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A Qualitative Exploration of Women's Experiences with a Community Health Volunteer-led Cervical Cancer Educational Module in Migori County, Kenya

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Abstract

Detection and treatment of human papillomavirus (HPV) and cervical precancer through screening programs is an effective way to reduce cervical cancer deaths. However, high cervical cancer mortality persists in low- and middle- income countries. As screening programs become more widely available, it is essential to understand how knowledge about cervical cancer and perceived disease risk impact screening uptake and acceptability. We evaluated women's experiences with a cervical cancer education strategy led by community health volunteers (CHVs) in Migori County, Kenya, as part of a cluster randomized controlled trial of cervical cancer screening implementation strategies. The educational modules employed simple language and images, and sought to increase understanding of the relationship between HPV and cervical cancer, the mechanisms of self-collected HPV testing and the importance of cervical cancer screening. Modules took place in three different contexts throughout the study: (1) during community mobilization; (2) prior to screening in either community health campaigns or health facilities; and (3) prior to treatment. Between January and September 2016, we conducted in-depth interviews with 525 participants to assess their experience with various aspects of the screening program. After the context-specific educational modules, women reported increased awareness of cervical cancer screening and willingness to screen, described HPV- and cervical cancer-related stigma and emphasized the use of educational modules to reduce stigma. Some misconceptions about cervical cancer were evident. With effective and context-specific training, lay health workers, such as CHVs, can help bridge the gap between cervical cancer screening uptake and acceptability.

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Authors' Contributions

All authors were involved in the preparation, review, and editing of the final manuscript. MJH conceptualized the study and led the data collection. SO and EB led study activities on the ground and assisted in conceptualization of the analysis. YC wrote the manuscript with contributions from the authorship team (SO, KA, EB, and MJH).

Keywords

Community Health Volunteer Education; cervical cancer screening; HPV testing; in-depth interviews; Kenya

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Introduction

Worldwide, cervical cancer is the fourth most common cancer and leading cause of cancer-related death among women, with 87% of cases occurring in low-resource settings.[1] While detection and treatment of cervical cancer precursors can be effective in reducing cervical cancer deaths, low- and middle-income countries (LMICs) continue to face a disproportionately high burden of cervical cancer and related mortality. Cervical cancer screening coverage throughout Africa is consistently below 20%, and in Kenya, screening rates are only 4% in urban areas and 2.6% in rural areas.[2] Limited screening availability, poor access to screening facilities and low socioeconomic status all contribute to the low screening rates. However, even when screening is available and accessible, other factors may play a part in a woman's decision to screen. These include limited knowledge or misconceptions about cervical cancer and human papillomavirus (HPV), screening mechanisms, and low perceptions of risk.[3–5]

Effective health education can increase health literacy and address beliefs that reduce screening uptake, especially in areas with limited health prevention services. However, effective education must be context-specific and appropriate for the target population. [6, 7] In a previous study of an educational intervention in rural Kenya, we found that an educational module on cervical cancer increased women's knowledge and awareness of screening, but did not increase actual rates of screening with visual inspection with acetic acid (VIA). [8] Other studies have found psychological barriers to screening from lack of health education, including stigma about cervical cancer and misperceptions about screening and the causes of cancer, which have led to women's reluctance to screen and access treatment.[9, 10] To our knowledge, very few studies have looked at educational interventions incorporating messaging about human papillomavirus (HPV), the causative agent for cervical cancer, which can be targeted in screening strategies. As HPV testing becomes more widely available in LMICs, effective education about risk, transmission and screening strategies will be essential to addressing misunderstanding and the potential HPV-related stigma.

Previous research has shown that community health volunteers (CHVs), lay health workers who liaise between the community and the health facility and work mostly in community settings, are a valuable resource for culturally-appropriate health education.[11, 12] CHVs are a key component of health information and basic services, and have been shown to improve maternal and child health, and control non-communicable and infectious diseases. [13] As health educators, CHVs have promoted cervical cancer screening in individual and group education settings [12, 14, 15] and used written educational materials[12, 14] and a media-based educational intervention among vulnerable or high-risk populations in the

United States.[16] However, studies exploring experiences with CHV-led cervical cancer education in LMICs, such as those in sub-Saharan Africa, are limited.

