

Developing a stigma-responsive educational program to promote uptake of HPV-based
cervical cancer screening and treatment in Kisumu, Kenya

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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2022

ABSTRACT

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Abstract

Background: Despite increasing availability of preventative HPV vaccines and screening strategies, uptake of these effective measures in Kisumu, Kenya is limited by cultural and logistical barriers. Limited understanding and societal perceptions of HPV and cervical cancer are potential sources of stigma that could negatively impact screening behavior. By designing and implementing a stigma-responsive educational intervention, we sought to improve understanding and risk perception and increase the likelihood cervical cancer screening.

Methods: We carried out a study of a stigma responsive strategy to deliver HPV-based cervical cancer prevention services in Kisumu, Kenya. Focus group discussions (FGDs) explored experiences of HPV and cervical cancer screening, health messaging and potential stigma sources. Qualitative analysis of the FGDs informed the development of a stigma-responsive educational video. Four Kisumu County healthcare facilities were randomized to either watch the video or receive standard HPV and cervical cancer education, after which participants at both sites completed a survey to measure HPV- and cervical cancer stigma. Stigma scores were compared between control and intervention groups using linear regression.

Results: Thirty women participated in the focus group discussions. Drivers of stigma included concerns about confidentiality and disclosure of HPV results, fears of cancer or implications of a sexually transmitted infection diagnosis. Anticipated outcomes included illness or death, financial hardship or family abandonment. The FGDs findings informed development of the educational video. A total of 288 women, 109 in the intervention group, completed the stigma survey. Mean HPV and cervical cancer scores were found to be statistically lower in the intervention arm, with Dholuo language associated with higher stigma levels in both arms.

Conclusions: This multi-step study explored knowledge, attitudes and beliefs specific to HPV and cervical cancer health messaging in western Kenya in order to develop and test a stigma-responsive education strategy. The stigma-responsive video demonstrated a quantitative decrease in stigma survey response means for those who watched the video. The pre-pilot design will drive a larger pilot study to examine the effect of the educational video on HPV self-sampling.

Dedication

To my family and friends who have seen me through my passion for global medicine, your tireless support means the most.

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List of Abbreviations

CC	cervical cancer
CHV	community health volunteer
FGD	focus group discussion
GoK	Government of Kenya
HIV	human immunodeficiency virus
HPV	human papillomavirus
KEMRI	Kenya Medical Research Institute
Pap smear	Papanicolaou smear
SD	standard deviation
VIA	visual inspection with acetic acid
VILI	visual inspection with Lugol's iodine
WHO	World Health Organization

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1. Introduction

1.1 Global Cervical Cancer Burden

Despite primary prevention methods, cervical cancer is the fourth leading cause of cancer in women worldwide, higher ranked in developing countries.¹ As of 2020, 604,127 new cases of cervical cancer were diagnosed and 341,831 deaths were recorded.² The World Health Organization (WHO) predicts that by 2040 the worldwide incidence of cervical cancer will be 777,000, and deaths will increase by almost 48%.^{1,2}

Driven by lack of effective national screening and prevention programs, the global cervical cancer burden is unequally distributed. In twenty-three countries, with the majority in Eastern Africa and other areas including Central and Southern Africa and South East Asia, cervical cancer is the most commonly diagnosed cancer.^{1,3-6} East Africa's cervical cancer incidence rate of 40.1 per 100,000 women and Southern Africa of 43.1 per 100,000 women are highest in the world.¹ East Africa has the highest death rate from cervical cancer, at 28.6 per 100,000 women, which is almost four times the global mortality rate.^{1,6}

Long-term infection with high-risk human papillomavirus (HPV), a common virus that almost all sexually active individuals will be exposed to over their lifetime, is the causal agent for nearly all cervical cancers and a high portion of other anogenital cancers. Other identified co-factors include tobacco smoking, high parity, long-term use of hormonal contraception and co-infection with human immunodeficiency virus (HIV).²

The global prevalence of HPV is difficult to determine due to the limitations of study methodologies and reporting of HPV infection in normal or cervical lesion cytologies.² The world age-specific HPV prevalence in women with normal cytology is almost 30% and reaching closer to 45% in Africa.²

1.2 Kenya's HPV and Cervical Cancer Burden

There are 16.2 million Kenyan women over the age of 15 at risk for cervical cancer with just over 5,000 new cervical cancer cases diagnosed in Kenya in 2020.^{2,7-9} A Kenyan woman has a lifetime risk of 3.8% for developing cervical cancer and a 2.5% risk of dying from cervical cancer.^{2,10} With 3,200 annual deaths, cervical cancer ranks as the leading cause of female cancer deaths in Kenya.^{2,7-9} Estimated from the Kenya Cancer Policy, women infected with oncogenic HPV at any given time is 9.1%, while a study conducted by Huchko et al demonstrate an oncogenic HPV positivity rate of 21% in Western Kenya (n=1043, 4944 total participants).^{11,12} HPV-based testing is available in limited supply and specific statistics regarding HPV in Kenya are also limited.

1.2.1 Kenya's HPV and Cervical Cancer Secondary Prevention

The 2014 Demographic and Health Survey (DHS) reported that 76% of Kenyan women had heard of cervical cancer screening, but only 14% had been screened.¹³ The majority of cervical cancer screening is performed through a Papanicolaou smear (pap smear) and about one-third completed with visual inspection with acetic acid (VIA) or Lugol's iodine (VILI).¹³ The Government of Kenya (GoK) has adopted the 2015 WHO

endorsed “screen and treat” approach to secondary cervical cancer prevention and treatment.¹⁴ These guidelines recommend use of provider or self-collected HPV-based screening over cytology or VIA. In the screen and treat model, a positive HPV DNA result is an indicator for elevated cervical cancer risk and immediate treatment is recommended. Treatment options include cryotherapy, thermoablation and a loop electrical excision procedure (LEEP), all of which are simple, safe and offered in outpatient clinics.¹⁴ The screen and treat model in Kenya has potential to be effective, if implemented with careful consideration of the health care system infrastructure and cultural climate. Although HPV-based sampling is prioritized, it is only available in a few county campaigns and provider-collected sampling is sparsely available in private hospitals.

Community acceptance of cervical cancer screening is restricted by limited understanding and cultural barriers of African traditions and taboos. Low cervical cancer knowledge and screening history is mostly among poor women lacking proper education and living in rural areas, and adolescent girls are least likely to know about cervical cancer screening.¹³ A two-phase, cluster randomized controlled trial was conducted in Migori, Kenya demonstrating that community health volunteer (CHV) lead community campaigns specific to HPV self-collection was culturally acceptable and proven to be cost effective.¹¹ CHVs continue to voice concern about inadequate topic-specific training in cervical cancer screening.

1.3 Impact of Stigma

Many medical disease processes carry negative associations, from side effects to financial burden. The existence of a quality, affordable healthcare infrastructure is important for treatment and management of disorders and disease and is reliant on patients seeking care. Outside of cost and accessibility, the decision for a person to seek care is heavily influenced by personal risk perception, understanding of disease process, and cultural norms, including stigmas.¹⁵ Stereotyping, discrimination and personal identity labeling based on a disease status interferes with health-seeking behaviors.^{16,17} Internalized or anticipated stigmas, self-applied negative attitudes or worry about future discrimination and prejudice, are understudied drivers of delay in personal health seeking.^{18,19} These delay drivers effect disease diagnosis and treatment, which impacts health status on a personal and community level.

With the evolution of HIV care, researchers and program planners have recognized the role of stigma in patient hesitation to access screening and treatment. Stigma specific interventions in HIV care are well studied, influencing the choice of testing or withholding disclosure. Individuals with reported high levels of HIV-specific stigma do not often test or disclose their status due to denial and avoidance.^{15,20,21} Because HPV shares similar characteristics with HIV – sexually transmitted viral disease – HPV and cervical cancer stigma may be impacting the effectiveness of established screening and treatment infrastructure.^{22,23}

Most health stigma research has been conducted in high income countries, but the impact is not specific to a region or country income level.²⁴ Prior studies in western Kenya, which has a high prevalence of HIV, linked poor knowledge, stigma and loss-to-follow-up in women who were screened for HPV.²⁵ In another study, researchers developed a framework of HPV and cervical cancer-related stigma after exploring attitudes that reflected internalized or anticipated stigma.¹⁵ Cultural aspects specific to polygamy, taboos, curses and cancer as a death sentence can be influential factors to HPV and cervical cancer stigma.

1.4 Importance of HPV and Cervical Cancer Stigma-Responsive Education

Stigma specific to cervical cancer has been demonstrated and impacts screening and treatment behavior.²⁶⁻²⁸ Qualitative work from western Kenya suggests that HPV stigma, driven by lack of basic understanding and importance of screening, may prevent women from seeking HPV-based prevention services.^{27,29} Fear of death, association with HIV and associations with promiscuity or lack of cleanliness are examples of drivers of stigma. Understanding the anticipated, internalized or experience stigma related to HPV and cervical cancer must be incorporated into designing educational interventions that can influence screening uptake behaviors. Normalizing preventative measures through improving understanding of basic disease process and fear reduction is necessary in successful intervention measures.

Stigma is not the only driver to low HPV and cervical cancer literacy or screening numbers as culture specific contexts, including partner and gender roles, are directly influential. To our knowledge, no study has evaluated the direct impact of an educational intervention specifically designed to address negative attitudes and stigma about HPV or cervical cancer.

1.5 Study Aims and Objectives

This study aimed to understand the potential strategies and content for an educational campaign to reduce HPV- and cervical cancer- related stigma and fears to increase screening behaviors. Specific aims were to: (1) understand community attitudes and preferred learning methods about HPV and cervical cancer through FGDs (2) develop a clinic-based stigma reducing cervical cancer education program in Kisumu, Kenya and (3) understand if a stigma-responsive educational video improves HPV and cervical cancer stigma survey responses.

Multiple methods and tools were explored to identify efficient and effective content and delivery modalities, including direction from successful stigma addressing frameworks and input from the local FGDs. The intervention specifically focused on increasing HPV-related knowledge and intention to screen and decrease stigma. The tool was intentionally designed to assist CHV education to be most effective at the clinical level. Uniquely incorporating stigma-responsive strategies in the existing

cultural context of a CHV educational format, we wanted to encourage individual and community behavior awareness and long-term changes to HPV-specific stigma.

The pre-pilot study was performed at four existing GoK clinics in Kisumu County, representing the community demographic. The main outcome was quantitative comparison of stigma levels between women who watched the video versus women who had undergone routine mobilization and education about HPV-based screening in Muhuroni County, Kenya. We used an HPV, cervical cancer and HIV stigma measurement tool currently in the validation stage. The information gained from the pre-pilot design will drive a larger pilot study to examine the effect of the educational video on HPV self-sampling.

