

Barriers and Facilitators to Cervical Cancer Screening, Diagnosis, Follow-Up Care and Treatment: Perspectives of Human Immunodeficiency Virus-Positive Women and Health Care Practitioners in Tanzania

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Key Words. Patient navigation • Cervical cancer • Tanzania • Human immunodeficiency virus • Screening • Focus groups • Social stigma

ABSTRACT

Background. This study was conducted to identify barriers and facilitators to cervical cancer screening, diagnosis, follow-up care, and treatment among human immunodeficiency virus (HIV)-infected women and clinicians and to explore the acceptability of patient navigators in Tanzania.

Materials and Methods. In 2012, we conducted four focus groups, two with HIV-positive women and two with clinicians who perform cervical cancer screening, diagnosis, follow-up care, and treatment. Transcriptions were analyzed using thematic analysis.

Results. Findings from the patient focus groups indicate the prevalence of fear and stigma surrounding cervical cancer as

well as a lack of information and access to screening and treatment. The clinician focus groups identified numerous barriers to screening, diagnosis, follow-up care, and treatment. Participants in both types of groups agreed that a patient navigation program would be an effective way to help women navigate across the cancer continuum of care including screening, diagnosis, follow-up care, and treatment.

Conclusion. Given the fear, stigma, misinformation, and lack of resources surrounding cervical cancer, it is not surprising that patient navigation would be welcomed by patients and providers. *The Oncologist* 2019;24:69–75

Implications for Practice: This article identifies specific barriers to cervical cancer screening and treatment from the perspectives of both clinicians and patients in Tanzania and describes the acceptability of the concept of patient navigation.

INTRODUCTION

Although the incidence of cervical cancer has decreased worldwide in recent decades, it remains the fourth most common cancer among women, with the majority of cases in less-developed regions [1]. In Eastern and Middle Africa, cervical cancer remains the most common cancer among women [1]. Within East Africa, Tanzania has one of the highest incidence rates of cervical cancer, with incidence and mortality rates of 54.0 and 32.4 cases per 100,000 women, respectively [1]. Compared with human immunodeficiency virus (HIV)-negative women, HIV-positive women are more likely to be infected with the human papilloma virus (HPV), have persistent HPV

leading to precancer, and have larger, more difficult to treat precancerous lesions, higher recurrence rates of precancer following treatment, and precancerous lesions that progress more rapidly to invasive cancer [2–5].

The Tanzanian Ministry of Health has recognized the increased risk of cervical cancer in women with HIV and released national guidelines that recommend women be screened for cervical cancer at the time of HIV diagnosis and annually thereafter, regardless of screening results. They also promote the use of cryotherapy to treat precancerous lesions in the HIV Care and Treatment Clinics (CTCs) [6]. However, this

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is not consistently done due to several barriers to care. Access to screening and treatment is a barrier for all Tanzanian women, regardless of HIV status. Seventy-five percent of reproductive-age women in Tanzania live in rural communities without easy access to screening [7]. Efforts are being made to train regional providers to screen for cervical cancer; however, positive screens are referred to the Ocean Road Cancer Institute (ORCI) in the nation's capital, and travel to Ocean Road for treatment is cost-prohibitive for many families. Additionally, many sociocultural beliefs limit treatment, such as the idea that diagnosis leads to death. In reality, by the time many of the women present for treatment, they have late-stage disease, which leads to higher mortality [8].

To address such barriers, the concept of patient navigation was introduced by Freeman in 1990 to increase breast and colon cancer screening and treatment among poor black women in Harlem. Navigators are usually laypeople from the same community who work to eliminate barriers to care [9]. Since its inception, patient navigation models have been shown to increase utilization of cancer screening and rates of follow-up for abnormal cancer screenings in the U.S. [10–12]. The benefits of patient navigation are also observed in diverse patient groups [13], most likely because patient navigators either speak the same language and/or originate from the same background as the population being navigated.