This study sought to understand women's experience with a CHV-led educational module delivered in three settings as part of an HPV-based screening program in rural western Kenya. As part of an ongoing cluster-randomized trial, we explored women's knowledge on cervical cancer and its prevention methods, perceptions of self-collected HPV testing, perceived risks of cervical cancer, and recommendations on how to improve the educational modules after exposure to a CHV-led educational module.

Methods

Study Setting and Population

This study was part of a two-phase, cluster-randomized trial that evaluated implementation strategies for HPV testing offered at community health campaigns and health facilities in Migori County, Kenya. [17] Using indepth interviews (IDIs), we explored women's experiences with a cervical cancer outreach and education strategy led by CHVs. The study was conducted in partnership with the government of Kenya (County Health Management Team), which utilizes a community health model employing CHVs and peer educators in HIV control strategies. The team purposively sought out a subset of approximately ten participants from each of the 12 study communities to complete IDIs during the community mobilization activities and after screening in either the community health campaigns (CHCs) or health facilities, where screening was offered. All women who received treatment for a positive HPV test were asked to participate in an IDI before leaving the treatment facility.

Educational Modules

We developed educational modules to explain cervical cancer and HPV, screening modalities and rationale for treatment, and how to self-collect a specimen for HPV testing. The modules were targeted at women aged 25–65 years living in the study communities, and were delivered during mobilization, immediately prior to screening and for all women undergoing treatment with cryotherapy (Table 1). The goal of the educational modules was to increase uptake and acceptability of HPV-based screening through a better understanding of cervical cancer, HPV, the importance of screening, and the steps involved in HPV self-collection. CHVs working in Ministry of Health outpatient clinics were trained to deliver the educational module during a two-day training session, and were supported throughout the implementation by research staff.

Educational Module Development

The educational modules included basic anatomy, definitions of cervical cancer and HPV, how screening works, available treatments, and how to conduct self-HPV testing (Table 2). Supporting materials included flip charts, posters with step-by-step instructions and illustrations for self-collection, and brochures to take home. Flipchart pages each had a brief message along with illustrations or diagrams that were designed to correlate to the prepared script. The brochures contained information about HPV, including mode of transmission, association between HPV and cervical cancer, HPV testing, recommended HPV treatment,

and the study contacts' information. The team designed all flipcharts and scripts to be interactive and sought participant questions throughout the module. Prior to implementation, the team sought feedback from focus groups with community members and used this to refine the material. All materials were in English and two local languages, Kiswahili and Luo.

Intervention: Educational Sessions at Different Study Phases

Mobilization and Outreach.—During the mobilization phase of the study, key stakeholders such as community leaders, local CHVs, and village elders received scripts and visual prompts on basic information on HPV, cervical cancer, and screening, such as health information brochures and posters. Study-trained CHVs worked with the key stakeholders to integrate the educational materials into their local gatherings such as community meetings to share information about cervical cancer. CHVs also directly delivered educational messaging in community settings, through door-to-door mobilization and over a public address system.

Screening Education.—The main educational module was offered in screening sites (health facilities and CHCs), and consisted of scripts, illustrated flipcharts, and health information brochures. Two CHVs provided a 15-minute education session in a group setting, aided by the scripts and flipcharts. In some health facilities, education sessions were provided one-on-one, depending on the participant volume. Questions were solicited throughout and at the conclusion of the module. Participants then received educational brochures, and were encouraged to ask questions when they met individually with a CHV prior to providing consent for the study.

Treatment Education.—Treatment education consisted of a script that reinforced the HPV screening and cervical cancer prevention messages, as well as detailed information about treatment and follow-up procedures. Nurses in the health facilities provided one-on-one education, which lasted approximately 10 minutes.

