

Attitudes to cervical cancer screening among HIV positive and negative Rwandan women

Degree project in medicine

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Abstract

Background:

Most developed countries have significantly decreased their incidence and mortality rates in cervical cancer in the past fifty years with effective screening programmes. In many developing countries cervical cancer is still a major problem. Rwanda is one of the worst affected countries with an incidence of 49/100 000 women.

In 2011 the Rwandan government made an ambitious effort to start fighting the disease by mass vaccinating all girls, and start a screening programme like those present in the developed world. The vaccinations seem to have been a success, but little information is available on the progress of the screening programme, and of Rwandan womens' attitudes to cervical cancer and screening. This study scrapes the surface of these questions.

Purpose:

To investigate the attitudes of Rwandan women to cervical cancer screening.

Method:

Using questionnaires from an ongoing cohort study, the attitudes of two cohorts of HIV positive and negative Rwandan women were investigated regarding previous screening and reasons for having or not having participated in screening, comparing the two cohorts. Each cohort included 200 women.

Result:

28.5% of the women in the HIV cohort and 6.5% of the women in the HIV negative cohort had been screened before, giving a 17.5% screening rate in the whole study population. The

most frequent reason for previous screening was recommendation from a doctor, which was more common in the HIV cohort. The most common reason to never have screened was unawareness of screening possibility.

Conclusion:

Few women had been screened before, and the main reason for this was unawareness of the availability of screening. The most common reason for having been screened before was recommendation from a doctor. This points to continuous contact with healthcare being a beneficial factor in likeliness to screen.

Key words:, *Cervical cancer screening, Rwanda, Attitudes, Screening frequency, Reason to screen*

Background

Cervical cancer and HPV

Cervical cancer was, in 2008 estimated the third most common malignant disease among women globally, with 530 000 new cases annually, as well as the fourth deadliest, with an estimated 7.8 million years of life lost (1). If the disease is caught in its early stages it is highly curable (2), but if detected late in its course treatments rapidly become demanding and costly, and curative treatment might not be possible at all (3). Early detection is thus important to reduce the number of deaths due to cervical cancer in the world, as has already been done through screening programmes in many high income countries countries (4).

It is well established that the Human Papilloma Virus (HPV) causes cervical cancer. Highly carcinogenic in other sites, such as the oropharynx, the anal region and the vulva as well, it is considered to be a necessary factor in the development of cancer in the cervix uteri. More than 150 different types of the virus have been found, and out of these 13 strains are considered high-risk types for oncogenic development of infected cells. HPV 16 and 18 stand out in the statistics and together account for about 70% of all cervical cancer cases in the world (5). Especially HPV 16 seems to be associated with an increased risk, increasing in proportion to the degree of cytological abnormalities found in test materials (1).

A majority of sexually active men and women will at some point during their lives be infected by HPV and it has been considered the most common sexually transmitted disease in the world. The prevalence was calculated to be 10.4% among 1 million women without cytological changes studied in a meta-analysis and even higher among women under the age of 25, reaching 16.9%. In 24% of the infected women in the same study, the HPV-virus was HPV 16 (6). More than 90% of HPV infections have regressed within a period of 6-18 months

(5). If the virus is not cleared by then, the infection will have a lower probability of being cleared at all and becomes chronic, which leads to the risk of developing cancer (7). Risk factors such as HIV and certain HPV-strains may promote a more persistent infection and thus elevate the risk of cancer further (6).

Risk factors for HPV infection

As the HPV virus is sexually transmitted many of the risk factors are linked to sexual behaviour and lifestyle. In many studies around the world early sexual debut, multiple sexual partners, use of hormonal contraceptives and a high number of pregnancies have been correlated to an increased risk to develop HPV infection (8). Of these risk factors, to have multiple sexual partners seems to be the clearest contributing factor, as has been seen in a large number of studies (8, 9, 10). A Spanish study on women being screened for cervical lesions showed that women with four or more lifetime sexual partners suffered a four times higher risk of having an HPV infection compared with women with only one sexual partner (11). It is also debated whether male circumcision have a protective effect on the transmission of HPV-infection and whether the use of condom protects against the virus (9, 12). Other, non-sexual factors where correlations are seen are young age, level of education, geographic region and tobacco use. Furthermore, immunodeficiency, due to HIV infection, immunosuppressant therapy after transplantation and malnutrition, may also promote the development of a chronic HPV infection and thereby increase the risk of cervical cancer. The number of pregnancies, oral contraceptives and smoking also seem to be independent risk factors of HPV infection (9). Young age is also a risk factor that stands out, however, like many other risk factors, it is also associated with sexual risk behaviour, which *per se* is a risk factor for HPV infection (6, 9, 11).

Cervical cancer in Rwanda and Sub-Saharan Africa

Cervical cancer is today to a large extent a disease of the developing world with an estimated 86% of new cases and 88% of deaths occurring in low income countries (4). In Africa, where a majority of the countries are considered low or middle income (13), malignant diseases in general are a growing problem due to an increase in life expectancy and prevalence of oncogenic risk factors. However, this issue still is not prioritized in most public health care systems in the region, due to limited resources and many other health issues that require attention (4). Among women cervical cancer is the second most frequently diagnosed cancer on the continent. In Sub-Saharan Africa the disease makes up almost 25% of all cancer cases in women (6, 14). In Rwanda it is the most common cancer among women, with an estimated incidence of 49 cases per 100 000 women (8).

Cervical cancer and HIV:

One contributing factor to the high incidence of cervical cancer in many Sub-Saharan countries is the high prevalence of HIV in the population. In 1993 cervical cancer was classified as an AIDS defining disease, and epidemiological studies have shown an association between HIV infection and cervical cancer, even though the association appears to be limited and its impact difficult to evaluate (15). As both HIV and HPV are sexually transmitted they also share many risk factors. However, there seems to be an independent increase in cervical cancer risk for HIV-infected individuals after stratifying for other confounding factors (9). With the vast HIV-epidemic in Sub-Saharan Africa even a low association between HIV and cervical cancer is bound to have a major impact on cancer incidence (15).

