Mtengezo and Lee, J Nurs Patient Care 2018, 3:2
DOI: 10.4172/2573-4571.1000124

Journal of Nursing & Patient Care

Research Article

A SCITECHNOL JOURNAL

HIV-Positive Women's Perceptions, Awareness, and Knowledge about Cervical Cancer Screening in Malawi: A Qualitative Study

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Received date: February 09, 2018; **Accepted date:** June 19, 2018; **Published date:** June 25, 2018

Abstract

Background: Malawi is among countries with highest rates of cervical cancer and HIV in the world. Evidence has shown that HIV-positive women have a higher risk of having abnormal cervical cells caused by human papillomavirus (HPV) than in HIV-negative women due to compromised immune system. However, there is a gap in the literature relating to cervical cancer and screening rate, knowledge, and behavior among Malawian HIV-positive women.

Objectives: To explore factors influencing cervical cancer screening among Malawian women living with HIV infection.

Methods: This qualitative study was conducted in one of the Christian Health Association of Malawi (CHAM) health facilities. Data were collected through an in-depth interview with 13 HIV positive women who were purposely selected to participate. Data were analyzed using content analysis.

Results: The study identified four major themes influencing screening which include 1) knowledge and attitudes; 2) social support networks; 3) socio-cultural factors; and 4) access to screening services.

Conclusion: The findings of the study should further be explored in a larger population based survey to develop specific and targeted interventions for promoting cervical cancer screening among Malawian women living with HIV infection.

Keywords

HIV; Cervical cancer screening; Perceptions; Awareness; Knowledge; Malawi

Background

Globally, health disparities exist in access to health care and disease burden. Almost nine out of ten (87%) cervical cancer deaths occur in the less developed regions [1]. Malawi has the highest rate of cervical cancer in the world [2,3].

Human papillomavirus (HPV) infection favors HIV acquisition, and HIV-infected individuals encompass a heavier burden of HPV and cervical cancer due to a compromised immune system [4]. HIV-positive women have a higher risk of having abnormal cervical cells caused by HPV than in HIV-negative women. In a study conducted recently in Malawi, the prevalence of a visual inspection with acetic acid (VIA) positive result was 7% among HIV- negative women and 33% among HIV-infected women [5].

Malawi's HIV prevalence is one of the highest in the world with women aged 15-49 years estimated at 10.8% [6]. Women account for more than half of all adults infected with HIV/AIDS. The use of antiretroviral therapy (ART) has extended survival for persons living with HIV/AIDS and allows them to live a longer healthy life. But HIV-infected individuals are prone to opportunistic and other sexually transmitted infections [7]. Lack of early diagnosis of HPV in HIV-infected women is linked to higher mortality from cervical cancer than from HIV/AIDS [8]. Malawi is the second poorest country in the world and women do not have access to the same methods of cervical cancer screening as women in developed countries [2]. In addition, more than 80% of cervical cancer in sub-Saharan Africa is detected at a later stage due to lack of awareness and resources to implement effective screening programs to identify and treat a pre-cancerous lesion or early stages of cervical cancer [9,10].

Cervical cancer is preventable and curable if detected at an early stage using VIA [3]. The VIA has demonstrated to be feasible, safe, accurate, affordable and an efficient way of reducing the cervical cancer burden [10]. Cervical cancer screening is effective in the prevention of cervical cancer in developing countries where this testing is available [3]. Despite the availability of screening services in Malawi, the WHO report indicated that the cervical cancer screening coverage for all women aged 18 and above in Malawi was as low as 2.6% [10]. Regardless of the risk and vulnerability of a high percentage of the population, cervical cancer screening studies have not been conducted among Malawian women with HIV to explain and understand the determinants of cervical cancer screening. The purpose of this qualitative study was to explore sociocultural, knowledge, attitudes, and health belief about HIV and HPV infection and cervical cancer screening among Malawian women living with HIV infection. The specific objectives include exploring HIV-positive women's perceptions, awareness, knowledge and health beliefs about cervical cancer; socio-cultural factors that influence cervical cancer screening; HIV-positive women's perceptions of stigma about HIV and cervical cancer.