Data Collection

After collecting demographic data from participants, trained research staff conducted IDIs consisting of open-ended questions to explore acceptability and effectiveness of the education module, covering topics ranging from understanding of cervical cancer and HPV, the appropriateness of time of day and settings for mobilization and education, and the role of the cervical cancer education in a woman's decision to screen. IDIs were carried out with participants at four time points in the study: post-mobilization; post-screening; post-notification of results, and posttreatment. Quantitative data was entered into Open Data Kit (www.opendatakit.org) and IDIs were recorded into an MP3 file. A team of three transcribed and translated interview data into text files and two study coordinators reviewed files for completeness and correct transcription against the audio-recordings.

Qualitative Data Analysis

The IDIs were coded independently by a team of four researchers using Nvivo 11™ qualitative data analysis software (QSR International Pty Ltd. Version 11. 2015). For each

set, the team developed a codebook using the interview guide and five randomly selected transcripts from each data set. The codebook was validated using additional IDIs and finalized. All interviews were coded independently by two researchers using an inductive approach. For this analysis, a subset of data was reviewed for themes specific to education from the postmobilization, post-screening, and post-treatment IDIs. We identified themes covering baseline cervical cancer awareness and knowledge, what women reported learning from the module, women's perception of the role of education in encouraging women to screen, personal risk perception, and myths and misconceptions associated with cervical cancer and screening. Finally, we characterized ideas for improving cervical cancer education and appropriate settings in which to conduct the modules.

Ethics

Written informed consent was obtained from each participant in her preferred language and ethical approval was obtained from the Kenya Medical Research Institute Ethical Review Committee, Duke University and the University of California, San Francisco's Committee on Human Research.

Results

Between January and September 2016, 525 women participated in IDIs across three study periods: postmobilization (N=95), pre-screening (N=111), and post-treatment (N=319). The average age of women who were interviewed was 36.2 years (SD=9.72), 82.5% of women had had some or completed primary education, and 75.6% were married or had a partner (Table 3).

Women's Baseline Knowledge about Cervical Cancer and Prevention

Most women reported that, prior to the educational modules, they had heard about cervical cancer but their level of understanding of cervical cancer was generally low. Women had mainly heard of cervical cancer outside of health facilities, either on the radio or through outreach campaigns. One participant recalled that she first became aware of cervical cancer through the educational modules, as she had previously "known that cancer could only affect breast and legs." Women also reported misconceptions about the causes of cancer among the general community. One participant said that some women thought "if you eat soil, you get [cervical] cancer and the uterus is removed." Another woman shared her prior understanding of how cervical cancer is caused:

"I have heard that [birth attendants] can also cause cancer. There are some people who insert their hands too deep, that you can feel as if they have touched your cervix, I have heard that it could cause some irritation in the cervix and could cause cervical cancer." -Participant, Screening

Knowledge Gained From the Educational Modules

When asked about what they learned from the educational modules, participants described an understanding of the relationship between HPV and cervical cancer accurately, exemplified by the statement that "[if a woman] has a positive HPV test result, it does not

mean that she has cervical cancer. HPV can be treated before it advances to cervical cancer.” Participants also gained a good understanding of HPV transmission and role in cervical cancer. For example, one woman stated:

“I learned that cervical cancer is caused by HPV, [HPV] transmission is through sexual intercourse, [and HPV] prevention is by the use of condoms. After screening and knowing your status, you can plan on what steps to take. For example, if [you screen] positive, seek treatment. If [you screen] negative, know when to rescreen. And for men, they should be circumcised to reduce the risk of HPV transmission.” - *Participant, Mobilization & Outreach*

Women spoke about the stages of cervical cancer and characteristic symptoms at each stage. Importantly, many discussed the importance of screening because symptoms tend to appear only after the cancer has reached an advanced stage, when treatment becomes more complex.

“We were told that it can even take up to 15 years without [you] knowing, because it doesn’t show any signs. You will not even feel any pain even though you have the virus. The first stage of [cervical cancer] clears on its own [...] when you reach the fourth stage, it becomes very difficult to treat. It’s important for a woman to get screened early so that she can get treatment for the little [HPV] that’s found.” - *Participant, Mobilization & Outreach*

Another area of increased understanding among women was that cervical cancer is indeed preventable.