Treatment of cervical cancer in Sub-Saharan Africa

Few registered data on cancer stage at diagnosis in African countries exist, but much points to that a majority of cancer patients in the region are diagnosed at a late stage of their disease. In Harare, Zimbabwe, more than 90% of the cervical cancer cases in major hospitals only came to medical attention in more advanced stages of their cancer (4).

Preferred methods for curative treatment of cervical cancer are surgery and radiotherapy. Lack of resources, such as facilities for radiotherapy and trained healthcare professionals as well as surgical tools make these treatments unavailable for a large portion of the population in many Sub-Saharan countries (4). Rwanda, with its 11 million inhabitants, opened its first oncologic centre at the Butaro District hospital, which serves as a national referral hospital for cancer care, in 2012. The centre offers diagnostics through histopathology, x-ray and ultrasound, and treatment in the form of surgery and chemotherapy. In spite of the fact that many of the patients are in need of radiotherapy, the centre does not have facilities to offer it. Patients are instead referred to Uganda for radiotherapy (3). However, after the linear accelerator in Mulago hospital, Kampala, broke in March 2016 the future availability of this treatment is uncertain (16).

Prophylactic action

There are two main ways to decrease the prevalence of cervical cancer (4). The first is through vaccination to avoid the infection that may lead to malignant development. The vaccines available today cover HPV 16 and 18, with or without the addition of low risk types HPV 6 and 11, and have in studies been shown to have an efficacy of at least 95% in preventing infection with the included HPV types in girls vaccinated before sexual debut, and to have an efficacy even higher for preventing cervical lesions due to the same virus types

(17). Education and change of behavioural patterns, are also important, although this is more difficult to implement as the risk factors for the infection, such as not using condom during intercourse, still are not fully understood (12, 17).

The development of cervical cancer may also be prevented by screening for cytological changes, such as in the screening programmes with pap smears, that is taking a cytological sample from the cervix to be examined by pathologists for cytological changes, which are present in many developed countries. More recently other, less resource demanding, methods, for example visual inspection with dilute acetic acid (VIA) and HPV DNA-testing have been validated for screening, and might be more suitable techniques for low income settings (18).

Primary prevention of cervical cancer in Rwanda

Implementing preventative measures against cervical cancer puts high demands on a country's health care system (17). The vaccines need to be included in national immunization programmes to reach a high enough coverage for a population effect by making them accessible for everybody and securing distribution to more rural areas where the vaccine otherwise might not be available (17).

Rwanda was the first African country to introduce the HPV vaccine in their national vaccination schemes. In order to reach a high coverage of immunization the vaccination was school based, preceded by national information campaigns and with communal follow-up of girls not attending school. In its first year the Rwandan scheme reached a 93% coverage of sixth grade girls in the country. As the HPV vaccines have been included in the Global Alliance for Vaccines and Immunizations (GAVI), this might soon be the case in more low and middle-income countries due to a substantially lowered price (17). However, obstacles for implementing and maintaining vaccination programmes exist. First there is the question of

financing the programme. Even with GAVI coverage the costs for efforts such as the one in Rwanda are high for a low-income country. Apart from the cost of the vaccine itself the infrastructural requirements for distributing three doses of vaccine per girl are many, *i.e.* storage of vaccine without breaking the cold chain, distribution, transportation, personnel and systems for monitoring the programme, administration and other staff. The clinical effect of the vaccination programme will not be possible to evaluate for another ten to twenty years, since cytological changes take years to develop. It is also unclear how vaccinations will affect the prevalence of other high risk HPV types. Thus vaccination cannot be the only measure taken to decrease the incidence of cervical cancer.

Cervical cancer screening methods

Early detection of cervical lesions is essential to effectively reduce death and mortality in cervical cancer in Rwanda. In Sweden incidence and mortality rates have decreased by over 50% since the introduction of screening with pap smears in the mid-sixties (19). Pap smears, however, are costly and highly demanding for the health care infrastructure (4), requiring both materiel and trained health care workers to collect and store the samples, as well as pathologists to interpret the results, all of which exist in shortage in large parts of Sub-Saharan Africa (17, 18).

Introducing screening programmes using less means-requiring methods such as VIA or Lugol's Iodine (VILI), where dilute acetic acid or Lugol's Iodine respectively are applied to the cervix has been suggested as a possible solution. Especially VIA is considered an appropriate method for less developed health care systems, being inexpensive and readily available. With VIA it is also possible to treat lesions with cryotherapy in the same session immediately after diagnosis (17).

Another method that has gained scientific support is HPV-DNA-testing with PCR. A major advantage of this kind of test is that the samples can be self-collected, and thus less personnel is needed for collecting the samples. Many of the techniques used for HPV analysis are still too expensive and advanced for hospital laboratories in Sub-Saharan Africa though, and thus not feasible for large-scale screening programmes. However, *Care-HPV*, which only tests for 14 of the most common high-risk HPV-types, might be a realistic method in developing countries (17). According to the WHO guidelines from 2013 the recommended screening method when possible is the HPV DNA-test, followed by VIA to test for existing lesions. If HPV DNA-test is not available, VIA can be used directly to identify lesions (20).

In the launch of a strategic campaign against cervical cancer in Rwanda in 2011, HPV-DNA-test followed by VIA was the preferred screening method in the screening program (2).

However little data exists on how the Rwandan screening program proceeds, and therefore it is difficult to evaluate how successful the programme has been. Gakidou et al found in 2008 that only 19 % of women in all developing countries are screened for cervical cancer, with significantly lower levels in several countries in Sub-Saharan Africa (21), and in a study on the knowledge attitudes and practices regarding cervical cancer in Rwanda's neighbouring country Democratic Republic of Congo, only 8.6% of the studied women had previously been screened (22).

Knowledge about cervical cancer and screening programs

Why women do or do not seek screening is a complex question where demographic factors such as age, marital status and education level as well as knowledge and attitude to cervical cancer and the procedure of screening play an important role. The accessibility to nearby screening facilities is also an important aspect. One study conducted in rural Tanzania

concluded that knowledge of cervical cancer and screening, and accessibility were the main factors influencing the decision to screen (23). Previous studies regarding the knowledge and attitudes of the Rwandan population regarding HPV-infection, cervical cancer and the benefits of screening are scarce, but a few studies from other Sub-Saharan countries exist. These point to a generally low knowledge in the region about cervical cancer, its causes, risk factors and prophylactic measures such as screening and vaccination (22, 24, 25, 26). Apart from knowledge of the possibility, important factors for choosing to screen for cervical cancer seem to be perceived risk of cancer, time and money for screening and travel, geographical accessibility, and attitudes of husbands or partners to the procedure (27).

