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Cervical cancer stigma in rural Kenya: What does HIV have to do with it?

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Abstract

Cervical cancer is a leading cause of cancer-related death amongst women in Sub-Saharan Africa, largely due to lack of early screening and treatment. In addition to poor access to screening services, inadequate uptake of available services is a barrier to early identification of precancerous lesions. Given that cervical cancer is caused by a sexually transmitted virus and is associated with HIV positivity, stigma is one of the potential barriers to utilization of cervical cancer programs in Sub-Saharan Africa. We conducted a cross-sectional survey of 419 women attending health facilities in rural western Kenya to measure levels of cervical cancer and HIV stigma, and to measure the associations between cervical cancer stigma, HIV stigma, and HIV status. Women who qualified for cervical cancer screening were asked to complete an oral questionnaire using a modified 9-point HIV stigma scale. Low cervical cancer stigma was reported in this study, with only 85/419 (20.3%) of respondents answering yes to at least one cervical cancer stigma question. However, cervical cancer stigma was highly correlated with HIV stigma (correlation coefficient 0.72) and was significantly lower in HIV positive women ($p<0.001$). Reducing cervical cancer stigma in the general population is an important part of promoting screening in Sub-Saharan Africa.

Keywords

cervical cancer; stigma; Sub-Saharan Africa; HIV; health education

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The authors have no conflicts of interest.

Introduction:

Cervical cancer is a leading cause of cancer and cancer-related mortality in women in Sub-Saharan Africa [1]. This high incidence and mortality is primarily due to lack of access to early screening and treatment services. [2]. With increasing attention to cervical cancer prevention in developing countries, several pilot screening programs have been initiated throughout Sub-Saharan Africa. As HIV-infected women have an increased risk for cervical pre-cancer and cancer, many screening programs have emerged out of the existing, well-funded HIV programs and later expanded screening services to HIV negative women, who are also at risk of cervical cancer [3–5].

It is well established that stigma frequently deters individuals from obtaining medical care and contributes to poor health outcomes [6]. HIV/AIDS stigma has been studied extensively in Sub-Saharan Africa and has been recognized as a major barrier to HIV testing and treatment [7]. Cervical cancer stigma on the other hand has not yet been widely studied. Cervical cancer has several characteristics that could potentially contribute to high levels of stigma. It is caused by the sexually transmitted human papillomavirus (HPV), it is more prevalent in HIV positive women, screening programs have frequently developed out of existing HIV programs, and screening requires a pelvic exam [2–5]. Furthermore, qualitative studies in Sub-Saharan Africa indicate that women often associate cervical cancer with promiscuity and with HIV, and suggest that stigma may be a barrier to cervical cancer screening in Sub-Saharan Africa [8, 9]. In a qualitative study of women in Zambia, most women reported cervical cancer to be a highly stigmatized disease due to its association with HIV/AIDS and sexual behavior [5]. However, there are currently no studies to our knowledge that have examined the extent of cervical cancer stigma or its impact on screening uptake.

In 2007, Family AIDS Care and Education Services (FACES) piloted a cervical cancer screening and prevention (CCSP) program at an HIV clinic in Kisumu, Kenya [3]. In 2012, FACES expanded this program to provide screening for both HIV positive and negative women at eleven FACES-supported government health facilities in Mbita and Suba, two rural districts in western Kenya where cervical cancer screening had not previously been a routine health service. This study looks at cervical cancer stigma, using a modified HIV/AIDS stigma scale, among HIV positive and negative women at these rural government health facilities. This study aims to: 1) quantify cervical cancer stigma in rural Kenya, 2) measure the association between cervical cancer stigma and HIV stigma, 3) identify demographic predictors of cervical cancer stigma with particular attention to HIV status, and 4) measure the association between cervical cancer stigma and screening acceptability.

Materials and Methods:

Women attending eleven CCSP-supported health facilities in Mbita and Suba, who were eligible for cervical cancer screening (non-pregnant women ages 23–64 years) but had not previously been screened, were invited to participate in this cross-sectional study. A total of 419 women were enrolled in the study, which was powered to detect a 14% difference in reporting any stigma. Trained interviewers administered an oral survey in English,

Kiswahili, or Dholuo and entered responses directly into Open Data Kit survey software (opendatakit.org) on tablet computers. The survey included questions on demographic characteristics and anticipated stigma associated with a diagnosis of cervical cancer or HIV.