Patient navigation programs are gaining popularity outside of the U.S. as well because of numerous barriers faced by residents of many low- and middle-income countries. Studies have shown major barriers to be low socioeconomic status, low awareness, inadequate funding, and a dearth of providers in low-resource countries globally [14, 15] and in sub-Saharan Africa in particular [16]. Several programs are using patient navigation to overcome some of these barriers [17, 18]. Specifically, patient navigators were used as part of a multipronged effort to increase cervical cancer screening among HIV-positive women in Zambia, who have similar barriers to screening and treatment as women in Tanzania [19].

Given the high incidence of cervical cancer among HIV-infected women in Tanzania, and the documented benefits of patient navigation in improving screening rates and treatment, this study was conducted to identify specific barriers and facilitators to cervical cancer screening and treatment across the cancer continuum of care including screening, diagnosis, follow-up care, and treatment for HIV-infected women and to specifically explore the acceptability of patient navigators across the cervical cancer screening and continuum of care. The concept of patient navigation utilized in this study is based on the Patient Navigation Model (PNM) developed by Freeman and colleagues [20, 21] to help women of low socioeconomic status adhere to breast cancer screening and treatment guidelines. The PNM has been used by one of our coauthors and other researchers to help vulnerable populations access reproductive health services and reduce cancer health disparities in low-resource settings in the Deep South states of Alabama and Mississippi [22, 23] and countries in Africa [24, 25]. Patient navigators would educate women and the community about cervical cancer, encourage women to get screened, talk with them about their screening results, provide emotional support, assist women with setting up appointments and arranging transportation, and accompany them to the cancer clinic for further

diagnosis and treatment. In other words, patient navigators would help the women overcome barriers to screening, diagnosis, and treatment of cervical cancer. This should increase screening and follow-up care for treatment of precancerous lesions too large for cryotherapy and ultimately reduce the rate of cervical cancer diagnosis among the women [20–25].

MATERIALS AND METHODS

In 2012, we conducted four focus groups, two ($n = 10$ and $n = 9$) with HIV-positive women, 19 years or older, who had been screened for cervical cancer and two with male ($n = 7$) and female ($n = 14$) clinicians (physicians and nurses; $n = 12$ and $n = 9$) who perform cervical cancer screening. We chose HIV-positive women who had been screened as participants in the patient focus groups, because HIV-positive women are at greater risk for cervical cancer than HIV-negative women. Also, women who have been screened are more aware of the barriers to cervical screening and possibly follow-up treatment; therefore, interviewing these women provided us with the greatest opportunity to gain insight into factors affecting cervical screening and acceptance of peer navigators. The age range for the participants was 24–57 years. Participants were recruited from 12 of the 29 Management and Development for Health (MDH) public HIV CTCs in Dar es Salaam, Tanzania. Topics covered in the focus group sessions included barriers to cervical cancer screening and treatment, knowledge of and attitudes toward cervical screening, and perceptions of and attitudes toward patient navigation. Clinician focus groups took place in the MDH meeting room, and patient focus groups took place at Amana Hospital. All participants provided informed consent prior to being enrolled in the study. The study was approved by the Institutional Review Boards at the University of Alabama at Birmingham and the National Institute for Medical Research in Dar es Salaam, Tanzania.

Focus groups were conducted by trained moderators and were audio-recorded, transcribed, and then translated into English. The transcriptions were analyzed based on thematic analysis [26], and Atlas.ti was used to facilitate the coding and analysis of data. The code list was initially determined based on the questioning frame, but new codes were included that emerged from the data.

RESULTS

Focus Groups with HIV-Positive Women

Knowledge/Awareness

When asked what they knew about cancer and its causes, most women associated all cancer with cervical cancer. In general, it was believed that cancer was a disease in women of child-bearing age that was contracted through sexual transmission or was a disorder in the blood. Further, cervical cancer was seen as a disease that “attacks” the womb and is widespread among women.