2. Methods

2.1 Overview

We conducted a three-part study from May 2021 to February 2022 in Kisumu County, Kenya to develop and pre-pilot an HPV and cervical cancer stigma responsive educational strategy (Figure 1). Between April and June 2021, FGD guides were designed and edited, followed by three (3) FGDs with community women and community health care workers. The transcripts were qualitatively analyzed using grounded theory. Beginning in August 2021, information from the FGDs were incorporated into developing a culturally appropriate stigma-responsive educational video. In February 2022 the educational video was shown to women in two healthcare facilities, paired against two control, standard-of-care facilities. Quantitative data was obtained through completion of an HPV and cervical cancer stigma scale, which is currently being validated. Survey responses were compared between arms.

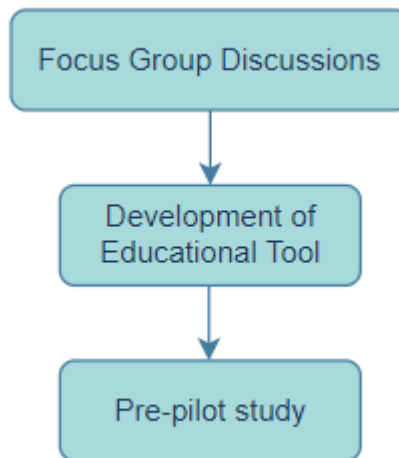


Figure 1: Schematic of three-part HPV and cervical cancer stigma-responsive education tool development study

2.2 Focus Group Discussions

Focus group discussions were designed to explore the stigma of HPV and cervical cancer and better understand women’s and healthcare provider’s experience related to education and screening for cervical cancer. Thirty participants were included for a total of three (3) FGDs. Two FGDs were with women of the community, and one was with CHV and healthcare providers. FGDs were analyzed qualitatively.

2.2.1 Focus Group Discussion Guide Development

The FGD guide was developed after review of existing literature. The content explored HPV and cervical cancer stigma, including questions about general understanding, cultural beliefs about cancer, attitudes specific to HPV and cervical

cancer and preferred methods for health literacy. The FGD was translated into the local language, Dholuo, and back translated to ensure clarity of content. See the FGD guides in Appendix A.

2.2.2 Focus Group Discussion Setting

From May to June 2021 three FGDs were conducted in a socially-distanced, private setting located on a GoK hospital campus in Kisumu, Kenya. Sessions were moderated and recorded by the research team. The discussion was transcribed and translated from Dholuo to English. The translation was reviewed for accuracy by the research team.

2.2.3 Focus Group Discussion Participants

Adult women from the community, women's health care providers and CHVs were purposively selected for the FGDs. Women were recruited to represent the community at large of Kisumu County and were recruited by direct contact from the research team. Some knowledge of cervical cancer and HPV was required to contribute to an insightful discussion. CHVs were recruited through the direction of the GoK, seeking CHVs knowledgeable about reproductive topics, and possibly those who have had experience with cervical cancer counseling. Healthcare providers were recruited through direct contact with the study team.

One FGD was conducted with CHV and healthcare workers and women over the age of 21 from the Kisumu community were enrolled in two staggered FGDs. Topics

explored included knowledge of HPV and cervical cancer, stigma, trustworthy sources of information, stigma as a barrier to cervical cancer prevention and educational strategies. After completion and analysis of the CHV/healthcare provider FGD and community women FGD, the FGD guide was edited to include detailed exploration of themes which emerged. Additional topics in the final FGD with the women of the community included level of trust in healthcare providers and fear of the screening process. Women recruited for the final FGD included a more diverse representation of age and education level in Kisumu.

2.2.4 Focus Group Analysis

The FGDs were transcribed and translated. The Duke University team developed a codebook, with five main themes of interest – HPV and cervical cancer knowledge and acceptance, stigma, trusted sources of information, stigma as a barrier to screening and educational strategies (Appendix B). Using deductive analysis, four researchers coded in pairs using NVivo, a qualitative data analysis software.³⁰ The coded transcripts were compared to address discrepancy and ensure proper thematic analysis. A report was written summarizing the findings, which further informed the second phase of the larger study.³¹

2.3 Stigma-Responsive Educational Tool Development

HPV stigma specific frameworks have not yet been studied. Literature supported healthcare stigma frameworks, from mental health and HIV health research,

influenced the design of the educational tool. Stigma tool mapping was performed for both the community women and healthcare providers, using literature-based formats and FGD feedback (Figure 2). Multiple delivery methods were considered to determine the most efficient method of content delivery. To allow for easy mobilization and with intention to augment existing CHV health-topic discussions, a culturally relevant short video was created. The video was designed to take place in a private clinic setting with a peer educator, providing the information in a relatable, yet confidential and trustworthy way. Emphasizing the experiences of a peer educator versus presenting numerous healthcare facts creates potential for a relatable situation, regardless of healthcare literacy. A small group of women interacting with the peer educator represents a safe, confidential support network. To address the concerns about CHV professionalism and healthcare literacy, the team designed the educational tool to augment the CHV health talks and be most effective at the clinic level in a high HIV prevalent setting.

Service delivery was also considered in the design of the educational model, with HPV self-testing as a component of the pilot study. We considered which populations should be tested for service delivery and recognized that only targeting high-risk women would itself be stigmatizing. Therefore, we targeted all women eligible for HPV self-screening to be encouraged to seek screening.

The original study design of a large community health campaign needed to be reconsidered for the safety of the general population after development of a world-wide pandemic. The targeted location, existing GoK clinics in western Kenya that support HIV care, continued services among the pandemic.

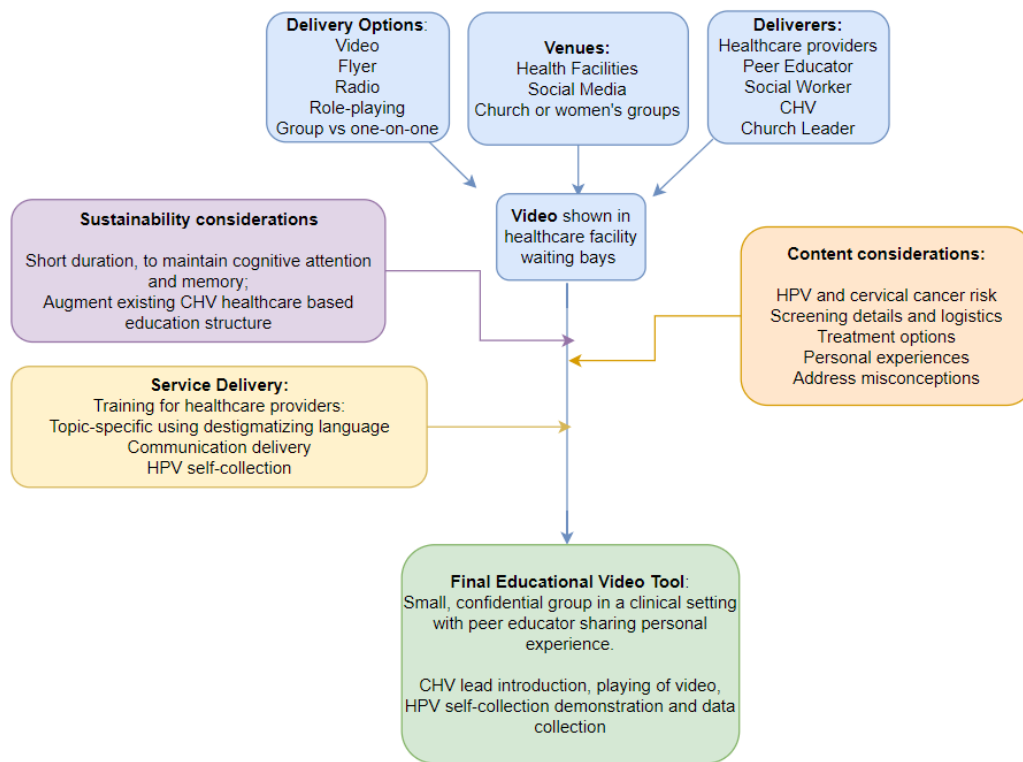


Figure 2: Educational tool design mapping, including participant experience and health care provider roles.

The video script was edited following numerous rounds of feedback from physicians, clinical officers, nurses, and volunteers. The succinct messaging focused on the benefits of screening, ultimately preventing the development of a stigmatizing cancer diagnosis. The final script was translated to Kiswahili and the local tribal language, Dholuo. A Luo videographer was hired for the recording and the research team was present during production and editing. Two videos were produced, one in English and the other in Dholuo, and both videos had Kiswahili subtitles. All actresses were women from the Kisumu community.

The live-action video runs for a total of five minutes and depicts a female peer educator previously screened and treated for HPV, sitting with four adult women, emphasizing confidentiality and privacy, while in support of a trusted friend or relative. The peer educator tells the story of her seeking cervical cancer screening, in both the traditional way (VIA) versus HPV self-sampling. Two women ask questions about the specifics of screening, the meaning of an HPV positive screening result and the methods of treatment. The video was produced without using stigmatizing language, addressing fears and misunderstanding as well as isolation, social distancing and labeling of women with HPV. Benefits of screening, ultimately preventing the development of stigmatizing cancer, was emphasized. A video introduction script, describing basic scientific information about HPV and cervical cancer incorporating stigma reductive language was also created (Appendix C).

2.4 Pre-Pilot Program

2.4.1 Setting

Clinic site assessments were conducted, and four clinics were chosen. The clinic sites were matched for similarity based on county location, catchment population and existence of cervical cancer screening services. Entire GoK clinics were randomized to either the stigma specific intervention or existing standard-of-care education.

2.4.2 Participants

Facility volunteers mobilized women to participate in the study, targeting to have at least fifty women per site (Table 1). The participants provided informed consent and basic demographic information. Participants in the intervention arm viewed the video in groups of five to seven. All participants completed the stigma measurement tool. Transportation compensation was provided to each participant.

Table 1: Study Participant Inclusion and Exclusion Criteria

Criteria	Description
Inclusion Criteria	Reproductive age females
Exclusion Criteria	Unable to provide informed consent or under the age of 18

2.4.3 Stigma Measurement Tool

Survey questions used in the pre-pilot were part of a two-year NIH-funded R21 (NIH 5R21TW011061-02) study, in which researchers will validate an HPV and cervical cancer stigma framework and measurement tool this year. Women in both study arms

completed the 200-item questionnaire through Redcap on a provided tablet, evaluating the relationship between HPV and cervical cancer stigma and prevention behaviors among HIV positive and negative women. The 28 HPV stigma, 14 cervical cancer stigma and 7 HPV knowledge questions, which all participants completed, were targeted for this pre-pilot study to evaluate our stigma-reductive educational video tool. See Appendix D for a list of sample questions being evaluated for validation.