The survey started with demographic questions, including a section asking women about their history of screening for sexually transmitted infections, HIV, and breast cancer (via clinician-performed breast exam and mammography). These responses were combined into a *Health Screening Behavior* variable in which a history of at least two previous screening tests was categorized as "high health screening behavior." The type of health facility at which the participant was recruited was also documented; the eleven facilities at which women were recruited included: 1) two district hospitals (highest level facility offering inpatient and outpatient medical and surgical procedures), 2) five sub-district hospitals (middle level facility with outpatient and inpatient services), and 3) four dispensaries (local outpatient facility). Finally, women were asked if they would accept cervical cancer screening and it was documented whether they got screened that day.

Cervical cancer stigma and HIV stigma was then measured using the same stigma questionnaire. The stigma tool used was based on a 9-item stigma tool that had been developed and shown to be valid and reliable as a measure of anticipated HIV stigma in sub-Saharan Africa [7, 10]. The questions asked about anticipated stigma in multiple relationships, (ie friends, family, work, healthcare providers, and partners). Although not previously used as a cervical cancer stigma tool, the general nature of the stigma questions was felt to be applicable to cervical cancer stigma and could be used as a direct comparison to HIV stigma in this population. Each respondent was asked: "Do you think any of the following things might happen to you, if you were to test positive for HIV and others found out about your HIV status?" The nine question items are included in Table 2. Respondents could answer yes or no or decline to respond. These questions were then modified to ask respondents how they would feel if they had a positive cervical cancer screen and others found out about their screening results. As the cervical cancer stigma scale was modified for use in this study, we measured internal validity with Cronbach's alpha.

The *HIV Stigma Score* and *Cervical Cancer Stigma Score* were each created on a scale of 0 to 9, with one point being given for every "yes" response and no points for a negative response or declining to respond. Stigma scores were then dichotomized for further analysis. Given overall low scores in both this study and previous studies using this HIV stigma scale [7, 10], participants were categorized as "having any stigma" if a respondent answered "yes" to at least one item on the scale or "not having any stigma" if no positive answers were indicated.

The correlation between cervical cancer and HIV stigma scores was measured using the Pearson correlation coefficient. Demographic predictors (including HIV status) of stigma were assessed in bivariate and multivariate analysis using chi-square and logistic regression where appropriate. Backwards elimination models were created using variables with at least borderline significance ($p<0.2$) in the bivariate analysis and controlled for interviewing using hierarchical clustering. Finally, chi-square was used to measure the association between any

reported cervical cancer stigma and 1) reporting acceptance of cervical cancer screening and 2) actually getting screened that day.

Data was analyzed using STATA version 12.0 statistical package (College Station, TX). Ethical approval was obtained from the Kenya Medical Research Institute Ethical Review Committee and the University of California, San Francisco Committee on Human Research.

Results:

A total of 419 women from eleven rural health facilities participated in this study. The mean age of respondents was 33.4 years old (SD +/− 9.3 years), the majority had achieved a primary school education or less (N=308; 73.5%), and approximately half (N=233; 55.6%) were HIV positive. (Table 1)

Reported rates of stigma for both cervical cancer and HIV were low. The mean overall stigma scores for cervical cancer and HIV were respectively 0.7 +/− 1.7 and 0.9 +/− 1.9 (out of 9 possible points). Internal reliability of the scale was high with a Cronbach's alpha of 0.9. The correlation between *Cervical Cancer Stigma Scores* and *HIV Stigma Scores* was high (correlation coefficient 0.72). Additionally, 'any reported stigma,' as defined by answering yes to at least one stigma question, was only 20.3% (N=85/419) for cervical cancer stigma and only 30.3% (N=127/419) for HIV stigma.