Methods

A descriptive qualitative study was conducted at a Christian Health Association of Malawi (CHAM) hospital in Malawi. The study targeted HIV-positive women aged 18 or older. Data collection commenced after obtaining local IRB approval, in addition to IRB approval from University of Massachusetts Boston. Participants' decision to take part in the research study was voluntary. Subjects were recruited using notices posted at strategic sites and through health talks at the clinics. Volunteers who showed up and gave written informed consent for participation were recruited consecutively. Saturation point was reached after interviewing 13 respondents.

Data collection

A 30 to 45 min semi-structured face-to-face audiotaped interview was conducted by the first author in a private room in the clinic. All participants preferred the local Chichewa version for the consent forms as compared to the English version, all were interviewed in Chichewa. During the interviews, probes and follow-up questions were asked to understand participants' perspectives and also to gather possible discrepant information and alternative explanations for these experiences and perceptions. Each interview began with a general question and moved to specific questions and then additional structural and comparison questions. For example: Questions that the study answered included "Have you ever been screened for cervical cancer?" "What have you heard about cervical cancer and screening?" "What do other people think about cervical cancer screening?" "How much does cervical cancer screening cost you?" "Who does the cervical cancer screening?" "How comfortable are you to have men or women examine you?" "What are your personal beliefs and perceptions about cervical cancer screening?" Interviews were conducted for 30-45 min by a bilingual PI and were audio-taped.

Data analysis

Data were transcribed verbatim for content analysis. After careful readings, the Chichewa transcripts were coded and translated into English by external translators who were bilingual and content experts. Then, the two investigators independently read transcribed data from each participant and selected key words and significant statements based on research objective as a general framework and created a priori codes from the discussions.

Coding was an interactive process and related codes from the two investigators were grouped together and color coded using shared characteristics or themes. The principal investigators reviewed the codes at a data analysis meeting. Discrepancies in coding were resolved and subsequently modified and agreed on a set of themes. Dependability was ensured through the review of the results by an independent person after analyzing each interview. The emerging themes, sub-themes and illustrative quotes are reported as results of the study.

Results

Table 1 highlights the participants' characteristics. Thirteen (13) women living with HIV were interviewed; 46.2% were married, 23.1% were divorced, 15.4% were widows, and 15.4% were single. The mean age was 34.15 years (SD=8.87) within the age group of 22-52 years; the mean years since HIV positive diagnosis was 5.23 years (SD=2.98); and the average number of children born to each woman was 3.3 (SD=2.59) and ranged between 0-8. About 15.4% (2) of the respondents had been screened for cervical cancer in the past.

The study identified four major themes as factors influencing cervical cancer screening which include 1) knowledge and attitudes 2) social support networks; 3) socio-cultural factors and 4) access to health care services.

Knowledge and attitudes

Cervical cancer in Malawi is called "Khansa ya khomo la chiberekero," which literally translates to cancer of the mouth of the womb. The participants narrated that they had heard about cervical cancer and screening. Women had heard about cervical cancer from fellow women, the radio, and at health talks from health care workers at HIV clinics. When participants were asked what they had heard about cervical cancer and screening, the women indicated that they were aware that cervical cancer is a dangerous disease and that there is no treatment.

Screened for Cervical cancer	n	%
Yes	2	15.4
No	11	84.6
Marital status		
Married	6	46.2
Divorced	3	23.1
Single	2	15.4
Widow	2	15.4
Source of cervical cancer information		
Fellow women	6	46.1
Radio	2	15.4
HIV Clinic	2	15.4
Fellow women and radio	1	7.7
Fellow women and HIV Clinic	1	7.7
Radio and HIV Clinic	1	7.7
Mean (SD)		Range
Age in years	34.15 (8.87)	22-52
No. of children	3.3 (2.59)	0-8
No. of years since HIV diagnosis	5.23 (2.98)	1-11 yrs

Table 1: Participants' characteristics.

Some women reported that cervical cancer is a sexually transmitted disease, transmitted by uncircumcised men. Some women stated that the procedure of cervical cancer screening is painful. On signs and symptoms of cervical cancer, the women narrated that those who have cervical cancer experience bleeding in between menses, abdominal pains, and have offensive or yellowish vaginal discharge. The participants had no information about cervical cancer prevention. One participant had this to share:

"The procedure of cervical cancer is painful" "Since I have never heard from doctors talking about cervical cancer, I have no information about it and how to prevent it" (Respondent 5).