“I have learnt a lot of things because before this, I always thought if I am found with it [cervical cancer], it is just like AIDS. I thought that what would follow is just death. But now I know that it has stages, which if detected early—before you start seeing the signs and symptoms [...], you can get treated and get well.” - *Participant, Mobilization & Outreach*

Women reported understanding that their positive HIV status put them at higher risk of developing cervical cancer, motivating them to screen.

“First of all, I am HIV positive and that means I am vulnerable. I really wanted to know my status. In every test you never know. Just like I was positive for HIV, so I may be positive for HPV also. I am vulnerable and as a woman, you are vulnerable.” - *Participant, Screening*

Several participants highlighted that the materials used during the educational modules were effective in acquiring and retaining information about cervical cancer. Women found visual aids to be particularly helpful, allowing them to conceptualize the disease process. One participant stated, “[the diagram of the cervix] is what struck me.” She further explained, “The way I saw the symptoms in the drawing, it made me have the confidence that if I start early, I can be treated.” Another participant found the illustrations to be informative and memorable, enabling her to seek treatment if needed.

“I forgot most of it [cervical cancer education], but the only thing I remember is that if you test positive for HPV, you need to receive treatment immediately. They

[the research team] showed us some pictures of how HPV infects body cells and leads to cancer.” *-Participant, Treatment*

HPV and Cervical Cancer-Related Stigma

Some women noted a general trend of de-stigmatization of cervical cancer as a result of the study and educational activities, which may have influenced their own acceptance of cervical cancer screening. One participant identified the availability of screening and treatment as a way to destigmatize HPV.

“I can just urge my fellow women to come for screening because it is a good thing even if you test positive [for HPV], you can get help. It is not like before when people could not know their status, so many died from it, but right now they have introduced the screening program and all it takes is one’s willingness. People should just go for the screening because it is a good thing, and they shouldn’t be afraid of it.” *-Participant, Screening*

Several women described decreased levels of HPV-related stigma, comparing HPV to the more stigmatized HIV.

“I can recommend it [HPV treatment]. It is sad when you die and leave your children so let us go for treatment since it is just like the HIV virus—people used to go for drugs secretly but right now it is compared to malaria you do not need to worry.” *-Participant, Treatment*

One participant felt that greater cervical cancer screening and education, coupled with prevention opportunities, would reduce cervical cancer stigma in the same way that HIV awareness and treatment have reduced HIV stigma.

“They used it in HIV de-stigmatization. I believe it [cervical cancer awareness campaign] is removing stigmatization. Like the other time I heard some women saying that, ‘we shall come for the screening because it is free and very confidential.’” *-Participant, Mobilization & Outreach*

HPV/Cervical Cancer-Related Misconceptions

Along with the improved knowledge that seemed to result from the educational activities, some participants still had misconceptions about HPV and cervical cancer after the educational modules. The most common misconception that women reported was that treatment would consist of medications for women who screened positive for HPV, despite descriptions and diagrams of cryotherapy and other procedures throughout the module. One participant stated, “we were told that if one had a positive HPV test result she would be given drugs before it advances.” Another participant recalled, “I will have to take drugs to help prevent the virus from advancing into cervical cancer.”

Women also had misconceptions about the effect of family planning on cervical cancer and the interaction between HPV and fertility. One participant mentioned that she had “heard that family planning methods can cause cervical cancer, so women should not go for family planning.” One woman, who had used a contraceptive injection, was worried that it may have increased her risk for cancer.

“When I heard [about] the use of injectable as a method of family planning can cause cancer, I got worried. This contributed to my decision to get screened so as to know my [cancer] status.” - *Participant, Screening*

Furthermore, many women believed that if HPV could affect their fertility. They believed that if they were infected with HPV, they could not give birth or become pregnant, or that they may transmit the infection to the fetus.

“I am worried that HPV would make me miscarry when I get pregnant. I thought that HPV would tamper with the cervix.” -*Participant, Treatment*

Recommendations for Improving Cervical Cancer Education

Participants provided suggestions for improving the current educational modules. Women felt that there should be more general health talks about cervical cancer prevention in the health facilities, in addition to mobilization activities, so they could seek more information from nurses or doctors. Some women suggested posters in schools, health campaigns through radio advertisements as ways to increase the spread of information. When asked about preferred settings to conduct the educational modules, some women suggested schools, community centers, open fields, and door-to-door campaigns, as well as social gatherings at markets and church gatherings. While many women emphasized the importance of group education to reach as many women as possible regardless of the location some preferred the education for self-collection should be one-on-one for privacy reasons.

