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Barriers and Facilitators to Cervical Cancer Screening in Western Kenya: a Qualitative Study

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Abstract

About nine out of 10 cervical cancer deaths occur in low-resource countries, with a particularly high burden in sub-Saharan Africa. The objectives of this study were to assess barriers and facilitators to cervical cancer screening in western Kenya from the perspectives of community members and healthcare providers. We conducted two focus groups with female community members (n = 24) and one with providers (n = 12) in Migori County, Kenya. Discussion guides queried about knowledge and awareness of cervical cancer prevention; structural, social, and personal barriers; and facilitators towards cervical cancer screening uptake. Group discussions were recorded, transcribed, and analyzed for emerging themes. Participants in both groups reported low awareness of HPV and cervical cancer screening in the community, and identified that as a main barrier to screening. Community members reported fear of pain and embarrassment as significant barriers to a screening pelvic exam. They also reported that providers' lack of knowledge and discomfort with a sensitive subject were significant barriers. A personal connection to cervical cancer and/or screening was associated with willingness to screen and awareness. Providers reported workload and lack of supplies and trained staff as significant barriers to offering services. Based on these findings, we identified three intervention components to address these facilitators and barriers to screening. They include utilizing existing social networks to expand awareness of cervical cancer risk and screening, training non-physician health workers to meet the demand for screening, and employing female-driven screening techniques such as self-collection of specimens for HPV testing. Cervical cancer prevention programs must take into account the local realities in which they occur. In low-resource areas in particular, identifying low-cost, effective, and culturally appropriate strategies for addressing poor screening uptake is important given limited funding. This study took a formative approach to identify facilitators and barriers to cervical cancer screening based on focus groups and interviews with community members and healthcare providers.

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Keywords

Cervical cancer screening; Health behavior; Reproductive health; Sub-Saharan Africa

Introduction

Over 570,000 women are diagnosed with cervical cancer every year with nine out of 10 cervical cancer-related deaths occurring in low- and middle-income countries (LMICs) [1]. The burden of cervical cancer is particularly high in sub-Saharan Africa, where cervical cancer incidence is 42/100,000 per year [1, 2], approximately four times higher than the incidence in high-income countries [3]. In attempt to address this inequity, the World Health Organization (WHO) recommends cervical cancer prevention strategies that employ low-cost and simple-to-use screening technologies for LMICs [4].

While population-based screening programs in high-income countries using cytological screening have been highly successful in the prevention and early detection of cervical cancers [5], countries in sub-Saharan Africa often lack the healthcare infrastructure and resources required for large-scale screening programs [6, 7]. Thus, cervical cancer screening rates remain low in sub-Saharan Africa [7]. A small number of countries in sub-Saharan Africa have implemented population-based screening programs yet the majority lack cancer prevention and control health policies [8]. Several studies have explored individual and systems-level barriers to cervical cancer screening and treatment in sub-Saharan Africa. Because the cytology laboratories are often centered in cities, women residing in rural areas may lack access to screening services or face long wait times [4]. Lack of adequate training and resources to provide cervical cancer screening have been cited as key barriers among healthcare providers [9]. Misconceptions about cervical cancer, fear of undergoing a pelvic exam, and receiving a positive diagnosis are common reasons for not undergoing HPV screening [10, 11].

Kenya is among the countries with the highest incidence of cervical cancer in sub-Saharan Africa. In Kenya, cervical cancer is the most common cancer among women, driven mainly by lack of screening programs [12]. Current estimates indicate that 2451 (51%) of the 4802 cervical cancer diagnoses result in death, reflecting both the later stage at diagnosis in the absence of screening programs and the limited availability of treatment [12]. For a significant proportion of women in Kenya, cervical cancer is detected at an advanced stage [13]. Despite the World Health Organization's recommendation for simplified screening protocols in which testing for human papillomavirus is followed by simple treatment for women who test positive, screening rates remain low throughout Kenya, ranging between three and 25% [14, 15]. Women in rural Kenya face added interpersonal, social, geographical, and cultural barriers to cervical cancer screening [16, 17]. Compounded with limited access to screening services, these barriers have resulted in most at-risk women never being screened [15]. Consequently, many cases present late when treatment is more difficult and expensive to obtain [6].

While there are numerous studies evaluating barriers to screening [18–21], little is known about potential barriers and facilitators of cervical cancer screening in the high-burden

region of western Kenya. This study attempts to address this gap in literature by assessing cervical cancer screening perspectives of both community members and healthcare providers towards the development and implementation of cervical cancer screening programs in Migori County, Kenya.