Aim of study

The aim of this study was to investigate the attitudes towards cervical screening among one cohort of HIV patients and one cohort of healthy controls in Rwanda.

This was done by attempting to answer the following questions:

- How many of the women had previously been screened for cervical lesions?
- What were the main reasons for previously having been screened respectively not having been screened?
- Did the attitudes to cervical cancer screening differ between HIV positive and HIV negative women?

Method

This master thesis was performed as a part of a larger, ongoing prospective cohort study within the Sweden-Rwanda collaboration (SIDA): Project “Immunological responses in the

cervix in response to HPV infection in a cohort of HIV-infected and non-infected Rwandan women”.

The first cohort contained 200 HIV-negative women who were recruited at the gynaecological and obstetric departments of the University Teaching Hospitals in Kigali (CHUK) and Butare (CHUB). The second cohort consisted of 200 HIV positive patients that were recruited at the HIV-clinic at CHUK. In the HIV-negative cohort many women sought out the study themselves to participate after hearing about it from friends and family. If the women met the inclusion criteria they were included after signing a written consent form.

Inclusion criteria for women recruited at the gynaecological clinics of CHUK and CHUB:

- Voluntary participation and signed consent form
- Age over 17 years
- Literacy in Kinyarwanda, French or English
- No plans to relocate in the next two years

Inclusion criteria for women recruited at the HIV clinic at CHUK:

- All criteria listed for the gynaecological clinic cohort
- HIV-infection and enrolment at an HIV clinic

Exclusion criteria for participation in the study:

- Presenting any known disease likely to limit life expectancy to less than 24 months
- Presenting other factors suggesting inability to comply with study protocol
- Cervical cancer diagnosis prior to time of inclusion
- Known vaginal or cervical infection besides HPV at time of inclusion

- Presenting any condition or major comorbidity that the study investigators believed would compromise the patient's ability to comply with the requirements of the study

Data collection

The participants were interviewed by a nurse according to a standardized questionnaire (appendix 1 and 2), available in English, French and Kinyarwanda, regarding demographic data, *i.e* age, educational level, occupation, marital status and current partner, number of live births; sexual history, including number of sexual partners, previous sexually transmitted diseases, and use of contraceptives; and questions regarding previous cervical screening. After this the patients underwent a pelvic examination by the study physician, and sampling from the cervix for HPV screening and cytology was performed.

Analysis:

I processed the data regarding previous screening and reasons for choosing or not choosing to screen in SPSS with descriptive statistics and presented in tables and charts according to cohort.

The data regarding previous screening was also processed with binary logistic regression in SPSS and presented as odds ratios adjusted for age, education and number of live births.

Ethics

The study was approved by the Ethical Review Board of the University of Gothenburg and the University of Rwanda. Participation in the study was voluntary. Patients were provided with both written information in English, French and Kinyarwanda, as well as information given orally via medical staff at the hospital in their preferred language. The information given included information about the study, its aims and how the data would be used. It was possible to withdraw from the study at any time without stating a reason for it. The patients were also informed about the confidentiality policy and the handling of collected data.

Results

General and Demographics:

In total answers from 400 women included at the start of the larger study were collected, *i.e.* 200 at the HIV clinics and 200 recruited at the gynaecological clinics. The demographic data is presented in *table 1*. Worth noting is that 111 of 200 women recruited at the gynaecological clinic were under the age of 40, while 159 out of 200 women recruited at the HIV clinic were over the age of 40. Regarding marital status 113 out of 200 women in the HIV cohort were widowed, while 25 women in the gynaecological cohort gave the same answer. Furthermore, 94 of 200 women in the gynaecological cohort worked in farming, while the corresponding figure in the HIV cohort was 7 women, whereas 129 women in the HIV cohort answered “other” when asked of their occupation, as compared to 15 in the gynaecological cohort.

Previous screening:

All 400 women answered the questionnaires, and 70 gave a positive answer to the question “Have you ever been screened for cervical cancer” (*Table 1*) giving a previous screening

percentage of 17.5% in the entire study population. Of these 57 women, or 81.4% of the previously screened population had been recruited at the HIV clinic and 13, 18.6%, at the gynaecological clinic (*Table 2*), giving the HIV group a significantly higher previous screening rate than the women recruited at the gynaecological clinic, with an odds ratio of 5.5 ($p < 0.001$) when adjusted for age, education and number of live births. None of these other factors had significant odds ratios in the adjusted model though. (*Table 3*).

Reasons for previous screening:

Women had been screened due to recommendation from doctors. This was particularly the case for the HIV cohort. 54 women (77.1 % of the positive respondents), of which more than 90% belonged to the cohort from the HIV clinics, stated this as their reason for previous screening. 13 women said that they had “decided on their own”, with 7 respectively 6 respondents in the gynaecological cohort and the HIV cohort. Only 3 had been advised by a friend (*table 4*)

Reasons for not having previously screened:

Of the 330 who had not previously been screened 2 women did not answer the question of why they had not been screened. 57.6% stated that their reason for not having been screened was that they “did not know about it”. 62.6% of the gynaecology cohort gave this answer, whereas 37.4% of the women in the HIV positive cohort did the same. Fifteen percent of the negative respondents stated that they had no money to pay for the screening, with a higher frequency in the HIV cohort. Women also stated that they did not know where to be examined (12.5%), did not think screening was necessary (9.8%), and 4.3% stated fear of the outcome of the test as their main reason for not having screened before (*table 5*)

Tables:

Table 1: Demographic data on the participating women in numbers and percent according to cohort.