Lastly, some participants stated that cervical cancer education could be improved by implementing a peer education component in which women who have previously been educated and tested for cervical cancer can “actively participate in cervical cancer prevention forums” and share their experiences with other women.

“The villagers who have screened have experience and can announce especially to their friends because you can find some cases of stigma causing some not to come. As a friend, you can talk to her and convince her to come.” -*Participant, Mobilization & Outreach*

Several women offered to assist in spreading awareness of HPV in the future.

“As one of those who had screened and found to be HPV positive, I can convince one by telling her [...] that it is not painful because most people believe that it is painful. I can tell her about my experience.” -*Participant, Mobilization & Outreach*

Another woman suggested accompanying a friend for cervical cancer treatment.

“You may find a friend who is a widow, is illiterate, and has children. I would explain to her what is written on the brochure about cancer. If transport hinders her from seeking treatment, I would find ways to get her to a clinic and even accompany her if she is willing.” -*Participant, Treatment*

Discussion

Women in LMICs face myriad barriers to cervical cancer prevention, including limited awareness and knowledge of cervical cancer and the availability of prevention strategies. We sought to improve awareness and knowledge of cervical cancer screening using a multi-pronged, CHV-led educational module in the context of a community-based HPV-testing strategy. Following the educational module, women demonstrated understanding of HPV transmission, personal perception of HPV risk, progression of cervical cancer, and prevention measures. Perhaps most important was women's understanding that cervical cancer is a preventable disease and that early screening is key to prevention. Women did not report HPV or cervical cancer to be a highly stigmatized illness, although we did identify some misperceptions about HPV and cervical cancer.

Our findings align with other studies conducted among underserved populations in the United States investigating the effects of educational interventions administered by community health workers on participants' knowledge about cervical cancer.[12, 16] In CHV-led educational interventions, some researchers observed a positive association between cervical cancer knowledge and screening behaviors, further demonstrating the importance of educational outreach as a component of health interventions. With CHVs taking the lead on the educational part of health interventions, efforts should be made to ensure adequate training and continued support for CHVs to carry these out effectively, especially in LMICs, where formal education may be limited. [18]

Qualitative data from focus group discussions in Zambia and Kenya have shown that cervical cancer is often stigmatized because of its connection to the sexually transmitted HPV, its association with HIV/AIDS and a fatalistic view of cancer and side effects of cancer treatment. [3, 19] We did not find this to be true in these interviews, where women used HIV as an example of a disease that, like HPV, was less stigmatized after greater education and treatment became available through multi-faceted HIV prevention campaigns that rely heavily on CHVs. However, we identified misconceptions about cervical cancer and its association with contraceptive use, fertility, and pregnancy. While women reported that overt stigma around HPV and cervical cancer was low, such misconceptions can stigmatize the disease and reproductive health services and prevent women from actively seeking early detection services for cervical cancer. Knowing these prevalent misconceptions, and identifying topics may not have been adequately understood or explained in the educational module will allow our team to effectively tailor the module to meet the health literacy needs of the population.

The misconceptions among women after the educational module may have resulted from the fact that the CHVs were attempting to provide simple, digestible health messaging with a level of detail that was not confusing. Given that those who reported misconceptions often recalled them from peer anecdotes, it is important to address community rumors or pre-existing myths as part of education. Peer-to-peer education may be a valuable way to address these rumors, with cervical cancer "champions" in communities, who can correct false information in informal settings. Previous studies have suggested that people are more likely to change their behaviors and beliefs when they observe actions by peers they perceive as

similar to themselves, [20–24] and, in fact, many participants in our study suggested peer-led education. This may effectively reduce HPV and cervical cancer-related misconceptions and stigma among women.