Several participants admitted to not knowing the causes of cervical cancer, and many inaccuracies were expressed. Causes mentioned included being inherited from a relative, ingesting certain substances (coal, soil, foods), participating in sexual intercourse, being raped at a young age, having a compromised immune system, contracting a sexually transmitted disease,

taking family-planning medications, having an abortion, having multiple births, and lacking cleanliness. Although inaccuracies and unawareness abounded in knowledge related to the causes of cervical cancer, most of the women were well aware of the symptoms based on personal experience or knowledge from a friend or relative.

Most participants believed that cervical cancer could be cured, especially if detected early. Several of the women did not know what types of treatments were available, although many did share treatment modalities such as surgery (hysterectomy) and radiotherapy. Regarding whether or not women could become pregnant after a diagnosis of cervical cancer, some felt that because of radiotherapy, a damaged womb, or advanced aged, pregnancy was not possible; others either did not know or thought it was possible in some cases.

The participants believed that, despite its prevalence, women in the community either had no knowledge of cervical cancer or had misinformation about cervical cancer, such as it being associated with witchcraft, and that television and radio messages were not effective in disseminating correct information. Cervical cancer, the participants felt, was viewed by women in the community as a death sentence, which caused them to “hide” instead of seek treatment. As expressed by one participant, “In our community, most of us suffer from breast cancer or cervical cancer but we fear to attend clinic for screening.”

Men in the community were seen as being less informed than women. Participants felt that men typically had no information about cervical cancer until their spouses or partners were diagnosed and told them about it. At that point, participants claimed, “a man most likely would desert his wife/partner because he believed she had been unfaithful to him by engaging in sexual intercourse with another man, because she could no longer provide him with conjugal rights,” or because he feared she would transmit the disease to him. A few of the participants believed that men who had accurate knowledge of cervical cancer were more likely to support their wives and encourage them to seek treatment. But the overwhelming feeling was that once a woman was diagnosed with cervical cancer, she would most likely be stigmatized, left by her husband/partner, and isolated.

Information Sources

The majority of participants said they first heard of cervical cancer from physicians or other health care providers, presumably at the time of screening. When asked who they trusted the most for advice about illnesses affecting their private parts, one participant said it was her spouse and two mentioned female relatives, while 71% said they most trusted physicians, and 10% said counselors. When asked if they trusted female relatives to give them advice about illnesses of their private parts, about one third said they did not trust any female relatives, because they felt their relatives would approach them in an accusatory way. The other two thirds felt comfortable discussing sensitive issues of the private parts with female family members such as mothers, sisters, aunts, and daughters. However, a different picture emerged when participants were asked if they would seek advice from their husband’s female relatives about illnesses of the reproductive system; only about one fifth said that they felt comfortable doing so. The others said that they

would not seek advice from their husband’s female relatives because they would be stigmatized and isolated. Several women claimed their husbands had isolated them or separated from them after they confided in one of his relatives about their illness.

Stigma

Stigma related to cervical cancer emerged as a theme. One participant summed up the sentiment this way: “Most men when they know that his wife is suffering from cervical cancer. . . stigmatize her; he will regard [her] as someone who has no value in his community. . . he will just stigmatize and isolate [her].” Women diagnosed with cervical cancer are commonly considered valueless because they can no longer have sexual relations with their husband/partners. As one woman stated, “When a man knows that his wife is suffering from cervical cancer, he no longer cares (for) her (and) may isolate her. When it reaches a stage when a woman dies, the man has already gone.”

Because of the threat of stigmatization and isolation, it is no wonder that the thought of cervical cancer evoked fear in the women. In fact, the participants voiced fear and worry as the first thing that came to their mind about cervical cancer, particularly the fear of dying young and leaving their children without a mother. Fear also extended to screening, in that it could lead to a discovery of cervical cancer.