Variable	Cohort			
	Gynaecological clinic		HIV clinic	
	Number	Percentage(%)	Number	Percentage(%)
<i>Age in years</i>	<i>(n=200)</i>		<i>(n=200)</i>	
<30	27	13.5	3	1.5
30-39	84	42	38	19
40-49	62	31	90	45
>50	27	13.5	69	34.5
<i>Education</i>	<i>(n=200)</i>		<i>(n=200)</i>	
None	12	6	17	8.5
Primary school	87	43.5	87	43.5
Secondary school	54	27	62	31
University	45	22	17	8.5
Other	2	1	17	8.5
<i>Current marital status</i>	<i>(n=200)</i>		<i>(n=200)</i>	
Married	132	66	66	33
Male partner, unmarried	19	9.5	1	0.5
Separated/divorced	12	6	14	7
Widow	25	12.5	113	56.5
Single	11	5.5	5	2.5
<i>Occupation</i>	<i>(n=200)</i>		<i>(n=200)</i>	
Farming	94	47	7	3.5
Civil servant	19	9.5	19	9.5
Businesswoman	34	17	36	18
Health worker	31	15.5	-	-
Student	5	2.5	-	-
Other	15	7.5	129	64.5
Unemployed	2	1	9	4.5
<i>Number of live births</i>	<i>(n=197)</i>		<i>(n=200)</i>	
None	25	12.7	8	4
1-3	101	50.3	103	51.5
>4	71	36	89	44.5

Table 2: Number and percentage of women previously screened for cervical cancer

Cohort	Have you ever been screened for cervical cancer?				Total number of women
	Yes		No		
	Number	Percentage (%)	Number	Percentage (%)	
Gynaecological clinic	13	6.5	187	93.5	200
HIV clinic	57	28.5	143	71.5	200
Total study population	70	17.5	330	82.5	400

Table 3: Unadjusted and adjusted odds ratios for likeliness to screen for cervical cancer confounding factors: age, education and number of live births

	Unadjusted		Adjusted	
	OR (95% CI)	P-value	OR(95% CI)	P-value
<i>Cohort</i>				
Gynaecological	Reference	-	Ref.	-
HIV clinic	5.7 (3.0-11)	<0.001**	5.5 (2.7-11)	<0.001**
<i>Age</i>				
<30	Ref.	-	Ref.	-
30-39	8.6 (1.1-67)	0.039*	2.1 (0.24-18)	0.51
40-49	2.1 (1.0-4.4)	0.041*	1.1 (0.45-2.5)	0.91
>50	1.1 (0.60-2.1)	0.73	0.96 (0.49-1.9)	0.90
<i>Education</i>				
None	Ref.	-	Ref.	-
Primary school	2.9 (0.69-12)	0.15	2.0 (0.44-8.9)	0.37
Secondary school	2.1 (0.75-6.0)	0.16	1.4 (0.45-4.1)	0.58
University	2.2 (0.75-6.5)	0.15	1.4 (0.46-4.3)	0.55
Other	2.2 (0.82-9.0)	0.10	1.0 (0.28-4.0)	0.95
<i>Live births</i>				
None	Ref.	-	Ref.	-
1-3	8.9 (1.2-68)	0.034	5.4 (0.64-45)	0.12
>4	1.5 (0.86-2.5)	0.17	1.4 (0.77-2.5)	0.27

*: P<0.05

** : P<0.001

Table 4: Numbers and percentages of reasons for previous cervical cancer screening

Reason for previous screening	Cohort					
	Gynaecological clinic		HIV clinic		All women previously screened	
	Number	Percentage (%)	Number	Percentage (%)	Number	Percentage (%)
Doctor's request	5	38.5	49	86	54	77.1
Own decision	7	53.8	6	10.5	13	18.6
Recommendation from a friend	1	7.7	2	3.5	3	4.3
Total	13	100	57	100	70	100

Table 5: Numbers and percentages of reasons for never having screened for cervical cancer

Reason for never having screened	Cohort					
	Gynaecological clinic		HIV clinic		All women never screened	
	Number	Percentage (%)	Number	Percentage (%)	Number	Percentage (%)
Did not know about it	119	63.3	71	49.7	190	57.6
No money to pay	12	6.4	37	25.9	49	14.8
Don't know where to go	26	13.9	15	10.5	41	12.4
Unnecessary	21	11.2	11	7.7	32	9.7
Fear of outcome	5	2.7	9	6.3	14	4.2
Fear of painful examination	1	0.5	-	-	1	0.3
Other	1	0.5	-	-	1	0.3
Missing	2	1.1	-	-	2	0.6
Total	187	100	143	100	330	100

Discussion

General discussion

Our results showed a previous screening percentage of 17.5% in the entire study population and 6.5% respective 28.5% in the gynaecological and HIV clinic cohorts. The most frequently named reason for previous screening was advice from a doctor whereas the most stated reason for not having been screened was unawareness of the possibility.

The number of women who had previously been screened for cervical lesions was low.

However, when splitting the results according to cohort, most of the previously screened women belonged to the HIV clinic cohort, whereas only 6.5% of the women in gynaecological clinic cohort had been screened. Certain demographic factors, such as age and education differed a largely between the groups, acting as possible confounding factors, but when adjusting for some of these factors, a comparison between the two groups still gave a significant higher odds ratio in the cohort recruited at the HIV clinic (*table 3*) whereas none of the other factors in the model gave a p-value <0.05 in the adjusted model. Thereby the enrolment at an HIV clinic can be seen as a beneficial factor for likeliness to screen for cervical cancer. The factors that could not be adjusted for in the model were occupation and marital status. The categories used to define occupation did not convey information on the socio-economic situation of the participants, which would have been more interesting to have access to in the analysis, and was thus excluded. The marital status however has been seen as a factor which may influence the decision-making of whether or not to screen in other studies and would have been interesting to adjust for, especially as the cohorts differed substantially in this aspect.

By far the most frequently stated reason for having participated in cervical screening prior to inclusion in the main study was to have been recommended to do so by a doctor; 77.1% of women with previous screening experience gave this answer. This was most common in the HIV cohort, suggesting that the HIV patients' increased contact with health care professionals makes them likelier to make use of cervical screening possibilities. Similar results have been seen in other African studies. One Gabonese study stated that also there, the main reason women screened for cervical cancer was their doctor's recommendation (25). A Kenyan study saw a significant association between duration of HIV diagnosis and both knowledge and acceptance of cervical screening, stating that this likely was due to the HIV patients' increased access to health education (28). This indicates that a continuous health care contact is beneficial for the patient's likeliness to screen for cervical lesions.