2.4.4 Analysis

Sample size was influenced by multiple delays to the pre-pilot design and was ultimately restricted due to limited research field time. Quantitative analysis of the educational tool was performed using Stata 17.0.³² Demographic and baseline clinical characteristics summary and descriptive statistics were performed. Knowledge questions were previously validated, and the score was calculated by total number of answers correct, with score possibilities of zero to seven. The main outcome of the pre-pilot stigma responsive educational tool was comparison of means among the standard-of-care versus the intervention arm. Stigma scores could be 0 to 3. Means calculated from the survey responses were measured using paired count-based score differences using multivariable logistical regression, including a two-sample T test.

2.5 Ethical Approval

Ethical approval was obtained from Duke University Campus Institutional Review Board (Pro00101931) and Kenya Medical Research Institute (KEMRI).

3. Results

3.1 Focus Group Discussions

A total of thirty (30) women participated in three focus group discussions from May to June 2021 in Kisumu, Kenya (Table 2). The healthcare provider and CHV FGD included 9 participants. Two staggered FGDs with women representing the community included a total of 21 participants. The mean age of FGD community women was 32.6 years and almost all had completed more than primary education. The healthcare providers were slightly older with a mean age of 34.7 years and represented CHVs, nurses, nurse officers and clinical officers. The healthcare providers had an average of 5.5 years (range: 3-8years) in sexual reproductive health counseling.

Table 2: Demographic characteristics of FGD participants

Demographic Characteristics (n=30)	Community Women (n= 21)	Healthcare workers (n=9)
Age, mean (SD)	32.6 (7.6)	34.7(4.6)
Age Categories (%)		
20-29	8 (38.1%)	1 (11.1%)
30-39	8 (38.1%)	6 (66.7%)
40-50	5 (23.8)	2 (22.2%)
Education Level (%)		
Completed some primary	1 (4.76%)	-
Completed Primary	4 (19.04%)	-
Some Secondary	4 (19.04%)	-
Completed Secondary	5 (23.82%)	-
University	5 (23.82%)	-
College	2 (9.52%)	9
Position		
Woman of the community	21	-
CHV	-	4
Clinical Officer	-	2
Nurse	-	1
Nursing Officer	-	2

3.1.1 HPV and Cervical Cancer Knowledge and Understanding

Five broad topics in the context of HPV and cervical cancer were discussed in both FGDs. Women demonstrated varying levels of understanding of the individual concepts of HPV and cervical cancer, although the majority referenced them both as cervical cancer. Participants knew that HPV was sexually transmitted, but it was not identified as a virus and few participants identified correct risk factors. Some showed understanding about the impact on the cervix, but incorrectly identified HPV as non-advanced cervical cancer. One woman shared a rumor she heard while in a salon, that sex causes cancer and should be limited to once a week. (FGD1, 40y/o) Many women asked for clarifying questions specific to HPV and cervical cancer during the discussion.

3.1.2 Stigma

Stigma was discussed, along with references to bad attitudes and fears. Women described observed, anticipated, and experienced discriminatory attitudes from the community and family members. Internalized stigma specific to HPV and cervical cancer was minimally discussed in the conversation.

With HPV and cervical cancer being reproductive health topics, women desired discrete healthcare visits to minimize association with a condition perceived to be related to prostitution or being unfaithful. Symptoms of advanced cervical cancer were also described as a source of stigma. A 35-year-old woman shared, "Being that you are smelling there will be stigma between you and the people who would not wish to sit

next to you.”(FGD2, 35 y/o) Another driver of stigma included traditional and religious beliefs, as one woman shared that “according to African traditions some diseases are a taboo.”(FGD2, 40 y/o) Woman did acknowledge that social networks could potentially be beneficial to helping reduce the stigma for those who have an HPV positive result or cervical cancer diagnosis.

Fear of stigma or isolation from the community or family was described numerous ways, which women shared honestly as a reason for not seeking screening or sharing their results.

“You find that instead of one saying how they feel, because they are avoiding being condemned by people, being judged by people, they would rather die their own death than say so, they would rather struggle on their own until the end.”(FGD2, 40y/o)

Women emphasized the anticipated impact of a positive HPV result on their relationship with their husband. One woman implied that if she suffered from cervical cancer, her husband would leave because they could not have sexual relations. (FGD2, 35 y/o)

3.1.3 Trusted Information Source

Women cited flyers, radio, hospitals and family members diagnosed with cervical cancer as the existing sources of HPV or cervical cancer healthcare information. Flyers with pictures were felt to be more impactful than flyers with just words. Radio was also a preferred method of receiving information, but women were frustrated with

the interruptions, some language barriers and lack of ability to interact with the health messaging.

When asked to identify trusted sources of information about HPV and cervical cancer, agreement was on “somebody who has been trained and is knowledgeable,” including the formalized training that physicians and nurses obtain. (FGD2, 50 y/o) Survivors of cervical cancer were also specifically identified. Participants in the first FGD identified that CHVs as a source of trusted information was not unanimous. In the second FGD, this idea was probed further, and women discussed concern that because CHVs are community members, they would not be able to keep secrets, especially in the roles of recruiting for screening of various diseases or gathering of community information. During discussion with the CHVs and healthcare provider FGD, there was no mention of possible disconnect or mistrust with the CHVs and their communities.

3.1.4 Stigma as a Barrier to Screening

Fear, embarrassment, lack of confidentiality and religious preferences impact the behavior of the women in the Kisumu communities. Reproductive topics are sensitive, and women choose to keep results private and shy away from asking for information or seeking the screening process. Many view test results as private, and the risk of sharing means the potential for “the information will have reached everyone [at the end of the day], yet it is not a must for everyone to know about it.”(FGD1, 35 y/o)

Spiritual-related beliefs impact social stigmas, especially influenced by local culture. For some, having a disease is seen as the result of being personally cursed, or sharing the burden of a family curse. For others, homeopathic medications from a local medicine doctor are trusted over Western medicine. Because cervical cancer screening requires a pelvic exam, many are fearful or consider it inappropriate to undress in front of a healthcare provider.

3.1.5 Educational Strategies

Privacy was emphasized for all reproductive health topics, but women and CHVs did not identify a single strategy they felt would be most impactful for increasing awareness specific to HPV and cervical cancer. Women who wanted a home-based educational setting liked the ability to ask vulnerable questions that would not be shared with others. Women who preferred a group setting in a hospital or clinic found comfort in numbers, learning from conversation and questions asked by other participants.

3.2 A Stigma-Reductive Educational Intervention: Pre-Pilot

The pre-pilot study was performed in February 2022 in four Level 3 and 4 health facilities in Kisumu County, Kenya. A total of 288 women participated, 179 in the standard-of-care (control) arm and 109 in the intervention group. Table 3 demonstrates demographics of each group. The mean age was 31.7 years, 33.6 in the control and 28.7 in the intervention ($p < 0.001$). Most women completed up to some secondary school, 61.4% and 41.3% respectively, with 58.7% of women in the intervention arm having

higher education ($p=0.029$). Most women were married or living together with a partner and used a form of contraception ($p=0.013$). Thirty-two percent of women in the control arm live with HIV, 25.7% in the intervention ($p=0.41$). A high percentage of women recorded previous cervical cancer screening, with a statistical difference between the study arms, at 67% of the control versus 42% in the intervention arm ($p<0.001$).

The mean responses to a 4-point Likert scale of 28 HPV and 14 cervical cancer stigma questions were calculated and stratified by language preference and HIV status for each study arm, with question examples in Appendix D. Significantly, both HPV and cervical cancer stigma means were higher for the control participants ($p<0.001$; Table 3). Cervical cancer stigma means were higher than HPV stigma in both arms. The control arm had a total score mean of 0.80 (HPV) and 0.97 (cervical cancer) compared with a mean of 0.57 and 0.68 respectively in the intervention arms ($p=0.005$, $p<0.001$; Table 3).

In addition to study arm, HPV and cervical cancer stigma score means were statistically impacted by language and age (Tables 6&7). As well as a continuous variable, we explored age as a categorical variable to identify trends across age groups, however none were identified. In a bivariate analysis, education level was statistically significant for HPV stigma score means, but not in multivariable analysis ($p=0.0032$; Table 4&5).

Given the predicted strong impact of language (reflecting both cultural and educational exposures) and HIV status and HIV-related stigma, we stratified on these

variables. For HIV negative women, those in the control arm had 0.2705 higher HPV stigma score means compared with HIV negative women in the intervention group ($R^2=0.2332$, $p=0.001$; Table 8). Women who preferred Dholuo also had higher stigma levels by 0.3061 ($R^2=0.2332$, $p<0.001$; Table 8). Age was statistically significant among HIV negative women, with lower stigma levels by 0.0198 in HPV stigma score means as age increases ($p=0.003$; Table 8). When stratified by those living with HIV, HPV stigma score means were not statistically affected by study arm, language preference or age ($R^2=0.1365$; $p=0.648$, 0.113 , 0.479 ; Table 8).

We stratified on language and HIV status for cervical cancer stigma score means (Table 8). For HIV negative status, study arm, language and age preference were statistically significant ($R^2=0.1888$). For HIV negative women, those in standard-of-care arm had higher stigma score means by 0.3044 in cervical cancer stigma score means compared with HIV negative women in the intervention group ($R^2=0.1888$, $p<0.001$). Women who spoke Dholuo also had higher stigma score means by 0.2786 ($p=0.003$) compared to English speakers. For every year increase in age, cervical cancer stigma scores lower by 0.0156 ($p=0.019$). When stratified by HIV positive status, Dholuo language preference remained significant, with higher cervical cancer stigma score means by 0.3346 compared to English speakers ($R^2=0.1233$, $p=0.037$). Educational levels did not remain significant.

For both study arms, the mean HPV knowledge question score was 5 out of 7 (Figure 3; control=5.11 (SD 1.379), intervention =5.02 (SD 1.309), $p=0.5282$). Women who chose to fill out the survey in Dholuo, had a statistically lower knowledge score by 0.6723, compared to women who completed the survey in English ($R^2= 0.0591$, $p<0.001$).

Women participating in the intervention arm were asked feedback questions on the educational video as part of the survey. Out of 109 women, only four (4) women reported the video was not relatable and not a useful learning tool. When prompted, some women responded that they would not have screened the same day because it takes too much time from work, believe they do not need to be screened, fear the procedure or they have recently been screened. The final free response question allowed for questions, which women inquired about the HPV vaccine, HPV symptoms, screening availability and intervals (Table 9). Most women expressed desire to be contacted when HPV self-sampling becomes available.