Screening

Despite fear, all the participants had been screened for cervical cancer themselves, and all responded that they would get screened again. At the time of screening, most were advised to attend follow-up appointments, which they did. A few were told to simply get screened again within a certain period of time. Motivations for screening included experiencing symptoms and/or being told by a counselor to seek screening. The participants were aware that screening was the only way to know if one had cervical cancer. Some expressed the idea that early screening and detection was important for a better outcome. The thinking among the women was that the time for screening was after symptoms had occurred, as opposed to screening in the absence of symptoms for the earliest detection. All but one stated that they were aware that they had screening available to them at no cost. Despite the availability of screening, they claimed that many women avoided screening because of lack of knowledge as well as fear, as discussed earlier. Some women claimed that screening was delayed because “. . . in the streets there is a belief that if you know early you have cancer, you die early,” and because one was bound to die, it was better to die at home.

Openness to Navigation

All the women were interested in participating in a navigation program, in learning about cervical cancer screening, and in helping other women prevent cervical cancer. They also were unanimous in their interest in providing assistance to other women who need treatment for cervical cancer, including escorting them to the ORCI. Although they all desired to participate in a program to help other women get screened and treated for cervical cancer, most of the participants felt that they would need compensation, especially to cover travel expenses that might be incurred.

Clinician Focus Groups

Background and Duties

Participants served in various capacities: Five identified themselves as assistant medical officers, one as a gynecologist, one as a nurse officer, one as a phlebotomist, two as nurses, three as clinicians, and five as nurse counselors. Participants had been in their current positions from 1 to 18 years, and they had been involved in HIV care at CTC between 3 and 8 years. Their duties consisted primarily of counseling, screening, treating, prescribing medication, and general administrative tasks.

Task Shifting

In addition to their routine assigned work duties, all but two participants said they were asked to “task shift” and perform jobs outside of their regular work. Some were asked to perform administrative duties, such as a counselor being asked to pull files. Others were asked to practice outside of their specialty, such as someone who works in HIV treatment being asked to participate in a C-section procedure. They were also asked to do extended shifts (i.e., to stay for the morning shift after completing the night shift). One participant summed up her thoughts about task shifting: “. . .my duty is to take care of and treat HIV/AIDS patients. There are many per day. You may attend 120 patients but sometimes you are asked to go outside your CTC duties maybe four, five, or six times per week to perform other duties. You don’t have time to rest. Your brain may even jam.”

Screening and Treatment Preparation

Approximately 70% of the clinicians had performed cervical cancer screenings. About one third of the participants reported receiving no formal training in cervical cancer screening, although some of those performed the procedures and learned through being mentored. Of those who did receive training, most received only a 2-hour orientation, and this took place between 2 and 5 years previously. The participants were primarily trained to do Pap smears, visual inspection with acetic acid (VIA), and visual inspection with Lugol’s iodine (VILI). Although the majority of the participants received limited training in cervical cancer screening, most received no training in the treatment of precancerous lesions using cryotherapy. For the few who did receive training in treatment, it was 4–8 years previously.

Most participants felt that the training they received in screening and treatment of precancerous lesions was insufficient, and this contributed to a lack of confidence in performing the procedures. They felt it was of poor quality not only because it was not long enough but because it was conducted at the end of the day when participants were tired, the location was not conducive to training, and the training consisted mainly of theory and no practice. A few of the participants said that their training was sufficient or even very good, and two suggested this was because their supervisors were available at all times if they needed assistance or had questions. Several participants expressed the importance of receiving more in-depth training in order to improve competence.

Challenges and Barriers

When asked about their main challenge in keeping up with their daily work, the participants listed their lack of training,

lack of staff, lack of or faulty equipment, crowded conditions, and unreliable power supply. They also mentioned the challenge of having the patients they refer to ORCI be turned away because they could not pay the required fees.

Similar answers were received when participants were asked what they believed were the major barriers to performing cervical cancer screenings. Because of the lack of space, providers often had to wait until their colleagues were finished with a room to take care of their patients, and wait times were long. Patients may leave the clinic without being seen because they simply get tired of waiting all day or because they do not understand the importance of waiting for their appointment. Another barrier related to staff and training is that screening training is generally limited to physicians. Several participants suggested that if all staff had training, staff shortages could be more easily managed. Finally, a lack of motivation among staff was seen as a barrier as well. Because screening may not be in each job description, it may be seen as a task added on top of the regular work of some employees, which decreases morale and motivation.