Some respondents had limited knowledge of the use of screening services as a means of preventing cancer in HIV positive women. One woman stated that "Government should advocate cervical cancer screening for all women. All women are equally at risk of having cervical cancer not just HIV positive women" (Respondent 7).

Social support networks

Participants were asked if they had ever been screened for cervical cancer. Those who reported to have undergone screening were asked the reasons for going for screening. The participants reported that a family member or a health care provider motivated them to undergo the screening as shown through narrations from two women as follows:

"My daughter in-law told me that the procedure is not painful and encouraged me to go for testing" (Respondent 1).

"The doctor told me that Screening helps to prevent cancer and for early care if you are found with cancer" (Respondent 4).

Those who had never been screened for cervical cancer were asked the reasons for not going for cervical cancer screening. The participants stated that the services were not readily available as illustrated below: "Cervical cancer screening services are not readily available. It took me the whole morning as there was a long queue and I returned back home without being examined" (Respondents 1, 3, 4, 6). One participant narrated that she did not go for screening because of religious beliefs. She expressed it like this: "My previous religious belief did not allow going to hospital" (Respondent 2).

The other participants stated that they did not go for screening as they feared the positive result as there is no treatment for cancer and it can be a double burden of having HIV and cervical cancer. They stated, "It can give us double stress and burden as we already have HIV that has no cure, the same with cancer. It is better to stay without knowing that I have cancer as I am already HIV positive" (Respondents 2, 3).

Socio-cultural factors

The participants stated that they were aware that both male and female health workers performed cervical cancer screenings. When asked if they would be comfortable to get a cervical cancer screening from a male or a female healthcare provider, some women stated that they would be comfortable with both female and male doctors but they fear the procedure because those who undergo screening must refrain from sexual intercourse after the procedure. One participant shared this: "The doctors told my friend not to have sex for one week after the procedure. Some husbands cannot stay without sex for one week" (Respondents 11).

Access to cervical cancer screening services

The participants shared several dimensions of access to cervical cancer screening: availability of health care providers and health equipment; affordability; approachability; and acceptability in their sociocultural settings. Women that had been screened reported that they did not pay anything for the procedure but they had to wait for a long time before screening as there was only one nurse providing the services. Those who had not undergone screening reported that they did not know the actual costs of performing cervical cancer screening. Some of the participants stated that the indirect costs included things like paying for the health profile book to be stamped, transport to access the services because screening services were not available in most ART clinics and long waiting time for screening services. One participant stated: "It took me the whole morning as there was a long queue and I returned back home without being screened" (Respondent 9).

Women also added that fragmentation of the HIV and cervical cancer services was a major barrier to cervical cancer screening. One woman shared this: "It is better if doctors examine us as we are starting ARV as part of our care package and follow up within our ARV appointment dates rather than going to cervical cancer screening clinic to save transport money and time" (Respondent 9). Therefore, access to screening services was a major barrier to screening services rather than socio-economic factors.

Discussion

The purpose of the study was to explore factors influencing cervical cancer screening among Malawian women living with HIV infection. Some respondents had limited knowledge on the use of screening services as a means of preventing cancer in HIV positive women. For example, a woman stated, "Government should advocate cervical cancer screening for all women. All women are equally at risk of having cervical cancer not just HIV positive women" (Respondent 7). This response could mean lack of knowledge regarding the increased risk of developing cervical cancer. On the other hand, HIV/AIDS is viewed as a stigmatized disease among the community and by advocating for cervical cancer screening for HIV positive women, it would also bring stigma to this preventive effort. This response could mean that HIV positive participants had limited knowledge that having HIV increases the risk of having cervical cancer. Cervical cancer can be prevented by screening and that the disease can be treated if diagnosed at an early stage.

In addition, HIV positive women have low knowledge regarding cervical cancer and screening as any other women. This is evidenced by the narrations from the participants that indicated that women did not have accurate knowledge about the disease. Women were asked what they had heard about cervical cancer and screening. Most women stated that they had heard that cervical cancer was a dangerous disease, but they could not state the signs and symptoms of the disease. Also, those who stated how the procedure was done indicated that the screening procedure was painful. Such knowledge deficits might explain why most of the participants did not go for screening as they thought the procedure was painful despite being aware of its usefulness. In addition, it might also indicate lack of information, education and communication of health awareness and promotional messages about cervical cancer and screening in the community. In the absence of adequate knowledge on the procedure, women are not likely to undergo for screening or may do so when the disease has reached an advanced stage as indicated by Maseko and colleagues [10]. Due to lack of knowledge about cervical cancer few participants accessed the services. This is in line with the WHO's report which indicated that few women (2.6%) have had cervical cancer screening in Malawi [10]. Therefore, the health care system should create health awareness day for cervical cancer and screening in the community. The awareness will increase women's knowledge about cervical cancer and screening services. The knowledge gained will also help to address women's misconceptions about the cervical cancer screening procedure. Health care workers have a crucial role in sensitizing the community and educating women about cervical cancer and screening procedure in Malawi.