Table 3: Demographic characteristics of stigma-responsive educational study participants

Demographic Characteristics	Control, N =179 (%)	Intervention, N= 109 (%)	Total, N = 288 (%)	p-value
Age, mean (SD)	33.64 (8.31)	28.66 (2.75)	31.76(8.27)	<0.001
Highest education completed				0.029
None	2 (1.1)	2 (1.8)	4 (1.39)	
Some Primary	23 (12.8)	9 (8.3)	32 (11.11)	
Completed Primary	42 (23.5)	14 (12.8)	56 (19.44)	
Some Secondary	43 (24.0)	20 (18.3)	63 (21.88)	
Completed Secondary	34 (19.0)	31 (28.4)	65 (22.57)	
Post-Secondary	35 (20)	33 (30.3)	68 (23.61)	
Number of children, mean (SD)	2.93 (1.70)	2.08 (1.62)	2.61 (1.72)	<0.001
Marital status				0.013
Single	24 (13.4)	31 (28.4)	55 (19.10)	
Married/Living together	137 (76.5)	71 (65.1)	208 (72.22)	
Separated/Divorced	7 (3.9)	4 (3.7)	11 (3.82)	
Other	11 (6.1)	3 (2.8)	14 (4.86)	
Living with HIV	54 (30.2)	28 (25.7)	82 (28.5%)	0.41
Prior cervical cancer screening	120 (67.0)	46(42.20)	166 (57.6%)	<0.001
Previous treatment for cervical cancer or precancer	17 (9.5)	14 (12.84)	31 (10.8)	0.36
Currently using contraception	106 (59.2)	59 (54.1)	165 (57.3)	0.49
Language Choice				<0.001
Luo	63 (35.2)	34 (68.8)	97 (33.7)	
English	116 (64.8)	75 (31.2)	191 (66.3)	
HPV Stigma Questions*				0.005
Mean (SD)	0.80 (0.55)	0.57 (0.53)	0.71 (0.55)	
Median (Q1, Q3)	0.8 (0.3, 1.2)	0.5 (0.1,0.9)	0.7 (0.2,1.1)	
Min, Max	0.0, 2.9	0,2,3	0,2,9	
CC Stigma Questions*				<0.001
Mean (SD)	0.97 (0.52)	0.68 (0.54)	0.86 (0.55)	
Median (Q1, Q3)	1.0 (0.6, 1.3)	0.7 (0.2,1.0)	0.9 (0.4,1.2)	
Min, Max	0.0, 2.9	0,2,4	0,2,9	

*0 = no stigma, 3 = most stigma

	HIV negative, English	HIV positive, English	HIV negative, Dholuo	HIV positive, Dholuo	Totals
Control	45	18	80	36	179
Intervention	61	14	20	14	109
Totals	106	32	100	50	

Table 4: HPV stigma score means bivariate analysis

	Coefficient	p-value	95% CI		R-squared
regress hpvstigTotal study_arm age					0.0666
Study Arm	0.2866	0.0000	0.1530	0.4203	
Age	-0.0109	0.0065	-0.0188	-0.0031	
Intercept	0.5970	0.0000	0.3119	0.8820	
regress hpvstigTotal educ_level study_arm					0.0708
Study Arm	0.1985	0.0028	0.0691	0.3279	
Educational Level	-0.0693	0.0032	-0.1151	-0.0235	
Intercept	0.6169	0.0000	0.3331	0.9008	
regress hpvstigTotal parity_number study_arm					0.0454
Study Arm	0.2156	0.0016	0.0825	0.3486	
Parity	0.0196	0.3059	-0.0180	0.0572	
Intercept	0.3137	0.0061	0.0901	0.5373	
regress hpvstigTotal marital_status study_arm					0.0514
Study Arm	0.2507	0.0002	0.1201	0.3813	
Marital Status	-0.0840	0.0916	-0.1817	0.0137	
Intercept	0.4712	0.0006	0.2038	0.7387	
regress hpvstigTotal prior_screen study_arm					0.0419
Study Arm	0.2308	0.0007	0.0982	0.3633	
prior cvx screening	-0.0059	0.9231	-0.1272	0.1153	
Intercept	0.3488	0.0281	0.0377	0.6599	

*Study arm = control, Age = continuous

Table 5: Cervical Cancer stigma score means bivariate analysis

	Coefficient	p-value	95% CI		R-squared
regress ccstigTotal study_arm age					0.0700
Study Arm (control)	0.3108	0.0000	0.1787	0.4429	
Age	-0.0054	0.1725	-0.0131	0.0024	
Intercept	0.5278	0.0003	0.2460	0.8097	
regress ccstigTotal educ_level study_arm					0.0679
Study Arm (control)	0.2715	0.0000	0.1431	0.3998	
Educational Level	-0.0257	0.2668	-0.0711	0.0198	
Intercept	0.5036	0.0005	0.2221	0.7852	
regress ccstigTotal parity_number study_arm					0.0727
Study Arm (control)	0.2580	0.0001	0.1281	0.3879	
Parity	0.0307	0.1012	-0.0060	0.0674	
Intercept	0.3622	0.0012	0.1440	0.5805	
regress ccstigTotal marital_status study_arm					0.0640
Study Arm (control)	0.2821	0.0000	0.1537	0.4106	
Marital Status	0.0081	0.8682	-0.0880	0.1042	
Intercept	0.3873	0.0041	0.1242	0.6505	
regress ccstigTotal prior_screen study_arm					0.0640
Study Arm (control)	0.2864	0.0000	0.1566	0.4161	
prior cvx screening	0.0103	0.8641	-0.1083	0.1290	
Intercept	0.3814	0.0143	0.0769	0.6859	

*Study arm = control, Age = continuous

Table 6: Multivariable regression of full model for HPV stigma means scores

	Coefficient	p-value	95% CI	R-squared
				0.1698
Study Arm (control)	0.1724	0.0135	0.0359	0.3089
HIV status (negative)	-0.0078	0.9143	-0.1502	0.1346
Language (Dholuo)	0.2931	0.0002	0.1393	0.4469
Age	-0.0140	0.0066	-0.0240	-0.0039
Educational Level	-0.0136	0.6339	-0.0698	0.0426
Parity	0.0405	0.1040	-0.0084	0.0895
Marital Status	-0.0811	0.1372	-0.1882	0.0260
prior cvx screening	-0.0319	0.5934	-0.1495	0.0856
Intercept	0.5880	0.0442	0.0152	1.1607

* Age is continuous

Table 7: Multivariable regression of full model for cervical cancer stigma means scores

	Coefficient	p-value	95% CI	R-squared
				0.1449
Study Arm (control)	0.2217	0.0016	0.0845	0.3589
HIV status (negative)	-0.0131	0.8572	-0.1562	0.1300
Language (Dholuo)	0.2964	0.0002	0.1418	0.4510
Age	-0.0111	0.0311	-0.0212	-0.0010
Educational Level	0.0474	0.0998	-0.0091	0.1038
Parity	0.0496	0.0480	0.0004	0.0988
Marital Status	0.0152	0.7819	-0.0925	0.1228
prior cvx screening	0.0210	0.7272	-0.0972	0.1391
Intercept	0.0831	0.7766	-0.4926	0.6587

*Age is continuous

Table 8: Multivariable regression of full model stratified by HIV status for HPV and cervical cancer stigma means scores

	HPV				Cervical Cancer			
	HIV positive							
	Coefficient	p-value	95% confidence interval	R ²	Coefficient	p-value	95% confidence interval	R ²
Study arm (control)	-0.0613	0.648	-0.3279, 0.2053	0.1365	0.0158	0.906	-0.2508, 0.2825	0.1233
Language (Dholuo)	0.2523	0.113	-0.0611, 0.5656		0.3346	0.037	0.0212, 0.6481	
Age	-0.0063	0.479	-0.0240, 0.0114		-0.0011	0.901	-0.0188, 0.0166	
Education Level	0.01846	0.752	-0.0975, 0.1344		0.08602	0.144	-0.0299, 0.2020	
Parity Number	0.0661	0.167	-0.0282, 0.1604		0.0503	0.292	-0.0440, 0.1445	
Marital Status	-0.0358	0.674	-0.2050, 0.1333		-0.0073	0.931	-0.1766, 0.1618	
Prior screen	-0.1980	0.128	-0.4542, 0.0582		-0.1950	0.134	-0.4512, 0.0613	
_cons	0.7131	0.185	-0.3488, 1.7751		0.2281	0.670	-0.8341, 1.2903	
	HIV negative							
Study arm (control)	0.2705	0.001	0.1109, 0.4301	0.2332	0.3044	<0.0001	0.1419, 0.4668	0.1888
Language (Dholuo)	0.3061	0.001	0.1294, 0.4827		0.2786	0.003	0.0988, 0.4584	
Age	-0.0194	0.003	-0.0322, -0.0067		-0.0156	0.019	-0.0286, -0.0026	
Education Level	-0.0198	0.544	-0.0840, 0.0444		0.0362	0.276	-0.0292, 0.1015	
Parity Number	0.0438	0.162	-0.0177, 0.1052		0.04922	0.122	-0.0133, 0.1118	
Marital Status	-0.1482	0.056	-0.3004, 0.0040		0.0135	0.863	-0.1414, 0.1684	
Prior screen	-0.0011	0.986	-0.1345, 0.1321		0.0709	0.304	-0.0648, 0.2065	
_cons	0.6535	0.045	0.0157, 1.2914		0.0554	0.866	-0.5937, 0.7046	

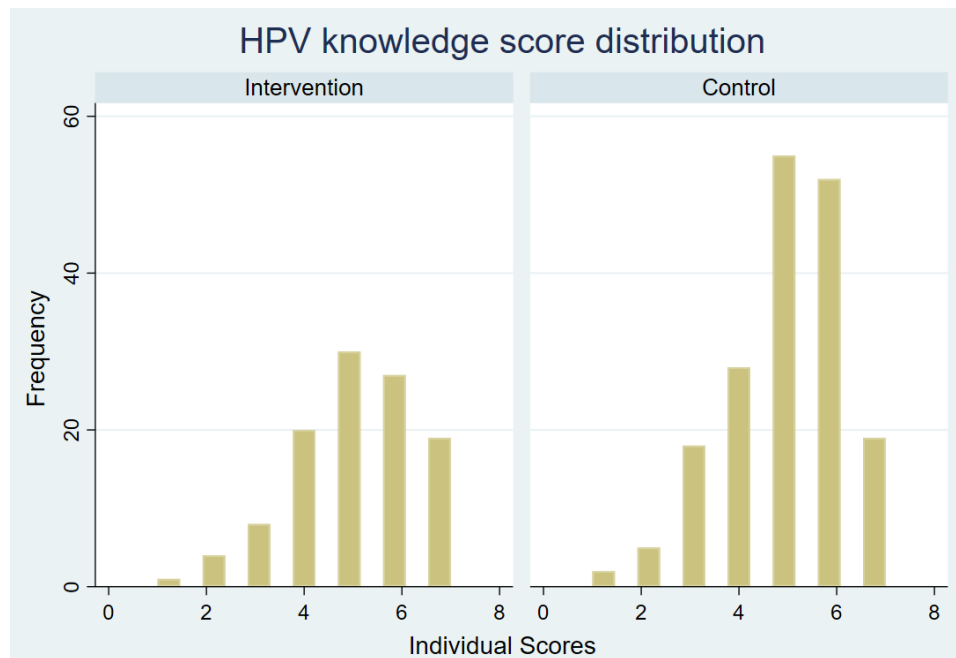


Figure 3: Knowledge questions answer distribution of control and intervention

*Score 0=7, 7 = all correct answers

See Appendix D for list of knowledge questions

Table 9: Responses to open ended “Any additional questions” following viewing stigma responsive educational video

Survey Prompt	Questions asked by women
HPV specific facts	How long can the virus take before it develops cancer? What time does the signs/symptoms start manifesting? How does that sickness affect my status when I am HIV positive? Can a person not on contraception acquire HPV? What are the symptoms?
Screening specific questions	Is it painful when being done? What is the HPV screening done at this hospital? For a HIV negative person how many times should I screen for HPV? Screening takes how long? Can I be screened while pregnant? When is the next visit and will the kits be available?
Treatment specific questions	Describe the treatment procedure for HPV.
HPV Vaccine Questions	Do I qualify for having vaccination? Is HPV vaccine only for girls ages 10?