A majority of the women who had not been screened before stated that their main reason for not having done so was that they did not know about it. This points to a lack of knowledge of the importance to screen in Rwandan society. Little or no data is published on this topic in Rwanda, though studies from neighbouring countries support that lack of knowledge of cervical cancer screening is common in the region (22, 23, 27)

Financial issues for not being screened was particularly common in the HIV cohort.

Cervical cancer screening is free in Rwanda, but still about 25% of the women in the HIV cohort stated that they could not afford it as their reason for not having screened.

Among the women in this population, few were worried about the examination itself or the results it might bring.

No major, more complex or in-depth conclusions regarding the reasons for Rwandan women to partake in cervical cancer screening can be made from the results above. Tendencies can,

however, be seen in the answers, such as that a majority of the participating women had not been screened for cervical lesions and were unaware of their possibility to do so, in spite of Rwanda's explicit goal of having eradicated cervical cancer by 2020 (29). It is also notable that 14.9 % of the women who had not screened had refrained from doing so based on not having the money to pay for the test, even though cervical cancer screening is free in Rwanda. This could however also be attributed to lack of screening facilities and the need to pay for travel to be able to screen and not necessarily lack of knowledge of free screening. Generally though, our results point to a problem in raising the screening rates being the low knowledge of the procedure and its availability among eligible women.

This is further supported by the higher percentage of women having previously been screened for cervical cancer in the cohort enrolled at the HIV clinic compared to the women recruited at the gynaecological clinics, as well as that a majority of the women who had been screened before had done so at request from their doctors. The higher number in the group enrolled at the HIV-clinic is most likely due to the steady health care contact these women have compared to the general female Rwandan population. Moreover, the awareness of the risk of developing cervical cancer among women with HIV, may also be higher than in the population in general.

However, only 28.5% of the women recruited at the HIV clinic had been screened for cervical lesions, and 37.6% of the women in the cohort still stated that they were unaware of cervical cancer screening. This indicates that even these established contacts do not guarantee proper information about the necessity of cervical cancer screening.

One possibility could be to educate healthcare professionals in general about inquiring and informing their patients of cervical screening and urge them to be screened. This “opportunistic screening” seems to be effective, judging from this being the clearly most frequent reason for the women in both this and other studies in Sub-Saharan Africa to have been screened before (24). This would also be a possible opportunity to register participation in the cervical cancer screening in order to properly evaluate the screening programme and improve it. Considering Rwanda’s very ambitious comprehensive cervical cancer programme, the lack of data on the programme and on awareness of the disease in the population should be a cause of concern, as lack of knowledge of the availability of screening possibilities is a clear barrier to its generalised practice (27).

Thus cervical cancer is still an important health issue in Rwanda, even though efforts have been made to decrease its impact on the country, including the successful vaccination programme.

Limitations:

This master thesis is based on data collected from questionnaires that did not have the main objective to assess the attitudes of Rwandan women to cervical cancer screening, meaning that questions that could have given a deeper understanding of the attitudes investigated were not asked. However, the present data indicates the importance to further assess attitudes of Rwandan women to cervical cancer screening in the future.

Another limitation is that the gynaecological cohort was mainly “recruited” through word of mouth from other participants and thus cannot be assumed to be a representative sample of

the female Rwandan population. However, how quickly this cohort was filled indicates a willingness among Rwandan women to screen if aware of the possibility.

Also the cohorts differed in composition regarding demographic factors such as age, education, marital status, number of live births and employment, which could act as confounding factors. However, the statistical model would not allow for adjustment for all of them, and therefore the adjusted results have to be regarded with this in mind, even if the statistical analysis that could be performed showed a very strong, statistically significant correlation between screening frequency and being enrolled at an HIV clinic.

Conclusion

My master thesis has begun to examine the attitudes to cervical screening among Rwandan women, finding that only 17.5% of women studied had previously been screened for cervical lesions, with five times higher screening rate for women enrolled at an HIV clinic as compared to patients recruited from a gynaecological clinic. The main reason for the low screening numbers seem to be lack of knowledge about cervical cancer screening, but little data exist on the matter. A study regarding the knowledge of cervical cancer, its causes and screening should therefore be performed among Rwandan women, as has already been done in many other Sub-Saharan countries with similar figures in prevalence and mortality, to further support the building of a future well-functioning cervical cancer screening programme in Rwanda.

Populärvetenskaplig sammanfattning: Rwandiska kvinnors inställning till livmoderhalscancerscreening

Detta examensarbete genomfördes som del i ett större projekt om HPV-infektioner hos hivpositiva och -negativa rwandiska kvinnor och hade som mål att undersöka rwandiska kvinnors inställning till livmoderhalscancerscreening. Detta ansågs viktigt då det är välkänt att screening kraftigt minskar antalet nya fall och dödligheten i livmoderhalscancer, då man kan hitta cellförändringar på ett tidigt stadium och behandla dessa innan de har utvecklats till cancer.

I Rwanda är livmoderhalscancer för närvarande en betydande orsak till sjuklighet och för tidig död och regeringen har påbörjat ett arbete med att bekämpa sjukdomen genom att införa allmän vaccinering av flickor mot högrisk-HPV-virus. Det är dock mer oklart hur det står till med screening i landet, då mycket lite data finns att tillgå på detta område.

I frågeformulären till den större studien efterfrågades bland annat tidigare screeningsfarenhet, och vad som var orsaken till att man hade, eller inte hade, screenat sig tidigare. Dessa svar analyserades och jämfördes sedan mellan de båda kohorterna för att få en bild av screeningsprevalensen bland hivpositiva och-negativa kvinnor. I studien ingick 200 hivpositiva kvinnor, som rekryterades på hivkliniken i på universitetssjukhuset i huvudstaden Kigali, och 200 hivnegativa kvinnor som rekryterades från gynekologiska kliniker på universitetssjukhusen i Kigali och Butare i landets södra del.

