounts of experiences with cervical cancer symptoms and screening from Kenyan rural women currently receiving treatment for cervical cancer. Our findings show that women seek care after symptoms intensify, misinterpret their symptoms, are misdiagnosed, and experience financial and multiple referrals as barriers to care. Our findings align with a study conducted in Uganda of 18 women diagnosed with cervical cancer.<sup>27</sup> The women in Uganda misattributed their symptoms to bodily changes and delayed seeking care, once women sought care, their care was delayed due to repeated consultations.<sup>27</sup>

In our study, women waited until their symptoms progressed to present to healthcare providers. Only one woman recounted being diagnosed with cervical cancer after a routine exam. Routine cervical cancer screening reduces the rate of mortality as cancers can be detected at early stages that are easier to treat.<sup>28</sup> In high-income countries, routine screening is credited with decreasing the burden of cervical cancer.<sup>29</sup> Women receiving recommendations for screening from providers during annual visits are more likely to be screened for cervical cancer.<sup>30</sup> HIV-infected women between 36 years and 44 years of age receiving care at Kenyatta National Hospital have a 46.3% rate of receiving cervical cancer screening.<sup>31</sup> The rate is considerably higher than the general population rate of 17% of women between the ages of 30 and 49 years ever being screened in Kenya.<sup>7</sup> In that study, women who received cervical cancer screening recommendations from their providers were significantly more likely to be screened for cervical cancer.<sup>31</sup>

Having access to providers is essential for screening; however, other barriers include a lack of awareness of cervical cancer and cervical cancer screening, fear of the screening procedure, embarrassment, the perception that the screening procedure is painful, and fear of positive cancer results.<sup>13,16,31,32</sup> Women in Thika, Kenya, reported avoiding cervical cancer screening because of hearing accounts from their social networks that the exam is painful.<sup>32</sup> In Uganda, HIV-infected women report avoiding screening after learning about the side effects of the procedure.<sup>26</sup> It is imperative that interventions that encourage early detection through routine screening address these barriers.

In Western Kenya, financial concerns were a noted barrier to screening, especially when women are asymptomatic.<sup>16</sup> In high-income countries, women with limited access to preventative care are significantly more likely to be diagnosed with late-stage cervical cancer.<sup>33</sup> Ugandan women reported waiting until their cervical cancer symptoms intensified to present to their providers.<sup>27</sup> Women also shared that high out-of-pocket costs for screening further delayed them from getting an earlier diagnosis. Even for those with NHIF, screening costs were a barrier as they reported that NHIF does not cover screening. As Kenya embarks on changes to NHIF as a universal care program,<sup>34</sup> there is a need to ensure that screening is covered so women can be screened routinely.

Some women in our study reported seeking out their screenings from private hospitals to hasten the process and timeline for diagnosis. Studies report that public health facilities in Kenya have limited screening resources, and a lack of staff who are trained on cervical cancer screening as institutional screening barriers.<sup>13,15</sup> These barriers likely contribute to long wait times that have also been reported in other studies.<sup>31</sup> Additionally, the screening tests were expensive. Several participants reported frustrations when their screening results were delayed or providers requested patients to repeat the tests for diagnosis confirmation. Adewumi et al, 2022 recommend interventions, including training nonphysician health workers on cervical cancer screening, integration with other screening services available in the community, such as HIV screening, and increasing access to self-sampling testing to increase access to screening.<sup>13</sup>

Women reported misinterpreting their symptoms and attributing their symptoms to other causes. Cervical cancer-specific knowledge is low among Kenyan women, especially rural women.<sup>9,15,18</sup> A study conducted at Kenyatta National Hospital found that cervical cancer patients attributed their symptoms to having an infection instead of as symptoms of cervical cancer.<sup>35</sup> There is a need to increase knowledge and awareness of cervical cancer symptoms to encourage women to seek care before their symptoms progress. Especially because women who are diagnosed with advanced cervical cancer stages have an increased risk of recurrence.<sup>36</sup> Some women who sought care when experiencing symptoms reported that their providers misdiagnosed them with other conditions, therefore delaying their cervical cancer diagnosis. Studies show that there is a need to increase awareness among providers.<sup>13</sup> Therefore, efforts to promote early detection should be emphasized.

Our study has some limitations. First, we interviewed women recruited through convenience sampling from one hospital in eastern Kenya; therefore, our findings may not be generalizable beyond that population. Our study involves qualitative interviews, which required women to self-report their experiences; recall bias and stigma may have influenced participant responses. Although all women currently receive care at the same hospital, they reported receiving their screenings from different places; therefore, their screening experiences may be unique to the specific facilities in which they received initial screening. Despite limitations, our study has several strengths. Very few studies focus on the experiences of women currently living with cervical cancer. We interviewed women receiving care at the same hospital; therefore, results could inform future studies in the specific area.

## Conclusion

The findings of this study give us a clearer picture of women's perspectives and experiences in screening and diagnosis of cervical cancer in rural Kenya. Three themes emerged from the qualitative interviews: (1) women seek care when symptoms intensify or are perceived to be life-threatening, (2) women misinterpret their symptoms and health providers misdiagnose women, potentially delaying the diagnosis of cervical cancer, and (3) the diagnosis process is costly and involves multiple referrals and repeated consultations.

## Practice Implications

Women with limited access to routine and preventative care in Kenya are likely missing opportunities to receive screening recommendations due to a lack of knowledge about screening, costly screening, and limited institutional resources for cervical cancer screening. Therefore, there is a need to make changes to improve access and uptake of cervical cancer screening in Kenya. It is crucial to educate women to understand the importance of screening before symptoms emerge and educate women with limited access to healthcare on the early symptoms of cervical cancer. Our

results call for the implementation of initiatives to increase knowledge and awareness of cervical cancer symptoms for both women and providers. Providers need training on cervical cancer and need to be equipped with resources that support screening. Additionally, there is a need to enhance institutional capacity to reduce screening delays that result from referring women to more resourced facilities, resulting in longer waiting periods for diagnosis confirmation. Lastly, the cost of screening is a barrier, therefore, Kenya NHIF should cover the cost of cervical cancer screening and diagnosis confirmation.

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## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Ethical Approval

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## Informed Consent

Written informed consent was obtained from the patient(s) for their anonymized information to be published in this article.

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## Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the University of Alabama, Mount Kenya University, and the Kenya National Commission for Science, Technology, & Innovation institutional review boards approved protocols.

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