4. Discussion

This three-step project explored health messaging related knowledge, attitudes and stigma related to HPV and cervical cancer to inform development and testing of a stigma responsive educational intervention designed to influence behavioral choices and increase cervical cancer screening in a highly impacted area. The preliminary data obtained through FGDs suggested the potential for impact of interpersonal and community-based HPV and cervical cancer stigma. Personal beliefs and health seeking behavior are influenced by numerous factors and the FGDs highlight the importance of succinct, structured, trustworthy information sources for women to have confidence in the local healthcare team to learn about easy and potentially life-saving screening service delivery.

It was postulated that both language and HIV status would heavily influence HPV and cervical cancer stigma as well as HPV knowledge. Regarding language, health related stigma has been closely correlated with knowledge and understanding of the health domain. In Kenya, speaking a tribal language such as Dholuo can be correlated with education status, as English is taught in schools. Preferring Dholuo was therefore postulated to correlate with lower understanding of HPV and cervical cancer resulting in higher levels of stigma. There may also be cultural beliefs that promote stigma among women who chose to complete the survey in Dholuo, compared to English. The regression model demonstrated that the Dholuo language was statistically significantly

associated with higher stigma scores, however educational status was not. HIV is a highly stigmatized disease, and women with HIV likely experience HPV and cervical cancer stigma and health messaging differently. Interestingly, our results showed a statistical difference in those living with HIV and those who are not. HIV negative persons in the control group had higher stigma scores compared to those living with HIV. A possible explanation is that HIV stigma health messaging has expanded over the last decade, encouraging people who live with HIV to think and talk about HIV in a less stigmatizing way, which could be impacting stigma in other health domains.

The surprisingly high HPV knowledge score and low HPV and cervical cancer stigma baseline rates and the high cervical cancer screening rate in both groups may be a result of the increasing HIV stigma health messaging with possible spillover into the HPV and cervical cancer realm and a recent increase of cervical cancer research studies in Kisumu and non-governmental organizations (NGOs) targeting awareness and screening options in Kisumu County. The FGDs emphasized cervical cancer stigma in African culture and taboo, which is reflected in the higher cervical cancer stigma scores in both arms. In addition, awareness of the influence of HPV's role in cervical cancer is relatively new, therefore specific negative associations of HPV may not have already been developed. With cervical cancer stigma scored higher than HPV-related stigma, the emphasis remains on targeting cultural and community-based attitudes about prevention.

Even with a small sample size, the statistical difference in stigma scores between the intervention and control group will help in the planning of a larger study to evaluate the impact on HPV testing. It is encouraging that educational feedback was overwhelmingly positive, and the questions asked and desire to be contacted with the HPV testing becomes available demonstrates improved health information seeking behavior. Although the overall stigma means were lower than anticipated, cervical cancer stigma remained high even after exposure to health information, emphasizing the importance of impactful interventions. However, the stigma measurement tool will continue to be refined, with additional norming that may impact the overall scores; this final scale will be used in the effectiveness pilot.

Information gathered from the pre-pilot is directly impacting the design of the above study, with emphasis on the implementation of effective service delivery. CHVs will run the entire HPV and cervical cancer health messaging with support through stigma responsive training, scripts and resources. HPV self-sampling will be available to both study arms, and the evaluation of a health behavior, rather than knowledge, attitude or intention, will provide a unique evaluation of the educational model.

4.1 Strengths and Limitations

A study specifically focused on an educational intervention to reduce HPV and cervical cancer-related stigma is unique to the literature. Women who participated in the focus group discussion are an unrepresented group, however specific cultural beliefs

and practices specific to western Kenya may influence the generalizability of the information obtained. There is potential for selection bias in that woman who offered their participation in the FGD and pre-pilot study may have higher levels of HPV and cervical cancer knowledge and lower health-related stigma than other women.

The original pilot study design included a powered sample size and HPV self-sampling activity as a secondary analysis of the educational tool. Due to multiple unforeseen delays, the HPV-testing machine not arriving to Kenya and thesis timeline requirements, the decision was made to proceed with a pre-pilot design to inform the later planned pilot. The pilot study will proceed as originally designed including a powered matched-demographic sample size, CHV led education and demonstration, offering of HPV self-sampling and an interval follow-up of participants who chose not to be screen on the day of the completing the survey.

The survey administered for the pre-pilot is currently in validation stage, with the control arm of this study contributing to the process. Some questions used to calculate the mean stigma for each subject in the pre-pilot may be removed or less weighted in the final calculation. Once the validation process is completed, we will re-calculate the scores using the sub-set of included items and their relative weights. The validated scale will also be deployed in the larger pilot to evaluate the impact of stigma on health behaviors.

4.2 Implications for Policy and Practice

This study will help inform the HPV and cervical cancer screening educational strategy in Kenya, with the potential to impact the national design and delivery strategy including a peer navigation process and Ministry of Health supported HPV self-sample testing availability. The video can be adapted to various formats and used in conjunction with increasing access to HPV self-sampling, and results from this pilot will help inform the submission of a grant to develop a broader stigma-reduction strategy for HPV-testing.

4.3 Implications for Further Research

The pilot program was intentionally designed to be integrated, if demonstrating impact, into a future study evaluating an effective screen and treat model for HPV and cervical dysplasia in low-and-middle income countries. The video will be qualitatively evaluated in a future project to determine efficacy.

5. Conclusion

This multi-step pilot study explored stigma, as well as knowledge, attitudes and beliefs specific to HPV and cervical cancer among women in western Kenya. The difference in stigma scores between the intervention and control group lend itself for consideration of adapting the use of the educational video in future facility-based education and may contribute to larger health messaging infrastructure in Kisumu, Kenya. This program has potential to contribute emphasis on improved CHV training and long-term adaptation of peer educator program as an impactful educational source to change the trajectory of cervical cancer screening strategy in HIV prevalent areas and world-wide.

Appendix A

Focus Group Discussion (FGD) Guide for Participants

Note to the moderator:

Please document nonverbal interactions during the interview. This includes body language, head nods and laughing. It is particularly important to write down the reactions at the specific question being discussed. If something happens, please make note of that. If people start to talk over each other, please write down other conversations that are happening. What questions made people excited, uncomfortable, turned people on/off from participating? Also, please reference the time when you ask each new question.

Welcome

Good morning/afternoon/evening. Thank you for spending some time and joining us to talk about your understanding and experience with HPV and cervical cancer. My name is _____. The goal of this discussion is to understand the community attitudes about HPV/cervical cancer to better help people learn and understand this topic. We would like to talk today to explore your ideas and preferences for learning about HPV/Cervical cancer so that you and your friends/family will feel comfortable to be screened, tested or treated.

Consent Process

As a group, we are going to go over the informed consent form before we start our discussion to make sure you understand why we are meeting and that you know it is voluntarily to participate.

About focus group discussions:

- Please start by asking the group if anyone has participated in a focus group before. Explain that focus groups are done to gather information to build further research.
- Tell the participants that they are the experts and that we want to learn from them, both the good and the bad. People do not have to agree or disagree, we are just gathering information. There is no right or wrong answer.
- We will record the conversation so that we can hear and understand everything that you are saying. My colleague will be taking notes as well, to help us understand the recorded discussion.

Ground Rules

- We would like everyone to participate and that one person talks at a time. It is important to hear the ideas of everyone.
- Remember, there is no right or wrong answer. We want you to feel comfortable to speak freely. Do not share any of the conversation outside of this room.
- This conversation will be audio recorded to help us later gather more detailed information about your responses. The leader will also take notes to check the data for accuracy.
- Remember that this is voluntary and that the information collected will be kept private. You can decline to answer a question or ask to leave the discussion at any time.
- Ask if there are any questions before starting.

Please turn on the tape recorder and say the date, time and location of the FGD.

<i>Question</i>	<i>Probes</i>	<i>Theme</i>
Have you heard of HPV/Cervical cancer?	Yes or No, Tell me about it. If yes, from where or from whom? - school, friends, family, neighbors Do you know anyone that has had HPV/cc? What do you think about that person? What is their experience like? - Neighbors, family members, friends	<i>Basic understanding of HPV/cervical cancer; Attitudes about cervical cancer/HPV</i>
What are some things that may make HPV/cervical cancer difficult to talk about?	Probes: Fear, shame, related to sexual activity, religious beliefs, none? At what age is it appropriate to introduce the topic of HPV/cc to your daughters? - How have you talked to your daughters about HPV or the HPV vaccine? If you have not, why not? Do you feel comfortable talking about this subject with your male family	<i>Barriers to discussion/understanding about HPV/Cervical cancer; Cultural and traditional significance of HPV/Cervical cancer; Attitudes about cervical cancer/HPV</i>