Våra resultat visade att endast 17.5% av kvinnorna i studien tidigare hade screenat sig. Om man tittade kohortvis var det mycket vanligare att ha screenat sig i den hivpositiva gruppen än i den hivnegativa. Den vanligaste anledningen kvinnorna angav till att ha screenat sig var att deras läkare hade rått dem att göra det. Också detta var vanligare bland de hivpositiva

kvinnorna. Den vanligaste orsaken till att inte ha screenat sig var att man inte kände till möjligheten att screena sig för livmoderhalscancer, följt av att det var för dyrt och att man inte visste vart man skulle vända sig för screening.

Den högre screeningfrekvensen i hivkohorten och att den främsta screeningorsaken var råd från läkare tolkas som att kontinuerlig kontakt med vård är en gynnsam faktor för screeningbenägenhet. Bristen på kunskap om livmoderhalscancerscreening får ses som ett problem för att få upp screeningfrekvensen i Rwanda. Dock skulle mer detaljerade studier för att kartlägga kunskap och attityd behöva göras för att få en helhetsbild av problematiken och vad som kan göras för att förbättra screeningdeltagandet i landet. .

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Appendix 1 – Questionnaire cohort 1

Cohort 1: Women seeking voluntarily a cervical cancer-screening test /*Itsinda rya 1: Abagore basa gusaba gukorerwa isusumwa rya cancer y'inkondo y'umura ku bushake bwabo*

Questionnaire identification number/*Umubare uranga ifishi y'ibibazo mu bushakashatsi* | _ | _ | _ | _ |

Participant Identification number in the study/*Umubare uranga uwagize uruhare mu gusubizo* _ | _ | _ |

Interviewer Name /*Amazina Y'ubaza*.....

Interview Date /*Italiki y'ibazwa*

| _ | _ | | | _ | | | _ | _ | | _ |

Day/*Umunsi* Month /*Umunsi* Year/*Umwaka*

I will ask some questions that will be recorded in this notebook. I must say that all the lady answering the interview will be strictly confidential, and the information gathered from various women participating in the study will be used only in scientific reports, without personal identification. /*Nguye kukubaza ibibazo maze ibisubizo byandikwe muri aka gatabo. Ndakwizeza neza ko abari abari muri ubu bushakashatsi bese bazagira ibanga ku bisubizo uri butange kandi ko bizakoresha gusa mu bijyanye n'itege z'ubu bushakashatsi.*

Instructions:

1. For multiple choice question ,encircle correct answer(s)

2. For sort answer questions, fill in gap provided

1. What is your age? /*Ufite imyaka y'amavuko ingaye?* | _ | _ |
2. What is your Highest educational level attained? /*Ni uruhe rwego rwanyuma rw'amashuri warangije? (Hitamo igisubizo kimwe)*
 - a. None/*Ntiyize*
 - b. Incomplete primary school/*Ntiyarangije abanza*
 - c. Complete primary school/*Yarangije amashuri abanza*
 - d. Secondary school incomplete/*Ntiyarangije ayisumbuye*
 - e. Complete Secondary school/*Yarangije ayisumbuye*
 - f. Incomplete University/*Ntiyarangije kaminuza*
 - g. Complete University/*Yarangije kaminuza*
 - h. Others (Specify) /*Ibindi(Sobanura)*.....
3. Occupation/*Umurimo*
 - a. Farming/*Umuhinzi*
 - b. Civil servant/*Umukozi wa Leta*
 - c. Business/*Arikorera Ku giti cye*
 - d. Health worker/*Akora mu buvuzi*
 - e. Others (specify)/*Ibindi (Sobanura)*_____
4. Currently, Mrs. /*Ubu tuvugana Madamu*
 - a. Is married/*Yarashatse/Arubatse*
 - b. Has a male partner but not married/*Afite uwo mubana ku bwumvikane*
 - c. Is separated/divorced/*Yatandukanye n'uwo mwashakanye*
 - d. Is widow/*Ni umupfakazi*
 - e. Is single (never been married or lived with a partner)/*Ni Ingaragu*

Now I would like to ask some questions about your sexual and reproductive lives./*Ubu naho ndashaka ko tuganira ibijyane n'ubuzima bw'imyorokere bwanyu*

5. Have you ever had sexual intercourse?/*Waba warigeze ukora imibonano mpuzabitsina?*
 - a. Yes/*Yego*
 - b. No/*Oya*

If the answer is No, go to question number 10/*Niba igisubizo ari oya, komeza ku kibazo cya 10*

6. At which age in years did you have your first sexual intercourse? /*Waba warakoze imibonanompuzabitsina bwambere ufite imyaka ingahe? _____|_|_|*
7. How many sexual partners have you had in your life? *Watubwira umubare w'abagabo waba warabonye nabo kuva icyo gihe? _____|_|_|*
8. How many live births have you had? / *Waba wibuka umubare w'inda zavutsemo abana bazima? _____|_|_|*
9. How many spontaneous and/or voluntary abortions have you had? *Waba warakuyemo indazingahe? _____|_|_|*
10. Have you had gonorrhea? /*Waba warigeze kurwara y'imitezi?*
 - a. Never/*Nta narimwe*
 - b. Once/*Inshuro imwe*
 - c. More than one time/*Inshuro zirenga imwe*
 - d. I don't know/*Simbizi*
11. Have you had chlamydia? / *Waba wararwaye kalamidia?*
 - a. Never/*Nta narimwe*
 - b. Once/*inshuro imwe*
 - c. More than one time/*Inshuro zirenga imwe*
 - d. I don't know/*Simbizi*
 - e. Other sexually transmitted diseases? (Specify)/ *Izindi ndwara zandurira mu mibonano mpuzabitsina (Sobahura).....*
12. Are you using hormonal contraceptives? *Waba ukoresha imoti iringaniza urubyaro?*
 - a. Yes/*Yego*
 - b. No, not right now but I have used it before. /*Oya ariko nigeze kuyikoresha*
 - c. No, I have never used it. /*Oya sinigeze nyikororsha*
 - d. I don't know/*Simbizi*
13. Do you use intrauterine device? *Waba ukoresha udupira two mu mura mukuringaniza imyaro*
 - a. Yes/*Yego*
 - b. No, not right now but I have used it before./ *Si ubu ariko nigeze kugakoresha*
 - c. No, I have never used it./*Sinigeze ngakoresha*
 - d. I don't know/ *Simbizi*
14. Are you smoker or ever smoked?/*Waba umwa cyangwa warigeze kunywa itabi?*
 - a. No, I have never been a smoker /*Oya ,sinigeze ndinywa*
 - b. Yes, I am currently a smoker /*Yego ndarinywa*
 - c. I am an ex-smoker/*Nigeze kurinywa*