There are several limitations to our study. Potential participants were identified by CHVs and research assistants, which may have led to a bias in favor of various aspects of the screening campaign, including the educational activities. Our data were based on face-to-face interviews, which may have introduced some level of social desirability bias. In addition, this was a qualitative exploration of women's comfort and experience with the educational activities, rather than a quantitative pre- and post-test measure of participants' level of knowledge and risk perception. This design limits the conclusions we can make about changes in knowledge, risk, stigma and behaviors as a result of the educational module. Instead, we restricted our focus to women's perceptions of the effects of the educational modules on their awareness about cervical cancer and screening, and how the educational modules could be strengthened to better meet their needs.

To our knowledge, this is the first study to evaluate a CHV-led cervical cancer educational module for women in rural Kenya. We examined an under-studied population and conducted a large number of interviews across 12 study communities to ensure breadth and depth of the analysis. The open-ended format allowed us to modify educational materials to incorporate women's ideas and experiences in their own words that may not have been identified otherwise. Given the promising results identified in these IDIs, future research should endeavor to evaluate the impact of education-modules on beliefs and behaviors using a quantitative design.

Conclusion

This analysis demonstrates how a CHV-led education program can promote community acceptability of early screening and treatment for cervical cancer, and may encourage women to seek cervical cancer prevention services. Women reported that the educational module increased their knowledge about cervical cancer and clarified misconceptions about cervical cancer and screening. Participants recommended a more context-specific approach to cervical cancer prevention; this may be achieved by strengthening CHV-led education, incorporating peer-to-peer learning, and expanding to other venues to conduct similar educational modules within the community. An effective, culturally appropriate educational module is an essential piece of cervical cancer prevention to promote screening uptake, which is especially important in high burden areas such as Kenya.

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Table 1.

Characteristics of Educational Modules by Delivery Setting

Delivery Setting	Types of Educational Materials	Educators	Locations	Group vs. Individual
Outreach & Mobilization	Educational scripts, brochures and posters with logistical information for brief messaging	Study-trained CHVs, key stakeholders including community leaders and village elders	Community meetings, public markets, health facilities, door-to-door	Group & Individual
Screening	Educational scripts accompanied by illustrated flipcharts for 15-minute sessions Brochures, posters with diagrams	Research team & Study-trained CHVs	Community Health Campaigns & Health facilities	Group
Treatment	Educational scripts with emphasis on treatment procedures and follow-up plans, 10-minute education sessions	Nurses	Health facilities	Individual

Table 2.**Types of Information Included in the Screening Educational Module**

Topics	Content	Materials
Anatomy of the female reproductive system	Diagram with labels	Flip chart
Cervical cancer knowledge	Definition of cancer, diagram of cervical cancer progression, basic cervical cancer information including symptoms, treatment, statistics	Flip chart
HPV knowledge	HPV symptoms (lack thereof), progression from HPV infection to cervical cancer, HPV testing as a way to identify cervical cancer	Flip chart
Screening methods	Types of precancerous screening (Pap smear, VIA/VILI, HPV testing), timing of screening and notification of results, diagrams of cervical cancer screening	Flip chart, brochure
Self-collected HPV testing	Step-by-step descriptions and illustrations of self-collected HPV testing procedure including pictures of HPV testing kit	Poster, flip chart
Post-screening and follow-up	Details of follow-up care, study team contact information Descriptions of when to follow up with a negative test and when and how to get treated with a positive test	Flip chart, brochure

Table 3.**Demographic Characteristics of Women Who Participated in IDIs**

Total number of Women	525
Age Mean (SD)	36.2 (9.7)
Age Category, n (%)	
25–29	134 (25.5)
30–39	215 (41.0)
40–49	114 (21.7)
50–65	62 (11.8)
Education Completed, n (%)	
Some Primary Education	243 (46.3)
Primary Education	190 (36.2)
Secondary Education	39 (7.4)
College & Post-college	27 (5.1)
None	26 (5.0)
Primary occupation, n (%)	
Agriculture/Fishing	226 (43.0)
Sales/Administrative Work	210 (40.0)
None	45 (8.6)
Skilled Trades	44 (8.4)
Relationship status, n (%)	
Married/Partnered	397 (75.6)
Divorced/widowed	116 (22.1)
Single	12 (2.3)