	members/partners? Why?	
Is there any stigma about HPV/cervical cancer?	<p>If yes or no, please explain.</p> <p>What do you worry about when you think or talk about HPV/cervical cancer?</p> <p>What do people in your community say about women who get screened for HPV? Diagnosed with HPV? Treated?</p> <p>Are their general stigma about sexually transmitted diseases?</p> <p>What prevents you from discussing cervical cancer openly? - Do only females discuss?</p>	<i>Cultural and traditional significance of HPV/Cervical cancer; Attitudes about cervical cancer/HPV</i>
What are some of the barriers/challenges that women face when accessing cervical cancer/HPV screening services?	<p>Fear of positive test, cost, transportation, mistrust of clinic, understanding of the screening and treatment process, provider attitudes, knowledge of availability of screening service, is there screening services available in your health facility?</p>	<i>Barriers to healthcare specific to HPV/cervical cancer</i>
What are some of the ways of reducing discomfort while talking and learning about cervical cancer/HPV?	<p>Where would you be comfortable having the education? - alone, in a group, at a clinic, your home</p> <p>What ways would you prefer to learn about HPV/cervical cancer? -from a flyer, radio station ad, from CHVs</p> <p>How do you think you learn best? - pictures, diagrams, models, skits</p> <p>Would you want something to take home? Why? - Brochure, flyer, book</p> <p>If you have heard some information about HPV/cervical cancer, what did you like/not like about the way the information was given?</p> <p>Are there topics that should be avoided in discussing HPV/cervical</p>	<i>Barriers to discussion/understanding about HPV/Cervical cancer; Desired ways to learn/discuss about HPV/cervical cancer</i>

	cancer? If so, which?	
If you learned about HPV/cervical cancer for the first time during an educational talk, would you be willing to be screened the same day?	<p>Why or why not?</p> <ul style="list-style-type: none"> - Need more information? Or more time? - Would transportation or work schedule or house chores play a role in the decision? 	<i>Basic understanding/general information of HPV/cervical cancer; Attitudes about cervical cancer/HPV</i>
How can we change negative attitudes about HPV/cervical cancer?	<p>Probes:</p> <ul style="list-style-type: none"> - More sensitization and education about HPV/cervical cancer? - Individual, partners, community members 	<p><i>How to be more accepting and minimize judgement of HPV/CC patients</i></p> <p><i>Education used to decrease stigma, improve attitudes, increase desire and intention to get screened.</i></p>
Who do you trust to teach you about women's health topics and HPV/cervical cancer?	<p>CHV, parent, sibling, friends, children, school, religious leaders</p> <p>What makes someone a good source of information?</p> <p>How would you feel about getting information from women in your community who have gone through the HPV/cervical cancer screening/treatment process?</p>	<p><i>Reactions to healthcare providers, CHV volunteers; Desired ways to learn/discuss about HPV/cervical cancer. Is there a central place for information? Is there a social movement that is spreading misinformation?</i></p>

Focus Group Discussion (FGD) Guide for CHV/Providers

Note to the moderator:

Please document nonverbal interactions during the interview. This includes body language, head nods and laughing. It is particularly important to write down the reactions at the specific question being discussed. If something happens, please make note of that. If people start to talk over each other, please write down other conversations that are happening. What questions made people excited, uncomfortable, turned people on/off from participating? Also, please reference the time when you ask each new question.

Welcome

Good morning/afternoon/evening. Thank you for spending some time and joining us to talk about your experience education about sensitive topics such as HPV and cervical cancer. My name is _____. The goal of this discussion is to understand the most effective way to educate the community about HPV and cervical cancer to decrease the stigma/negative attitudes. The goal is to have more women feel comfortable to get screened or treated for HPV/Cervical cancer. We would like to talk today to explore your ideas and preferences for teaching about HPV/Cervical cancer.

Consent Process

As a group, we are going to go over the informed consent form before we start our discussion to make sure you understand why we are meeting and that you know it is voluntarily to participate.

About focus group discussions:

- Please start by asking the group if anyone has participated in a focus group before. Explain that focus groups are done to gather information to build further research.
- Tell the participants that they are the experts and that we want to learn from them, both the good and the bad. People do not have to agree or disagree, we are just gathering information. There is no right or wrong answer.

Ground Rules

- We would like everyone to participate and that one person talks at a time. It is important to hear the ideas of everyone.
- Remember, there is no right or wrong answer. We want you to feel comfortable to speak freely. Do not share any of the conversation outside of this room.
- This conversation will be audio recorded to help us later gather more detailed information about your responses. The leader will also take notes to check the data for accuracy.
- Remember that this is voluntary and that the information collected will be kept private. You can decline to answer a question or ask to leave the discussion at any time.
- Ask if there are any questions before starting.

Please turn on the tape recorder and say the date, time and location of the FGD.

<i>Question</i>	<i>Probes</i>	<i>Theme</i>
<p>What do you consider sensitive health topics? Describe your experience talking with clients about sensitive or embarrassing topics.</p>	<p>What healthcare topics are challenging?</p> <p>Are they difficult to talk about? If so, why? Provide examples.</p> <p>What are some strategies that you've used to help clients understand these topics? Reduce embarrassment or stigma? Increase adherence?</p>	<p><i>Community receptivity to learning about sensitive topics</i></p>
<p>Describe your experience in talking with patients about HPV or cervical cancer specifically.</p>	<p>How is cervical cancer similar or different to counseling about HIV? Family Planning? STIs?</p> <p>What are some concepts about HPV/cervical cancer that women find confusing/embarrassing?</p> <p>What are some specific topics about HPV/cervical cancer that are the most important for patients to know about?</p> <p>How have some of the topics women find embarrassing affected their decision to get screened or get treatment?</p> <p>Describe any methods you have used to reduce HPV stigma and/or to urge patients to be screened.</p>	<p><i>Educator experience with teaching sensitive topic (HPV/cervical cancer)</i></p>
<p>What topics of cervical cancer do you consider</p> <p>(A) simple or comfortable to teach? Why?</p>	<p>Probes: HPV, vaccination, cervical cancer screening and treatment</p> <p>Why are some topics easier to understand than others?</p> <p>How do you develop comfort in a teaching environment?</p>	<p><i>Topics that CHV feel are easy/comfortable to teach (and why that is)</i></p>
<p>What topics of cervical cancer do you consider</p> <p>(A) difficult or (B)</p>	<p>Probes: HPV, vaccination, risk factors (sexually transmitted), cervical cancer</p>	<p><i>Topics that CHV feel area difficult/uncomfortable to teach (and why that is)</i></p>

<p>uncomfortable to teach? Why?</p>	<p>screening and treatment</p> <p>Have you experienced any uncomfortable teaching environments? Provide an example, please.</p> <p>What creates an uncomfortable teaching environment?</p>	
<p>What educational strategies have you found to be effective while teaching on HPV/ cervical cancer?</p>	<p>Probe: Small group talk? Poster? Flip chart? Anatomy models</p> <p>Where do you think is the best place to teach about HPV/cervical cancer? -How many people should be in the room? -Who can be in the room? Daughter? Other Family?</p> <p>Is there a particular style of teaching that creates the most engagement from women (formal, informal, Q&A style)?</p> <p>What educational activities get women to ask questions?</p> <p>Are there any teaching methods that you think are creating misconceptions around HPV/cervical cancer?</p> <p>How can this education or messaging be delivered in a community setting? What needs to be changed? Where should women be targeted?</p>	<p><i>Effective educational strategies</i></p>
<p>What educational materials do you (A) like to and (B) not like to work with while teaching on HPV/ cervical cancer?</p>	<p><i>Flip board, tablet, poster, paper script</i></p> <p>Is there a certain material that helps you best illustrate what HPV/cervical cancer are?</p> <p>Do you like to use mostly words and texts or do you find pictures/models to be more useful?</p>	<p><i>Effective educational materials</i></p>
<p>Can you tell me what resources you need or could use to better assist you in teaching about HPV and cervical cancer?</p>	<p>Where has your previous training been?</p> <p>After training, have you felt prepared to teach women? If not, what could help?</p>	<p><i>CHV educational support</i></p>

	<p>Would you benefit from more training?</p> <p>Have you needed physical models?</p>	
<p>What are your ideas or thoughts on new teaching techniques/styles that have not been used before but may be good/effective for cervical cancer?</p>	<p>Do you have a well-working system of teaching sensitive topics related to women's health?</p> <p>Would you be open to learning how to teach differently?</p>	<p><i>Innovative/novel teaching techniques</i></p>

Focus Group Discussion (FGD) Guide for Participants REVISED

Note to the moderator:

Please document nonverbal interactions during the interview. This includes body language, head nods and laughing. It is particularly important to write down the reactions at the specific question being discussed. If something happens, please make note of that. If people start to talk over each other, please write down other conversations that are happening. What questions made people excited, uncomfortable, turned people on/off from participating? Also, please reference the time when you ask each new question.

Welcome

Good morning/afternoon/evening. Thank you for spending some time and joining us to talk about your understanding and experience with HPV and cervical cancer. My name is _____. The goal of this discussion is to understand the community attitudes about HPV/cervical cancer to better help people learn and understand this topic. We would like to talk today to explore your ideas and preferences for learning about HPV/Cervical cancer so that you and your friends/family will feel comfortable to be screened, tested or treated.

Consent Process

As a group, we are going to go over the informed consent form before we start our discussion to make sure you understand why we are meeting and that you know it is voluntarily to participate.

About focus group discussions:

- Please start by asking the group if anyone has participated in a focus group before. Explain that focus groups are done to gather information to build further research.
- Tell the participants that they are the experts and that we want to learn from them, both the good and the bad. People do not have to agree or disagree, we are just gathering information. There is no right or wrong answer.
- We will record the conversation so that we can hear and understand everything that you are saying. My colleague will be taking notes as well, to help us understand the recorded discussion.

Rules

- We would like everyone to participate and that one person talks at a time. It is important to hear the ideas of everyone.

<i>Question</i>	<i>Probes</i>	<i>Theme</i>
Tell me how you know of HPV/Cervical cancer?	<p>school, friends, family, neighbors</p> <p>Do you know anyone that has had HPV/cc? What do you think about that person? What is their experience like?</p>	<i>Basic understanding of HPV/cervical cancer; Attitudes about cervical cancer/HPV</i>
What are some things that may make HPV/cervical cancer difficult to talk about?	<p>Probes: Fear, shame, related to sexual activity, religious beliefs, none?</p> <p>How do you feel about religious leaders talking to you about HPV/cervical cancer screening? How would you feel about sharing your results with them? What are things that make this a good idea? A bad idea?</p>	<i>Barriers to discussion/understanding about HPV/Cervical cancer; Cultural and traditional significance of HPV/Cervical cancer; Attitudes about cervical cancer/HPV</i>
<p>Explain HPV/cervical cancer stigma.</p> <p>Explain how stigma about HPV/cervical cancer can be reduced. Provide examples.</p>	<p>What do people in your community say about women who get screened for HPV? Diagnosed with HPV? Treated?</p> <p>Does keeping screening results confidential promote stigma?</p> <p>-Presenting to screening with other family member? Community education vs at a clinic?</p>	<i>Cultural and traditional significance of HPV/Cervical cancer; Attitudes about cervical cancer/HPV</i>
What are some things that you fear about screening for HPV/CC? Explain.	<p>-Pain? Training of provider? Religious beliefs not allowing? Fear of positive test? Not understanding the process</p> <p>How do you feel about being screened by a male provider?</p>	<i>Barriers to healthcare specific to HPV/cervical cancer</i>