Methods

Study Setting and Participant Recruitment

The study took place in Migori County in the Nyanza Province of western Kenya. For the community member focus groups, we recruited participants from the population of women in Migori County to take place in one of three 90-min focus group discussions (FGDs). Community participants for FGDs were purposefully sampled from participating villages. The study staff worked closely with community health workers (CHWs) and community leaders to recruit female participants considered knowledgeable about cervical cancer and health care or considered to be opinion leaders in the community. The study staff worked in coordination with the county reproductive health coordinator to identify and recruit health care providers, who are knowledgeable in cervical cancer and health care, or are part of the health management team.

This qualitative study took place prior to the implementation of a randomized control trial evaluating women's willingness to undergo HPV testing using self-sampling in clinics versus community-based screening campaigns (R01 CA18824) [22].

Ethics Approval

This study was approved by the ethical review boards at the Kenya Medical Research Institute, Duke University, and the University of California, San Francisco. All participants gave written informed consent before participation in the study.

Focus Groups

Three FGDs were conducted between October 2015 and April 2016. FGDs were facilitated by project staff trained in interviewing and focus group facilitation. All FGD facilitators were female with undergraduate level education or higher. Each focus group had 12 participants. FGD guides were developed by the research team in collaboration with community health workers and clinicians who had been working in cervical cancer prevention in the Nyanza Province. Guides piloted in a previous study were used and covered baseline knowledge and awareness of cervical cancer and screening strategies, personal experience with screening, personal and perceived barriers, and suggestions for improvement at various points of the cervical cancer screening cascade (awareness, uptake of screening, notification of results and linkage to treatment). Some focus group questions were designed to assess strategies to increase uptake of the screening via HPV testing with self-collected specimens. The FGD guide was administered in English for the provider interviews and in Luo (the local language) for the community members. Discussions were audio recorded and transcribed, and a facilitator took notes throughout the discussion to capture important points that arose during the discussion and assisted in transcription.

Transcripts were then reviewed and revised by the two FGD facilitators as needed to ensure accuracy and completeness.

Data Analysis

A qualitative approach was used for analysis by two authors (MH, HN). Content analysis was performed to identify core themes using the qualitative data analysis software NVIVO Version 13 (QSR International; 2016). Two authors initially independently coded all transcripts and then iteratively and collaboratively reviewed the initial codes to identify preliminary categories and themes leading to a second round of coding. Then authors met to review the codes, resolve discrepancies, revise codes as necessary, and agree on the final organization of the thematic structure.

Results

We conducted two focus groups with female community members (n = 24) and one with healthcare providers (n = 12). A total of 10 nurses and one CHW participated in the provider focus group. The average provider was 42 years old (Table 1). The providers had on average 17 years of service and represented in six districts in Migori County. A total of 24 female community members, ranging in age from 25 to 60 years, were selected for the two community FGDs.

Fear and Stigma around Cervical Cancer Diagnosis as a Barrier

Fear and stigma among female community members were common themes that arose from the analysis. Most women feared and, therefore, avoided screening because they viewed a positive result as a "death sentence." This concept was associated with misconceptions about the process of cervical cancer screening (women felt that a positive result meant they had cancer) and an awareness of the lack of treatment options in their community for invasive cancer. Some women specifically cited fear of a positive screening result because of their inability to afford treatment services as a barrier. In addition, some women expressed fear of her husband's reaction to a positive diagnosis, suggesting an association between cervical cancer and promiscuity.

"... my fear is if I have cervical cancer screening then my uterus will be removed and then my husband will ask me where I got the disease from... 'did I become very sexually active when I was a girl and that's where I got it from or what?' The cause is the problem because once I know that I have it then it is just death I am seeing."

-Community Member

Health Facility and Provider Factors

Both community members and healthcare providers reported that conditions in local health facilities limited the access to and uptake of screening. Both groups mentioned low staff numbers, provider workload, and a lack of staff specifically trained in cervical cancer screening. These factors left providers feeling overburdened and unwilling or unable to provide screening services, resulting in either no services or negative experiences for

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patients. Among healthcare providers, there was a belief that women feared loss of confidentiality.

"For somebody to offer the service, that person must be trained either through formal training or on job training, so it is not a service where people came with a knowledge from the basic training and that has been a burden and that's why you find that most of our facilities don't offer this service because they lack people who are trained on cervical cancer screening."