15. Have you ever been screened for cancer of the cervix (if **No** go to question 19)/*Waba warigeze wisuzumisha umbwabdu bwa canceri y'inkondo y'umura? (Niba ari oya jya ku kibazo cya 19)*
- Yes/*Yego*
 - No/*Oya*
16. If Yes why? *Niba ari yego ni iyihe mpamvu yaba yarabiguteye?*
- Doctor's request /*Muganga yarabinsabye*
 - I decided on my own /*Nabifashe mo icyemezo*
 - Advice from friend /*Inshuti yabingiriyemo inama*
 - Others (specify)/*Ibindi (Sobanura)* _____
17. How regularly do you screen? / *Ni iyihe gahunda ihoraho yawe yo kwisuzumisha?*
- Not regularly / *Nta gahunda ihoraho ngira*
 - Every 6 months /*Buri mezi atandatu*
 - Once a year /*Rimwe mu mwaka*
 - Once in two years /*Rimwe buri myaka ibiri*
 - I have screened once and it has been more than 2 years ago now / *Nisuzumishije rimwe gusa ubu hashize imyaka irenga ibiri*
 - Others (specify)/*Ibindi (Sobanura)* _____
18. When was your last Pap smear test/ *Hashije igihe kingana iki wisuzumishije bwa nyuma?*
- Less than 5 years ago/*Imyaka iri muni y'itanu*
 - 5 years ago or more than 5 years ago/*Hashize imyaka itanu cyangwa irenga*
 - I don't know/ *Simbizi*
19. If No, why? / *Niba ari oya ni iyihe mpamvu yabiguteye?*
- I did not know about it / *Ntabwo nzi iyo gahunda*
 - Fear of outcome/ *Ni ugutinya ibisubizo byavamo*
 - I didn't have money to pay / *Nta mafaranga yo kwishyura nari mfite*
 - I didn't know where to go /*Ntabwo nari nzi aho najya*
 - It was not necessary /*Ntabwo byari ngombwa*
 - Other reasons, specify/*Izindi mpamvu sobanura* _____
20. For this visit, what is the reason that pushes you to consult doctor? /*Uyu muni, ni iyihe mpamvu yaba yaguteye kuza kureba muganga?*
- It is in line of my regular check up plan /*Biri muri gahunda yanjye isanzwe yo kwipimisha*
 - It is because of vaginal discharge/*Ni uko nagize amaperite adasanzwe mu gitsina*
 - It is because of pelvic pain /*Ni ukubera ububabare mu kiziba k'inda*
 - It is because of irregular bleeding/*Nagize kuva kudasanzwe*
 - It is because of post coital bleeding/*Ni ukuva nyuma yo gukora imibonan ompuzabitsina*
 - It is because of post menapausal bleeding/*Nagize kuva kandi nari naracuze*
 - Others (Specify)/*Ibindi (Sobanura)* _____

Thank you for your time and effort! /Murakoze Ku gihe n'ubwitange byanyu!

Appendix 2 – Questionnaire cohort 2

Cohort 2/Itsinda rya 2: HIV+ Women /Abagore babana n'ubwandu bwa Virusi itera SIDA

Questionnaire identification number/Umubare uranga ifishi y'ibibazo mu bushakashatsi:|_|

|_| Participant Identification number in the study/Umubare uranga uwagize uruhare mu gusubiza

....._|_|_|

Interviewer Name /Amazina Y'ubaza.....

Interview Date /Italiki y'ibazwa |_|_|_|_|_|_|_|_|_|_|
Day/Umunsi Month /Umunsi year/Umwaka

|_|_|

I will ask some questions that will be recorded in this notebook. I must say that all the lady answering the interview will be strictly confidential, and the information gathered from various women participating in the study will be used only in scientific reports, without personal identification./Ngiye kukubaza ibibazo maze ibisubizo byandikwe muri aka gatabo.Ndakwizeza neza ko abari abari muri ubu bushakashatsi bose bazagira ibanga ku bisubizo uri butange kandi ko bizakoreshwa gusa mu bijyanye n'intego z'ubu bushakashatsi.

Instructions:

- 1. For multiple choice question, encircle correct answer(s)**
- 2. For sort answer questions, fill in gap provided**

1. What is your age?/Ufite imyaka y'amavuko ingaye ?|_|_|
2. What is your Highest educational level attained? / Ni ikihe cyiciro cy'amashuri wize?
 - a. None/Ntiyize
 - b. Incomplete primary school/Ntiyarangije abanza
 - c. Complete primary school/Yarangije amashuri abanza
 - d. Secondary school incomplete/Ntiyarangije ayisumbuye
 - e. Complete Secondary school/Yarangije ayisumbuye
 - f. Incomplete University/Ntiyarangije kaminuza
 - g. Complete University/Yarangije kaminuza
 - h. Others (Specify) /Ibindi.(Sobanura) _____
3. Occupation/Umurimo
 - a. Farming/Umuhinzi
 - b. Civil servant/Umukozi wa Leta
 - c. Business/Arikorera Ku giti cye
 - d. Health worker/Akora mu buvuzi
 - e. Others (specify)/Ibindi (Sobanura) _____
4. Currently, Mrs. /Ubu tuvugana Madamu
 - a. Is married/Yarashatse/Arubatse
 - b. Has a male partner but not married/Afite uwo mubana ku bwumvikane
 - c. Is separated/divorced/Yatandukanye n'uwo mwashakanye
 - d. Is widow/Ni umupfakazi
 - e. Is single (never been married or lived with a partner)/Ni Ingaragu

Now I would like to ask some questions about your sexual and reproductive lives./*Ubu naho ndashaka ko tuganira ibijyane n'ubuzima bw'imyororokere bwanyu*