<p>What information about HPV or CC would convince you and your family to seek out screening for HPV/CC?</p> <p>How do we make women (and everyone) aware and not fear about HPV/cc??</p>	<p>Where would you be comfortable having the education? - alone, in a group, at a clinic, your home</p> <p>What ways would you prefer to learn about HPV/cervical cancer? -from a flyer, radio station ad, from CHVs</p> <p>How do you think you learn best? - pictures, diagrams, models, skits</p> <p>Would you want something to take home? Why? - Brochure, flyer, book</p> <p>Are there topics that should be avoided in discussing HPV/cervical cancer? If so, which?</p>	<p><i>Barriers to discussion/understanding about HPV/Cervical cancer; Desired ways to learn/discuss about HPV/cervical cancer</i></p> <p><i>How to be more accepting and minimize judgement of HPV/CC patients</i></p> <p><i>Education used to decrease stigma, improve attitudes, increase desire and intention to get screened.</i></p>
<p>If you learned about HPV/cervical cancer for the first time during an educational talk, would you be willing to be screened the same day?</p>	<p>- Why or why not? - Need more information? Or more time?</p>	<p><i>Basic understanding/general information of HPV/cervical cancer; Attitudes about cervical cancer/HPV</i></p>
<p>Who do you trust to teach you about women's health topics and HPV/cervical cancer?</p> <p>What specific changes should CHVs implement to make women willing to open up and share with CHV?</p>	<p>- Counselors, CHV, parent, sibling, friends, children, school, religious leaders</p> <p>What makes someone a good source of information?</p> <p>How would you feel about getting information from women in your community who have gone through the HPV/cervical cancer screening/treatment process?</p> <p>How would you feel if you heard about HPV/cc on the media? Children being taught in school?</p>	<p><i>Reactions to healthcare providers, CHV volunteers; Desired ways to learn/discuss about HPV/cervical cancer. Is there a central place for information? Is there a social movement that is spreading misinformation?</i></p>

- Remember, there is no right or wrong answer. We want you to feel comfortable to speak freely. Do not share any of the conversation outside of this room.

- This conversation will be audio recorded to help us later gather more detailed information about your responses. The leader will also take notes to check the data for accuracy.

- Remember that this is voluntary and that the information collected will be kept private. You can decline to answer a question or ask to leave the discussion at any time.

- Ask if there are any questions before starting.

Please turn on the tape recorder and say the date, time and location of the FGD.

Appendix B

FGD codebook

Participants

Code	Code Definition
Understanding	When a participant indicates prior knowledge in a conversation topic
- HPV	When a participant shares prior knowledge of HPV and the information is correct
- HPV Mis	When a participant shares prior knowledge of HPV and the information is incorrect or lacking (i.e. common misconceptions, silence)
- CC	When a participant shares prior knowledge of cervical cancer and the concepts are correct
- CC Mis	When a participant shares prior knowledge of cervical cancer and the information is incorrect or lacking (i.e. common misconceptions, silence)
Stigma	When a participant indicates sources of negative attitudes surrounding HPV and cervical cancer (screening, treatment, vaccination)
- Individual	When a participant shares existence of judgement and/or biases found within themselves
- Interpersonal	When a participant shares existence of judgement and/or biases found within family and friends
- Institutional	When a participant implies the existence of judgement and/or biases from institutions as a result of seeking healthcare for/diagnosis with HPV/cervical cancer (schools, church, hospitals, town halls)
- Community	When a participant shares existence of judgement and/or biases found within the social setting (cultural contexts like religion, gender influences)
HPV/CC Education	When a participant discusses topics related to HPV and cervical cancer education and awareness

- Willingness to learn more	When a participant demonstrates a desire to learn more information about HPV/cervical cancer
- Identification of learning methods	When a participant shares ways in which they think HPV and CC education delivery is most successful
Trust	When a participant references trust or doubt in a neutral sense
- Positive	When a participant expresses trust or lack of doubt in specific entities or organizations (religious figures, CHWs)
- Negative	When a participant expresses a lack of trust or doubt in specific entities or organizations (religious figures, CHWs)
Vulnerability	When a participant shared an intimate story/detail about HPV and/or cervical cancer
Fear	When a participant expresses feelings of fear in relation to HPV/cervical cancer (i.e. screening process, fear of cancer diagnosis, fear of death)
Futility	When a participant expresses a lack of motivation in screening/diagnosis/treatment
Responsibility	When a participant discusses spreading awareness within the younger female generation and the community (screening)
Religious Belief	When a participant discusses the importance and roles of God/faith/religion with respect to HPV/CC

CHVs

Code	Code Definition
Understanding	When a CHV highlights patients' prior knowledge of a conversation topic
- HPV	When a CHV highlights patients' prior knowledge of HPV and the concepts are correct / well understood
- CC	When a CHV highlights patients' prior knowledge of cervical cancer and the concepts are correct / well understood
- Misunderstanding	When a CHV highlights patients' prior knowledge of HPV/CC and the concepts are incorrect / misunderstood
Stigma	When a CHV indicates sources of negative attitudes surrounding HPV and cervical cancer in patients (screening, treatment, vaccination)
- Individual	When a CHV shares existence of judgement and/or biases found within individual patients
- Interpersonal	When a CHV shares existence of judgement and/or biases found between patients and their peers (family / friends)
- Institutional	When a CHV shares existence of judgement and/or biases from institutions as a result of seeking healthcare for/diagnosis with HPV/cervical cancer (schools, church, hospitals, town halls)
- Community	When a CHV shares existence of judgement and/or biases found within the social setting (cultural contexts like religion, gender influences)
HPV/CC Education	When a CHV discusses topics related to HPV and cervical cancer education and awareness

- Identification of learning methods	When a CHV shares ways in which they think HPV and CC education delivery is most effective (in terms of uptake)
- Teaching methods	When a CHV shares ways in which they think HPV and CC education is taught most effectively
- Ineffective learning methods	When a CHV shares ways in which they think HPV and CC education delivery is least effective / ineffective (in terms of uptake)
Trust	When a CHV references concepts related to patient trust or doubt in a neutral sense
- Positive	When a CHV expresses patients' explicit trust in specific entities or organizations (religious figures, CHWs). This includes empathy, privacy, and confidentiality
- Negative	When a CHV expresses patients' lack of trust in specific entities or organizations (religious figures, CHWs)
Vulnerability	When a CHV shares an intimate story/detail about HPV and/or cervical cancer, mostly as expressed by patients and their experiences
Fear	When a participant expresses feelings of fear in relation to HPV/cervical cancer (i.e. screening process, fear of cancer diagnosis, fear of death)
CHV Discomfort/ Helplessness	When a participant expresses a lack of motivation in screening/diagnosis/treatment
Responsibility	When a participant discusses spreading awareness within the younger female generation and the community (screening)

Appendix C

Stigma video script, English

Together, we can prevent cervical cancer

Navigator: Hello, my name is Irene. I am going to share my HPV screening and treatment journey. Remember, the goal is to remain healthy and prevent cervical cancer even before it starts! Some women are nervous about the screening process because they do not know the details. I will help you to feel comfortable talking with others to share how screening made me feel in control of my health.

Pan out and show the peer navigator sitting with a small group of 3 women.

Navigator: Many women let their fears about screening outweigh the many benefits. Us as women need to change our way of thinking, to focusing on the good outcomes of protecting our health. If you have HPV, they can treat the abnormal cells of the cervix, which will prevent developing cancer in the future. Having HPV does NOT mean you have cervical cancer. Most women with HPV will never develop cancer!

Woman from the crowd asks, “tell me about the screening.”

Navigator: There exists good options for detecting and treating HPV and cervical cancer. I have been screened two times now. The first screening was the traditional way, called VIA, with a pelvic exam performed by a provider. The provider kept my privacy, was gentle and I did not have any pain. The second time I was screened was with HPV screening. I collected the sample myself in a private room, so a provider did not have to perform an exam.

A healthcare provider or CHV will provide detailed information about how to collect the sample. You do not have to be afraid, because you have control of collecting the sample. Getting screened for HPV throughout your life is one of the best ways of staying healthy from cervical cancer. There even is an HPV vaccine to help our young children become healthy adults.

Woman from the crowd asks, “Did you share your results with anyone?”

Navigator: I was scared when I first found out about my HPV positive result. But I shared the result with my auntie whom I trust. She encouraged me to go for treatment to “safeguard my own life.” Either result is not something to worry about! If you test positive, you can get treated to prevent cervical cancer. If you test negative, your mind will be at ease for at least 5 years! People who know about HPV makes it much easier to get the support that I needed.

At first my husband was not sure about it as he had never heard of HPV. But he knew my health was important, and he supported me to get treatment. He was able to come to the clinic and had all his questions answered.

The treatment experience was positive because it was free, simple, one-time short treatment with minimal discomfort. You don't need to take medications for HPV. It's just a one visit treatment. Afterward, you'll need to take care of yourself for a few weeks, but after that, women can still have relations with their husband, get pregnant if they want and have health babies. The treatment won't impact any pregnancies in the future. Now I feel good knowing I likely won't have to worry about cervical cancer.

Again, pan away from the navigator and focus on one woman in the group. She says...

Learning from one of my sisters about the HPV screening experience helped me to feel comfortable and get to know the importance of early screening.

Back to the navigator...

So if you can change the way you think about HPV and cervical cancer, then we can change the way the whole community thinks about HPV and cervical cancer. Share the correct information about HPV and cervical cancer among your adolescents, partners and friends. Encourage even one of your sisters or friends to be screened.

Introduction and conclusion to Video

CHV introduction (live).

It is good that you have come today! I want to share information on a very important topic, HPV and cervical cancer. You may or may not have heard about this topic, but you will now learn the proper information about HPV and cervical cancer.

Any woman can be affected by HPV and cervical cancer, no matter where you were born or where you live now. HPV is a common virus that most men and women will have at some point during their lifetime. In women, HPV affects the cervix and most of the time it clears on its own. For some women, HPV does not go away on its own and may change the cells in the cervix so that they eventually become cancer. Since we have learned more about how this works, women can get tested for HPV. Those who have HPV can have a short, safe procedure on their cervix to prevent the growth of abnormal cells or cancer.

The goal of screening is to prevent cervical cancer before it even begins to grow! The best way to prevent cervical cancer is to not give the opportunity for abnormal cervical cells caused by HPV to grow. This is easily done by a 'screen and treat model' that is occurring here in Kenya. First, you have an HPV or VIA screening. If the HPV virus or abnormal cells are found, a short treatment will stop the abnormal cells from developing into cancer.

You may be considering getting tested for HPV and cervical cancer, but still are not sure. Like many women, you have questions and maybe some concerns or fears. Let's see what we can learn from a woman who has been through the process of cervical cancer screening. After this video you should feel empowered to know the truth and the steps to being screened.