Solutions

Participants discussed solutions to barriers. More training for staff was seen as a primary solution to improving patient care and decreasing wait times, but there were differing opinions regarding how to address staff shortages. Whereas some felt that there should be permanent staff assigned to screening alone, others felt that the number of staff was adequate but that all staff should be trained in screening procedures so that there would be individuals available to cover those who are absent. It was suggested that clinics such as those of MDH cooperate with ORCI to provide periodic refresher training courses for staff to improve their competence and confidence. In terms of motivation, participants suggested that an allowance or incentive be given to staff to motivate them to do screenings well. Lack of patient awareness was also seen as a barrier, and it was suggested that adding educational materials such as posters in waiting or treatment areas may help with this. Some felt that better clinic procedures could improve patient flow and decrease wait time. Finally, it was suggested that they could go to the Ministry of Health in an effort to find solutions.

In terms of improving clinic procedures, participants were asked if it would be difficult to screen and treat patients on the same day. Most, but not all, said it would currently not be possible due to the lack of resources described previously. However, with more space, trained staff, and improved clinic procedures, participants felt it would be feasible to screen and treat patients in a single day.

Navigation Program Acceptance

The participants unanimously felt that a navigation program would be beneficial to patients. First, they thought it would improve awareness of cervical cancer and the need to be screened, thereby increasing early detection and treatment and decreasing mortality. It would also improve follow-up and simplify services for patients. One participant summed it up: “We need such a project because many women are from poverty suffering families, which fail to go to Ocean Road for

economic reasons.” Also, the dire situation in which these patients find themselves makes this an important program. As one participant voiced, “I think it is good project because patient has two big problems. Firstly, she is HIV-positive, whereby she thinks her life has reached at the end of the road. Secondly, she has cancer, which she also regards as end of the road. So I think it is good project and she needs support.”

In order for the program to be successful, participants felt that there needed to be standard operating procedures in place for referrals, communication, and follow-through. Procedures that support cooperation between ORCI and the clinics would be important, as would having a focal person to manage patients to ensure that they follow through with making appointments and have appropriate and reliable transportation.

DISCUSSION

This study highlights the lack of access to not only cervical cancer screening and treatment but to accurate information regarding cervical cancer, its association with HIV, and the importance of early screening. The patient focus group consisted of women who had received cervical cancer screening, but their knowledge of the disease and how it is contracted was low. Many women believed hygiene, certain foods, or birth control could cause cervical cancer, which is similar to other studies on perceptions regarding cervical cancer in Africa [27]. This is despite evidence that HIV-positive women presenting for cervical cancer screening in Tanzania tended to be more highly educated than HIV-negative women who presented for screening [28]. Most women had not gotten screened for cervical cancer and only presented for care after experiencing symptoms. The delay in seeking care likely leads to advanced stage of cancer at presentation, which is not amenable to attempts at removal at the CTC via cryotherapy. Therefore, they are then referred to ORCI for further management, but are often lost to follow-up.

Many women also said they could not ask family members for advice regarding screening for fear of being stigmatized. In particular, the patient focus group participants expressed fear that their husband/partner would equate a cervical cancer diagnosis with an admission of infidelity, which agrees with other studies of barriers to screening in the region [29]. Furthermore, the women felt that men knew even less about cervical cancer and could potentially be more supportive if they had more education. At the time of this paper, no study on male perceptions of cervical cancer screening/treatment in Tanzania has been completed, although a study on male perceptions of cervical cancer screening in Ghana showed similar misperceptions [30].

The women said they most trusted physicians to provide them with information regarding cervical cancer screening and treatment. However, although all of the women in the study had received screening, they still had low knowledge of the etiology of cervical cancer and that early treatment could prevent more serious symptoms. This could be because they forgot the information they received or because they never received the information at all. A patient navigator could fill this gap as a nonpartisan third party that women could access for education and support without fear of rejection. All the women voiced support for the patient navigation program and were willing to

become navigators themselves; however, most desired compensation. Compensation is typical in many American patient navigation programs for breast and cervical cancer screening [31].