5. Have you ever had sexual intercourse? /*Waba warigeze ukora imibonano mpuzabitsina?*
 - a. Yes/*Yego*
 - b. No/*Oya*
- If the answer is No, go to question number 10/*Niba igisubizo ari oya, komeza ku kibazo cya 10*
6. At which age in years did you have your first sexual intercourse? /*Waba warakoze imibonano mpuzabitsina bwambere ufite imyaka ingahe?* _____ | _ | _
|
7. How many sexual partners have you had in your life? Watubwira *umubare w'abagabo waba warabonye nabo kuva icyo gihe?* _____ | _ | _ |
8. How many live births have you had? / *Waba wibuka umubare w'inda zavutsemo abana bazima?* | _ | _ |
9. How many spontaneous and/or voluntary abortions have you had? *Waba warakuyemo indazingahe?* _____ | _ | _
10. Have you had gonorrhea? /*Waba warigeze kurwara y'imitezi?*
 - a. Never/*Nta narimwe*
 - b. Once/*Inshuro imwe*
 - c. More than one time/*Inshuro zirenga imwe*
 - d. I don't know/*Simbizi*
11. Have you had chlamydia? / *Waba wararwaye kalamidia?*
 - a. Never/*Nta narimwe*
 - b. Once/*inshuro imwe*
 - c. More than one time/*Inshuro zirenga imwe*
 - d. I don't know/*Simbizi*
 - e. Other sexually transmitted diseases? (Specify) / *Izindi ndwara zandurira mu mibonano mpuzabitsina (Sobahura).....*
12. Are you using hormonal contraceptives? *Wana ukoresha imoti iringaniza urubyaro?*
 - a. Yes/*Yego*
 - b. No, not right now but I have used it before. /*Oya ariko nigeze kuyikoresha*
 - c. No, I have never used it. /*Oya sinigeze nyikororsha*
 - d. I don't know/*Simbizi*
13. Do you use intrauterine device? *Waba ukoresha udupira two mu mura mukuringaniza imyaro*
 - a. Yes/*Yego*
 - b. No, not right now but I have used it before. / *Si ubu ariko nigeze kugakoresha*
 - c. No, I have never used it. /*Sinigeze ngakoresha*
 - d. I don't know/ *Simbizi*
14. Are you smoker or ever smoked? /*Waba umwa cyangwa warigeze kunywa itabi?*
 - a. No, I have never been a smoker /*Oya, sinigeze ndinywa*
 - b. Yes, I am currently a smoker /*Yego ndarinywa*
 - c. I am an ex-smoker/*Nigeze kurinywa*

15. Have you ever been screened for cancer of the cervix (if **No** go to question 19)/*Waba warigeze wisuzumisha umbwabdu bwa canceri y'inkondo y'umura? (Niba ari oya jya ku kibazo cya 19)*
- Yes/*Yego*
 - No/*Oya*
16. If Yes why? *Niba ari yego ni iyihe mpamvu yaba yarabiguteye?*
- Doctor's request /*Muganga yarabinsabye*
 - I decided on my own /*Nabifashe mo icyemezo*
 - Advice from friend /*Inshuti yabingiriyemo inama*
 - Others (specify)/*Ibindi (Sobanura)* _____
17. How regularly do you screen? / *Ni iyihe gahunda ihoraho yawe yo kwisuzumisha?*
- Not regularly / *Nta gahunda ihoraho ngira*
 - Every 6 months /*Buri mezi atandatu*
 - Once a year /*Rimwe mu mwaka*
 - Once in two years /*Rimwe buri myaka ibiri*
 - I have screened once and it has been more than 2 years ago now / *Nisuzumishije rimwe gusa ubu hashize imyaka irenga ibiri*
 - Others (specify)/*Ibindi (Sobanura)*-----
18. When was your last Pap smear test/ *Hashije igihe kingana iki wisuzumishije bwa nyuma?*
- Less than 5 years ago/*Imyaka iri munsu y'itanu*
 - 5 years ago or more than 5 years ago/*Hashize imyaka itanu cyangwa irenga*
 - I don't know/ *Simbizi*
19. If No, why? / *Niba ari oya, ni iyihe mpamvu yabiguteye?*
- I did not know about it / *Ntabwo nzi iyo gahunda*
 - Fear of outcome/ *Ni ugutinya ko ibisubizo byavamo*
 - I don't have money to pay / *Nta mafaranga yo kwishyura nabona*
 - I don't know where to go /*Ntabwo nzi aho najya*
 - It is not necessary /*Ntabwo ari ngombwa*
 - Other reasons, specify/*Izindi mpamvu sobanura* _____
20. How long has it been since you were diagnosed with HIV infection? /*Hashize igihe kingana iki bagusuzumye mo Virusi itera SIDA?*
- Less than 1 year/*Nta mwaka urashira*
 - 1-3 years/*Umwaka umwe kugeza kuri itatu*
 - 4-6 years/*Imyaka ine kugeza kuri itanu*
 - More than 6 years/*Imyaka irenga itandatu*
21. Are you under antiretroviral treatment? *Uri ku miti irwanya ubwandu bw'agakoko gatera SIDA?*
- Yes /*Yego*
 - No/*Oya*

If yes, for how long, in months? /*Niba ari yego haba hashize igihe kingana iki (Mu mezi)?*

Is it ok that we contact your physician for information on your HIV staging, CD4 counts and viral load? / *Urumva ntacyo byaba bitwaye umuganga wawe aduhaye amakuru ku kigero cy'ubwandu ugezeho, umubare w'abasirikare ufite no k'umubare wa virusi ufite?*

- ï Yes/*Yego*
- ï No/*Oya*

Name of your physician and clinic/*Amazina y'umuganga wawe* _____

Thank you for your time and effort! / *Murakoze Ku gihe n' ubwitange byanyu*

To be completed by a physician from patient file / *Byuzuzwa n'umuganga*

22. Patient's HIV Clinical staging _____

23. CD4 + Count

(cells/ dl) c. <
200

d. 200-500

e. > 500

24. HIV viral load

(copies/ml) f. <
400

g. 400-5000

h. >10000

25. ARVS treatment :

- a.
- b.
- c.
- d.