This video was designed from input by women of your community who have been screened before, because they want to make sure you are comfortable with knowing about HPV and cervical cancer. Thank you for your attention.

CHV starts the video

CHV stops the video.

Appendix D

HPV	<p>People with HPV have only themselves to blame for getting HPV.</p> <p>People with HPV must have done something wrong to get it.</p> <p>I would not want someone with HPV to look after my child.</p> <p>Women with HPV should not get pregnant.</p> <p>Once you have HPV, you're never "normal" again.</p> <p>If I had HPV, people would avoid me.</p> <p>If I had HPV, people would blame me.</p> <p>If I had HPV, people would not want to be friends with me.</p> <p>If I had HPV, people would be uncomfortable around me.</p> <p>If I had HPV, people would be angry with me.</p> <p>If I had HPV, I would be treated badly by health workers.</p> <p>If I had HPV, I would lose my job, customers, or livelihood.</p> <p>If I had HPV, I would be treated badly in my community.</p> <p>If I had HPV, I would be physically abused by my partner.</p> <p>If I had HPV, my relationship would end.</p> <p>If I had HPV, I would lose friends.</p> <p>If I had HPV, I would not be allowed to participate fully in the church or mosque.</p> <p>If I had HPV, I would lose respect/standing within my family or community.</p> <p>I would be ashamed to have HPV.</p> <p>If I had HPV, I would struggle with feeling worthless because I have HPV.</p> <p>If I had HPV, I would feel that I did not deserve to live.</p> <p>If I had HPV, I would feel that I brought a lot of trouble to my family.</p> <p>If I had HPV, I would feel that I am no longer a woman.</p> <p>If I had HPV, I would feel responsible for getting HPV.</p> <p>If I had HPV, I would feel ashamed for getting HPV.</p> <p>If I had HPV, I would feel embarrassed about having HPV.</p> <p>If I had HPV, I would feel guilty for getting infected with HPV.</p> <p>If I had HPV, I would feel disappointed in myself for getting infected with HPV.</p>
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<p>Cervical Cancer</p>	<p>I would find it hard to talk to someone with cervical cancer. I would feel embarrassed discussing cervical cancer with someone who had it. I would feel angered by someone with cervical cancer. If I had cervical cancer, my relationship would end. If I had cervical cancer, I would be shunned at social gatherings. If I had cervical cancer, I would lose friends. If I had cervical cancer, I would lose respect/standing within my family or community. If I had cervical cancer, people would gossip about me. If I had cervical cancer, I would be ashamed by my symptoms (bleeding, weight loss). I would be ashamed to be diagnosed with cervical cancer. If I had cervical cancer, I would feel that I brought a lot of trouble to my family. If I had cervical cancer, I would feel that I am no longer a woman. I would feel embarrassed about having cervical cancer. I would feel angry if I learned I had cervical cancer.</p>
<p>Knowledge (HPV)</p>	<p>We will now ask you some questions about HPV and cervical cancer. We will read two answer options. Please pick the sentence that you believe is true.</p> <ol style="list-style-type: none"> 1. If a woman has HPV, but no symptoms: <ol style="list-style-type: none"> a. She can pass it to a sexual partner. b. She cannot pass it to a sexual partner. 2. Testing positive for HPV: <ol style="list-style-type: none"> a. Means she also has cervical cancer. b. Does not mean she has cervical cancer now, but is at a higher risk for getting cervical cancer in the future. 3. If a woman tests positive for HPV: <ol style="list-style-type: none"> a. She is not able to have children. b. She is able to have children in the future. 4. Using family planning methods will: <ol style="list-style-type: none"> a. Increase the chance a woman tests positive for HPV. b. Not increase the chance a woman tests positive for HPV. 5. Condoms: <ol style="list-style-type: none"> a. Can help reduce the risk of HPV. b. Do not reduce the risk of HPV. 6. Treatment for HPV consists of: <ol style="list-style-type: none"> a. Taking medications every day. b. A brief procedure in the clinic. 7. People living with HIV: <ol style="list-style-type: none"> a. Have an increased risk for acquiring HPV. b. Do not have an increased risk for acquiring HPV.

Please note, some questions used to calculate the mean stigma for each subject in the pre-pilot may be removed or less emphasized in the final calculation.

References

1. Bray, F. et al. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2018;(68):394-424.
2. Bruni L, Albero G, Serrano B, Mena M, Collado JJ, Gómez D, Muñoz J, Bosch FX, de Sanjosé S. *Human Papillomavirus and Related Diseases in Kenya*. ICO/IARC Information Centre on HPV and Cancer (HPV Information Centre); 2021.
3. Jemal, A. et al. *Global Cancer Statistics*. *CA. Cancer J. Clin.*; 2011:61, 69-90.
4. Ferlay, J. et al. Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer.* 2015;136:e359-389.
5. Sankaranarayanan, R., Swaminathan, R., Jayant, K. & Brenner, H. An overview of cancer survival in Africa, Asia, the Caribbean and Central America: the case for investment in cancer health services. *Sci Publ.* Published online 2011:257-291.
6. Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA Cancer J Clin.* 2021;71(3):209-249. doi:10.3322/caac.21660
7. WHO, IARC. *Kenya*. The Global Cancer Observatory; 2021. <https://gco.iarc.fr/today/data/factsheets/populations/404-kenya-fact-sheets.pdf>
8. Masika MM, Ogembo JG, Chabeda SV, Wamai RG, Mugo N. Knowledge on HPV Vaccine and Cervical Cancer Facilitates Vaccine Acceptability among School Teachers in Kitui County, Kenya. *PLoS ONE.* 10(8):e0135563. doi:10.1371/journal.pone.0135563
9. Ragan KR, Buchanan Lunsford N, Lee Smith J, Saraiya M, Aketch M. Perspectives of Screening-Eligible Women and Male Partners on Benefits of and

Barriers to Treatment for Precancerous Lesions and Cervical Cancer in Kenya. *Oncologist*. 2018;23(1):35-43. doi:10.1634/theoncologist.2017-0053

10. Arbyn M, Weiderpass E, Bruni L, de Sanjosé S, Saraiya M, Ferlay J, Bray F. Estimates of incidence and mortality of cervical cancer in 2018: a worldwide analysis. *Lancet Glob Health*. 2020;8(2):e191-e203. doi:10.1016/S2214-109X(19)30482-6.
11. Huchko, M. J. et al. Cervical cancer screening through human papillomavirus testing in community health campaigns versus health facilities in rural western Kenya. *Int J Gynaecol Obstet Organ Int Fed Gynaecol Obstet*. 2018;141:63-69.
12. Kenya Ministry of Health. Kenya Cancer Policy 2020. Accessed March 25, 2022. www.health.go.ke
13. Kenya National Bureau of Statistics, Ministry of Health/Kenya, National AIDS Control Council/Kenya, Kenya Medical Research Institute & National Council for Population and Development/Kenya.; 2014.
14. World Health Organization (WHO). *WHO Guidelines for Screening and Treatment of Precancerous Lesions for Cervical Cancer Prevention.*; 2013.
15. Ginjupalli R, Mundaden R, Choi Y, et al. Developing a framework to describe stigma related to cervical cancer and HPV in western Kenya. *BMC Womens Health*. 2022;22(1):39. doi:10.1186/s12905-022-01619-y
16. Link B, Phelan JC. Conceptualizing Stigma. *Annu Rev Sociol*. 2001;(27):263-285.
17. Scott N, Crane M, Lafontaine M, Seale H, Currow D. Stigma as a barrier to diagnosis of lung cancer: patient and general practitioner perspectives. *Prim Health Care Res Dev*. 2015;16(06):618-622. doi:10.1017/S1463423615000043

18. VA Office of Research and Development. *Reducing Internalized Stigma in People With Serious Mental Illness.*; 2016. clinicaltrials.gov

19. Earnshaw VA. Anticipated stigma and quality of life among people living with chronic illnesses.

20. Rueda S, Mitra S, Chen S, Gogolishvili D, Globerman J, Chambers L, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. 2016;(6):e011453.

21. Turan B, Hatcher AM, Weiser SD, Johnson MO, Rice WS, Turan JM. Framing Mechanisms Linking HIV-Related Stigma, Adherence to Treatment, and Health Outcomes. 2017;(107):863-869.

22. SA Golub, KE Gamarel. The Impact of Anticipated HIV Stigma on Delays in HIV Testing Behaviors: Findings from a Community-Based Sample of Men Who Have Sex with Men and Transgender Women in New York City. *AIDS Patient Care STDs*. 2013;(27):621-627.

23. WW Rankin, S Brennan, E Schell, J Laviwa, SH Rankin. The Stigma of Being HIV-Positive in Africa. *PLOS Med*. 2005;(2):e247.

24. *Overcoming Barriers to Low HPV Vaccine Uptake in the United States: Recommendations from the National Vaccine Advisory Committee*. National Vaccine Advisory Committee; 2016:17-25.

25. Rosser JI, Njoroge B, Huchko MJ. Changing knowledge, attitudes, and behaviors regarding cervical cancer screening: The effects of an educational intervention in rural Kenya. *Patient Educ Couns*. 2015;98(7):884-889. doi:10.1016/j.pec.2015.03.017

26. Kenya S, Carrasquillo O, Fatil M, Jones J, Jean C, Huff I, Kobetz E: Human Papilloma Virus and Cervical Cancer Education Needs among HIV Positive Haitian Women in Miami. *Womens Health Iss*. 2015;25(3):262-266.

27. Bingham A, Bishop A, Coffey P, et al. Factors affecting utilization of cervical cancer prevention services in low-resource settings. *Salud Pública México*. 2003;45:408-416. doi:10.1590/S0036-36342003000900015
28. Williams M, Kuffour G, Ekuadzi E, Yeboah M, ElDuah M, Tuffour P. Assessment of psychological barriers to cervical cancer screening among women in Kumasi, Ghana using a mixed methods approach. *Afr Health Sci* 2013. 2013;13(4):1054-1061.
29. Ngugi CW, Boga H, Muigai AW, Wanzala P, Mbithi JN: Factors affecting uptake of cervical cancer early detection measures among women in Thika, Kenya. *Health Care Women Int*. 2012;33(7):595-613.
30. QSR International Pty Ltd. *NVivo Qualitative Data Analysis Software*.; 2020. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
31. Saisahana Subburaj, Avanti Shah, Cassidy Connett, Madeline McNee, Emily Herfel DO, Breandan Makhulo, Sandra Yvonne, Megan J. Huchko MD MPH. *Understanding How Outreach and Education Can Impact Cervical Cancer Stigma: A Qualitative Study in Western Kenya*. Duke University; 2022.
32. *StataCorp*. 2021. *Stata Statistical Software: Release 17*. College Station, TX: *StataCorp LLC*.