Cervical Cancer Stigma Scores were lower in HIV positive women compared to HIV negative/unknown women, and only 13.7% (N=32/233) of HIV positive women reported any cervical cancer stigma, compared to 28.5% (N=53/186) of HIV negative/unknown women (OR=0.4; 95% CI 0.2–0.7; p<0.001). (Table 2) HIV positive status remained a significant predictor of lower cervical cancer stigma on multivariate analysis (OR 0.4; 95% CI 0.3–0.7; P=0.002) adjusting for occupation, knowing someone with cervical cancer, higher health seeking behavior score, and sexual debut. Cervical cancer stigma was also significantly lower in women who worked outside the home (OR 0.6; 95% CI 0.4–1.0; p<0.05) and higher in women with a high Health Seeking Behavior Score (OR 1.5; 95% CI 1.1–2.0; p<0.01) in multivariate analysis. (Table 3)

Similarly, *HIV Stigma Scores* were lower in HIV positive women compared to women with a negative or unknown HIV status, and only 23.2% (N=54/233) of HIV positive women reported any HIV stigma, compared to 39.3% (N=73/233) of HIV negative/unknown women (OR=0.5; 95% CI 0.3–0.7; p<0.001). (Table 2) HIV positivity remained a significant predictor of lower HIV stigma in multivariate analysis (OR 0.4; 95% CI 0.2–0.8; p=0.004) adjusting for facility, health seeking behavior score, and transportation type.

The majority of women (N=333/419; 79%) said they would accept cervical cancer screening if offered, and there was no difference in screening acceptability between women who reported cervical cancer stigma (OR=1.1; 95% CI 0.6–2.1; p=0.66). Only 9.4% (N=8/85) of women who reported cervical cancer stigma got screened that day compared to 15.9% (N=53/334) of women who did not report cervical cancer stigma, however these screening rates were not significantly different (OR=0.6; 95% CI 0.3–1.2; p=0.14) and the primary reason given for declining screening that day was lack of time. (Table 3)

Discussion:

In this survey of women in rural Kenya, cervical cancer stigma was found to be low. Cervical cancer stigma was also highly correlated with HIV stigma. Moreover, HIV positive women had significantly lower levels of both HIV and cervical cancer stigma compared to women with a negative or unknown HIV status. Reported stigma was not significantly associated with intention to undergo cervical cancer screening or screening rates on the day of the interview.

The concern that stigma, particularly due to cervical cancer's association with HIV, may be a barrier to cervical cancer screening in Sub-Saharan Africa has been raised by other investigators in Eastern Africa [5]. However, the present study uniquely measures cervical cancer stigma and shows a direct association with HIV stigma and HIV status. The strong correlation between HIV and cervical cancer stigma scores in this study may partially reflect individual tendencies to respond to any stigma questions in a certain pattern; more importantly, this correlation implies that individuals who stigmatize HIV are more likely to stigmatize cervical cancer, likely due to the multiple associations between the two diseases as described in the introduction. The fact that HIV positive women reported less HIV and cervical cancer stigma suggests that HIV positive women may have gone through a process of de-stigmatizing their own disease, which may carry over to other similarly stigmatized diseases like cervical cancer.

Interestingly, previous studies of HIV stigma using the same instrument yielded mildly higher rates of reported HIV stigma [7, 10]. This difference could be attributed to the increasing availability and integration of HIV-care into outpatient clinics, resulting in an overall increase in HIV-related awareness and decrease in stigma over the last several years. The difference is also likely due to differences in demographic characteristics of the study populations. In the Botswana study, men were included which would very likely change stigma scores [10]. In the Turan study, set in the same region of western Kenya, this scale was administered to pregnant women who had never been tested for HIV or who tested negative more than three months previously [7]. This study provides a particularly interesting comparison. Our study population did not include pregnant women and over half of participants had previously been diagnosed with HIV. Our study found that women who were either HIV negative or HIV status unknown had higher levels of reported stigma compared to HIV positive women. Therefore, based on our study, one would predict that a population of HIV negative/unknown women would actually have higher reported stigma, as seen in Turan's study.