-Provider

"...a person comes to the facility and tests suspicious for cancer and since not all working at the health facility are medics who are bound by the confidentiality oath, it is likely to get to hear about such information in the community that 'so and so was tested for cancer and she is dying soon.""

-Provider

Women discussed negative experiences with healthcare providers during the cervical cancer screening process as barriers to screening. Community members described discontent with the providers' communication during the pelvic exam. Furthermore, there were concerns among community members about providers' ability to counsel women about sensitive topics such as the pelvic exam procedure or a potential cancer diagnosis. Women were specifically hesitant to undergo counseling and a screening examination by a male provider who they would likely see often in their small communities.

"I was not counseled... I had gone for [family planning] services but I was told that I had to undergo cervical cancer screening so when I entered the room I was told undress, I then got perturbed by what the doctor said then I was told, 'lie on the bed'. I just did all these things but with question marks in my mind. There is something that looks like a mirror then I was told to move at the edge of the bed then there was a stick that had cotton wool at the tip then he inserted it inside me then he told me to wake up and dress."

-Community Member

"There are days I used to go for clinic you find posters on cervical cancer but nobody takes responsibility of telling you more about it, so you just read the poster and go back home and that's it."

-Community Member

Role of Social Networks and Community Leaders

Peer influence and personal and community networks were identified as potential facilitators to screening. The presence of peers or relatives to model preventive behavior was cited as an important factor in increasing acceptability of cervical cancer screening. Several community members and providers talked about having personal connections to the disease such as a friend, neighbor, or family member who experienced an abnormal screening test or cervical cancer diagnosis which influenced their awareness of cervical cancer and their willingness to get screened. Women's groups were also mentioned as a potential mechanism by which the information on cervical cancer screening can be spread.

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"I think those who have gone through the process can influence me too, reflecting on their changed lives can encourage me to test too. I am very sure that very many people have it and they don't want to be tested...."

-Community Member

"Sometimes we have a women's group. Maybe one can share. They sometimes come without even being told. We encourage them to tell others... somebodys comes to the hospital, they get information, they go and share it with the others. You just encourage them to go and share it with others at home."

-Provider

Screening as a Woman's Personal Decision

Almost all focus group participants felt that the decision to screen is made by the woman herself. When probed about male or partner influence in screening, women believed that their partner would not oppose screening. In fact, some participants mentioned that male partners could play a supportive role in encouraging screening.

"[Women] are empowered by information...once somebody has information; they will make an informed choice to be screened."

-Provider

"I have my partner... he is the one who first heard about it before me. He urged me to go for it by then I was pregnant but the way I heard him talk about it... based on the way those who had gone for it were saying, I got scared and I have not gone for screening."

-Community Member

Integrating Screening with Other Health Services

Change at a systems level arose as a facilitator to cervical cancer screening. Some providers suggested that the availability of alternatives to the pelvic exam and integration of cervical cancer screening with other services such as HIV screening campaigns could potentially facilitate cervical cancer screening uptake.

"One approach that worked out was during a community health week if I remember at Migori TTC, this happened during a music festival period and many attended the screening services. It is our strategy that every health function has cervical cancer screening integrated which has worked well."

-Provider

"[HPV or Cervical cancer screening] cannot stand as a service on its own, we have just to integrate all services like breast cancer so that during that health talk, the client will voluntarily choose on what she wants just like in a supermarket scenario... So if we talk about integration of activities so that everyone coming on board talks about these services, then we will meet our target."

-Provider

Discussion

The objective of this study was to identify barriers and facilitators influencing uptake of cervical cancer screening in rural western Kenya. Similar to other studies, our qualitative analysis revealed that fear and stigma associated with the pelvic exam were important individual-level barriers to screening in this population. A qualitative study of barriers to participation in screening programs among a general population of women from Thika, Kenya, found that some women were fearful of the exam after hearing from friends that it could be painful [23]. Similarly, a 2005 study of knowledge and attitudes towards cervical cancer among women in Limuru, Kenya, reported that women feared potential embarrassment or positive diagnosis of cancer [24]. To our knowledge, our findings are unique in their assessment of barriers and facilitators to cervical cancer screening from the perspectives of both community members and healthcare providers within the target region.