There were numerous barriers to screening and treatment as identified by the health care staff interviewed in this study. The providers cited a lack of confidence due to limited training in screening and treatment of precancerous lesions. These findings are not unique and have been found in surveys of health care providers in similar environments such as Kenya [32]. In addition, limited space and equipment hampered attempts at screening.

The providers had a willingness to participate in same-day see-and-treat plans, as have been enacted in other locations such as Nigeria [33] and Ghana [34]. In this system, women are screened for cervical cancer with VIA or VILI methods. Abnormal results are treated the same day by cryotherapy. As mentioned previously, same-day see-and-treat plans are encouraged by the Tanzanian Ministry of Health [6]. However, providers cited the lack of resources as prohibitive. Providers also suggested that a lack of feedback from cases referred for higher levels of care as a barrier to screening, as they were never made aware of the outcomes of cases they referred. Additionally, they believed that additional health care staff such as nurses could be trained in the screening technique to address staff shortages. Training of additional staff such as nurses may require a large education component, as indicated by Urasa [35], who found that nursing staff in a large regional hospital in Tanzania had low knowledge of cervical cancer, and many had not been screened themselves.

Participants in both types of focus groups, clinician and HIV-positive women, agreed that a patient navigation program would be an effective way to increase cervical cancer screening and follow-up treatment, especially for those patients referred to ORCI. These results corroborated with a recent quantitative study of HIV-positive women in Tanzania that found $\geq 97\%$ of participants would like services of patient navigators such as assistance with explanation of medical terms, emotional support, and setting up appointments and transportation; and 88% reported that they would appreciate the assistance of a patient navigator in accompanying them for cervical evaluation and treatment [36]. Given the fear, stigma, and misinformation surrounding cervical cancer reported among the HIV-positive women participants as well as the lack of resources voiced by the clinicians, it is not surprising that programs offering support, such as patient navigation, would be welcomed by both patients and providers. Although most of the provider concerns, such as training and space, would not be addressed by a patient navigation program, since government and Ministry of Health officials were made aware of the information brought out in the focus group discussion sessions (without revealing the names of the participants making particular statements), it is expected that these matters would be addressed by these officials.

CONCLUSION

The small sample size and narrow nature of the sample are limitations of this study that must be taken into consideration in interpreting the results. The small sample of women who

participated in the focus group discussion sessions precludes generalization of the results to larger population groups of women in Tanzania. Only HIV-positive women who had been screened for cervical cancer were included in the focus group discussion sessions, so the findings could be different for women who had not been screened. Although only a small number of clinicians participated in the clinician focus group sessions, we took care to include representation of clinicians at different levels and from different clinics or institutions. Regardless of the limitations, we believe that the overwhelming support for the use of patient navigation in assisting women with cervical cancer screening, diagnosis, follow-up care, and treatment could increase the number of women accessing these services and ultimately lead to a reduction in cervical cancer diagnoses among the women.

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DISCLOSURES

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For Further Reading:

Kathleen R. Ragan, Natasha Buchanan Lunsford, Judith Lee Smith et al. Perspectives of Screening-Eligible Women and Male Partners on Benefits of and Barriers to Treatment for Precancerous Lesions and Cervical Cancer in Kenya. *The Oncologist* 2018;23:35–43

Implications for Practice:

This article provides important insight into female and male partner perspectives regarding benefits, facilitators, and barriers to treatment for precancerous lesions and cervical cancer. These novel research findings can inform the development of targeted community health interventions, educational messages, and resources and aid stakeholders in strengthening strategic plans regarding treatment coverage and cervical cancer prevention. Because several treatment barriers identified in this study are similar to barriers associated with cervical cancer screening in low- and middle-resourced countries, effective messaging interventions could address barriers to receipt of both screening and treatment.