Women got information about cervical cancer and screening from their friends or relatives. The decision to go for cervical cancer screening was influenced by their social network members' information. One participant shared this: "The doctors told my friend not to have sex for one week after the procedure. Some husbands cannot stay without sex for one week" (Respondent 11). This can mean that the friends are a source of information that influences behavior. On the other hand, it may mean that information is not correctly shared among the community. Another woman also stated that "The procedure of cervical cancer is painful" "Since I have never heard from doctors talking about cervical cancer screening, I have no information about it". Therefore, incorrect information that women share about screening procedure may be a barrier to cervical cancer screening among Malawian women. On the other hand, Women who reported that they underwent screening, reported that a family member or a health care provider motivated them to undergo the screening as shown through narrations from two women as follows: "My daughter in-law told me that the procedure is not painful and encouraged me to go for testing" (Respondent 1). "The doctor told me that the screening helps to prevent cancer and for early care if you are found with cancer" (Respondent 4). This suggests that the type of social networks of women living with HIV-infection interacts and the type of information shared facilitates and hinders screening uptake.

Most respondents reported on indirect costs of screening such as lack of availability and accessibility of the screening services. The cervical cancer screening services were offered at a hospital level, and some clinics refer cases to hospitals that are situated very far away. Money for transport to go to a hospital to receive cancer services was a significant barrier to receiving care when the cancer was treatable. Although there are no user fees to access cancer services in public health facilities, there was indirect cost as the women were required to travel long distances and purchase health passports if they did not have one. In addressing this problem, training more service providers and procurement of resources may help to open more cervical cancer screening centers and improving access cervical cancer services.

All the participants were aware that both male and female health workers perform cervical screening. Some women were not comfortable to be screened by a male service provider. This indicated that the gender of the healthcare provider performing the cervical cancer screening appeared to be a barrier to access screening services for some of the participants. Refusing to be screened by men reflects cultural unacceptability of reproductive health services like cervical cancer screening to be provided by male service providers. Likewise, age of service providers is a critical component of secondary prevention of cancer in a culturally sensitive environment when women have no signs and symptoms of the disease to undergo screening.

Women also added that fragmentation of the HIV and cervical cancer services was a barrier to cervical cancer screening. One woman shared this: "It is better if doctors screen us as we are starting ARV as part of our care package and follow up within our ARV appointment dates rather than going to cervical cancer screening clinic to save transport money and time" (Respondent 9). Therefore, access to screening services was a barrier to screening rather than the socio-economic factors.

Limitations

The study used a qualitative design and purposive convenience sampling, therefore, the results of the study cannot be generalizable to all HIV positive women in Malawi. Further, the participants reported that they had all heard about cervical cancer and had a positive attitude towards cervical cancer screening that raised questions about social desirability and generalization of findings to a greater population. Lastly the study did not exclusively explore participants' knowledge and attitudes regarding cervical cancer and screening that might be important factors contributing to screening behavior in this study population.

Implications for practice

Health care workers have a crucial role in providing cervical cancer services to the women. Therefore, the findings of the study will help to:

1. Raise community and health care providers' awareness of the barriers and facilitators of cervical cancer screening among Malawian women living with HIV infection.

2. Develop group-specific educational and promotional interventions to promote cervical cancer screening among Malawian women living with HIV infection.

3. To train health care providers in VIA which is a simple and cost effective method to detect abnormal cancer hence increasing cervical cancer screening rate

4. Validate the findings of this study with a population based survey.

Conclusion

This study adds valuable information regarding factors influencing cervical cancer screening among Malawian women living with HIV infection. Targeted educational and promotional interventions regarding cervical cancer prevention are needed for Malawian women living with HIV infection.

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