Facilitators of cervical cancer screening included women as the primary decision-maker to screen, integration of screening services with other health services, and the utilization of social networks to model screening behavior. For community members in our study, knowing someone that had previously screened for cervical cancer was a significant facilitator to accepting screening. This finding is consistent with other studies throughout sub-Saharan Africa that found an association between knowing someone that has screened and willingness to accept screening [25, 26]. Our analysis revealed peer and community networks increased awareness of cervical cancer. The use of community networks could potentially be enhanced through the engagement of community leaders such as chiefs and religious figures in the promotion of cervical cancer screening and education. Such strategies can be seen in previous studies in which community members and community leaders promote health behavior capitalize on social networks to facilitate social learning opportunities [27].

Providers and community members reported systems-level barriers such as lack of trained providers, poor perceived attitude among providers, and unmanageable workload. Such systemic inefficiencies prevent consistent availability of services. Our findings are consistent with other studies related to systems-level barriers to cervical cancer screening. A study conducted in East Africa found that cervical cancer screening is still largely being performed by physicians, even though the WHO recommends protocols that utilize non-physician clinicians [28]. Similarly, a study of challenges to obtaining treatment in western Kenya found that lack of access to transportation and reliable communication resulted in loss to follow-up for a significant number of women. A recent meta-analysis summarized psychosocial, social, and systems-level barriers to screening which included fatalism, modesty, familial obligations, misconceptions about risk and screening, poor provider attitude, and cost of screening [11].

To address some of the systems-level barriers found in this study including lack of train physicians and unmanageable physician workload, a task-shifting approach educating nurses and community health workers to conduct screening with WHO-recommended methods for low-resource methods could be particularly effective. Prior studies have found that

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non-physician healthcare providers can accurately provide cervical cancer screening with these methods and thereby increase the capacity for screening [4, 29–31]. This strategy may be enhanced by capitalizing on women's belief that decision to screen for cervical cancer is her own which is a significant facilitator to screening. Giving women more control over the screening process by utilizing methods such as self-collection of HPV specimens has been found to both an acceptable and accurate method of screening in rural and low-resource settings [4, 32, 33].

Social networks can be an important source for social learning of screening behavior. For example, a study of Hispanic women in the USA found that social networks were a facilitator of cancer screening, particularly for pap smears [34]. The community can also facilitate accessibility of screening services, which can increase screening uptake. Studies have also found that a multi-faceted approach to cancer screening including clinicbased strategies (chart reminders, exam room prompts) and community-based strategies (educational sessions, community events, church sessions) showed improved screening uptake. These studies have shown that implementing effective cervical cancer screening programs requires the involvement of the larger community in which at-risk women reside. However, there has been less research documenting the role of the community members in the implementation of cervical cancer screening programs in rural and low-resource settings with limited infrastructure.

A key strength of our study is that it provides practical, evidence-based intervention strategies to address cervical cancer screening barriers and to capitalize on previously unpublished facilitators. The findings of this study must be considered in light of its limitations. Female community members recruited by CHWs and willing to participate in the focus groups may be more engaged in health care services than others in their community. The participation in our provider FGD was almost exclusively nurses, with only one CHW. As CHWs are often the frontline health providers and may have a closer connection with the community, valuable insights from this group may be missing. Finally, because focus groups were designed to help develop an implementation strategy for screening with self-collected HPV specimens, many of the questions targeted concepts that would aid or hinder that specific strategy.

Conclusion

Cervical cancer screening programs that address barriers and incorporate facilitators within the local community context have the potential to be effective in reducing mortality rates. In low-resource settings with utilizing community strengths, low-cost mechanisms and culturally appropriate strategies for addressing low screening uptake are important in this low-resource context. This study took a systematic approach to identifying intervention strategies to increase screening at the pre-implementation phase based on focus groups with community members and healthcare providers. The findings from this study suggest that the development and implementation of cervical cancer screening programs in Migori County may need to address the beliefs and misconceptions about screening processes that propagate fear.

Data Availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Abbreviations

FGD	Focus group discussion
HPV	Human papillomavirus
VIA	Visual inspection with acetic acid
VILI	Visual inspection with Lugol's iodine

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Table 1

Sociodemographic characteristics of provider focus group participants

Characteristics	n	%
Profession		
Nurse	10	90.9
Community health worker	1	9.1
Site		
Migori	3	27.3
Nyatike	3	27.3
Rongo	1	9.1
Suna East	1	9.1
Suna East and West	1	9.1
Uriri	2	18.2
Age*	42.2 ± 10.2	
Years of service *	17.80 ± 11.8	

 ${}^{*}Mean\pm SD$