Our study findings would also suggest the converse to be true: that a population of HIV positive women would have lower stigma scores. This stigma tool was used to measure cervical cancer and HIV stigma amongst HIV positive women at an HIV clinic in Kisumu and, again as our study would predict, stigma was even lower in this exclusively HIV positive population. In fact, average cervical cancer stigma scores and HIV stigma scores in the HIV positive women in Kisumu were 0.4 and 0.6 respectively, which is very similar to the scores in the HIV positive subpopulation of this current study [11].

Although this study is novel in its subject matter, survey instrument, and target population, there are limitations. Given the potentially sensitive nature of stigma questions, this survey is vulnerable to social desirability bias and thus underreporting of stigma; in particular, some participants may not have felt comfortable reporting stigma verbally to an interviewer. However, we felt it was important to administer the survey orally so as to include all willing women regardless of literacy, which is quite low in this population, and all interviewers were trained to ask questions in a nonjudgmental fashion. Despite the small number of women reporting stigma, the association between HIV status and stigma was highly significant in both bivariate and multivariate analyses. Another limitation of the study is that given the lack of previous research on cervical cancer stigma and lack of validated cervical cancer-specific stigma surveys, the stigma tool had to be adapted from an HIV stigma questionnaire. For the purposes of this study, this adapted tool served as a good cervical cancer stigma measure. Using this HIV stigma questionnaire enabled us to compare cervical cancer stigma to HIV stigma and our results in general to other HIV studies in this region that used this particular stigma scale.

Cervical cancer stigma as we have conceptualized it arises from the associations with HIV and sexually transmitted infections. Other psychological factors are also potentially important barriers to screening acceptance. Fear or embarrassment around the pelvic exam as well as fear of a positive diagnosis and being unable to access adequate treatment may inhibit a woman from accepting screening. It is encouraging that in this study the modified stigma scale maintained internal validity and measured cervical cancer stigma was low and was not associated with a lower screening rates. However, additional validated measures that incorporate multiple aspects of cervical cancer-specific stigma and psychological factors associated with cervical cancer screening are needed in order to better understand how stigma affects screening uptake by both HIV positive and negative women. Finally, access to services remains a major barrier to screening. Integrated HIV-cervical cancer programs are a key component to expanding services. As screening services continue to expand to both HIV positive and negative individuals, the association between HIV status and cervical cancer stigma needs to be further explored in order to design outreach and education programs that positively impact screening uptake without increasing stigma.

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Table 1:

Demographic Characteristics (n=419)

	N (%) or mean (+/−sd)
Age (years)	33.4 +/− 9.3
Relationship Status	
Married	282 (67.3%)
Single/Widow/Divorced	137 (32.7%)
Highest Educational Level	
Primary school or less	308 (73.5%)
Beyond primary school	111 (26.5%)
Occupation	
Works outside the home	249 (59.4%)
Housewife/farming/fishing	170 (40.6%)
Facility Type	
District Hospital	108 (25.8%)
Sub-District Hospital	189 (45.1%)
Dispensary	122 (29.1%)
Transportation to clinic	
Walking	244 (58.2%)
Motorcycle	163 (38.9%)
Other	12 (2.9%)
Travel time to clinic (minutes)	47.5 +/− 40.2
Primary source of health information	
Health facility or healthcare worker	356 (85.0%)
Other source (radio, church, school, etc)	63 (15.0%)
Knows someone with cervical cancer	121 (29.0%)
Prior health seeking behavior	
STD testing	81 (19.4%)
Clinician breast exam	25 (6.0%)
Mammogram	17 (4.1%)
HIV testing	390 (93.1%)
Reproductive History	
Gravidity	3.4 +/− 2.4
Age of sexual debut (years)	16.5 +/− 2.6
# of current sexual partners	0.9 +/− 0.5
# of lifetime sexual partners	2.2 +/− 1.3
Use of Modern Family Planning	
None	229 (54.7%)
Depo/Injectables	94 (22.4%)
Long-term: IUCD/Implant	44 (10.5%)
Condom	21 (5.0%)

	N (%) or mean (+/−sd)
Other	16 (7.4%)
HIV Status	
Positive	233 (55.6%)
Negative	114 (27.2%)
Unknown *	72 (17.2%)
Mean years since tested positive	3.3 +/− 2.8

* HIV Unknown = never screened or no negative test in the last year

Table 2:

Anticipated HIV & Cervical Cancer Stigma (n=419)

Do you think any of the following things would happen to YOU if you were to have a positive HIV/cervical cancer screen and others found out about your status?	*HIV Stigma N (%)*		*Cervical Cancer Stigma N (%)*	
	HIV Status*			
	HIV+ (n=233)	**HIV− (n=186)**	**HIV+ (n=233)**	**HIV− (n=186)**
Be treated badly by health workers.	17 (7.3%)	45 (24.2%)	7 (3.0%)	15 (8.1%)
Lose your job/livelihood.	15 (6.4%)	35 (18.8%)	11 (4.7%)	20 (10.8%)
Be denied care by family if sick.	10 (4.3%)	29 (15.6%)	7 (3.0%)	25 (13.4%)
Be rejected by family.	11 (4.7%)	36 (19.4%)	10 (4.3%)	26 (14.0%)
Be treated badly at work or school.	3 (1.3%)	25 (13.4%)	6 (2.6%)	18 (9.7%)
Be physically abused by your partner.	8 (3.4%)	26 (14.0%)	9 (3.9%)	24 (12.9%)
Experience break-up of your relationship.	17 (7.3%)	30 (16.1%)	13 (5.6%)	28 (15.1%)
Become a social outcast.	7 (3.0%)	19 (10.2%)	4 (1.7%)	12 (6.5%)
Lose your friends.	17 (7.3%)	27 (14.5%)	16 (6.9%)	26 (14.0%)
Overall Stigma Score ** **(mean +/− SD)**	**0.5 (+/− 1.1)**	**1.5 (+/− 2.4)**	**0.4 (+/− 1.2)**	**1.0 (+/− 2.2)**
Any Reported Stigma ***	**54 (23.2%)**	**73 (39.3%)**	**32 (13.7%)**	**53 (28.5%)**

* HIV- includes HIV negative and HIV status unknown

** "Overall Stigma Score" represents the score out of 9 point, with 1 point given for every "Yes" response. HIV positive women were significantly more likely have lower HIV Stigma Scores (correlation coefficient=−1.01; p<0.001) and lower Cervical Cancer Stigma Scores (correlation coefficient=−0.69; p<0.001).

*** "Any Reported Stigma" represents the number of women who answered any of the 9 questions with "Yes". HIV positive women were significantly less likely to report any HIV stigma (OR=0.5; p<0.001) and any cervical cancer stigma (OR=0.4; p<0.001).

Table 3.

Demographic Characteristics & Cervical Cancer Stigma (n=419)

	Stigma	
	Unadjusted OR (95% CI)	***Adjusted OR (95% CI)***
Age (>30yrs)	1.1 (0.7–1.8)	-
Married	1.3 (0.8–2.2)	-
Education (beyond primary school)	0.8 (0.4–1.3)	-
Occupation (works outside the home)	0.7 (0.4–1.2)	**0.6 (0.4–1.0)** *
Site (recruited at district hospital)	0.6 (0.3–1.1)	-
Transportation (>30 minutes)	0.8 (0.5–1.3)	-
Knows someone with cervical cancer	**2.3 (1.4–3.8)** ***	2.1 (0.6–7.6)
Health Seeking Behavior Score	**2.0 (1.2–3.4)** **	**1.5 (1.1–2.0)** **
Sexual debut (at least 18 yrs)	**2.0 (1.2–3.2)** **	1.6 (0.8–3.0)
Lifetime Sexual Partners (>3)	0.7 (0.4–1.1)	-
Uses Family Planning	1.1 (0.7–1.8)	-
HIV Positive	**0.4 (0.2–0.7)** ***	**0.4 (0.3–0.7)** **
Duration HIV+ (>4 years)	0.6 (0.3–1.2)	-
Screening acceptance	1.1 (0.6–2.1)	-
Actually screened that day	0.6 (0.3–1.2)	-

OR, Odds Ratio; CI, Confidence Interval

* p≤0.05;

** p≤0.01;

*** p≤0.001