



# When Shame Kills: Cervical Cancer and Fear of the Vulva

By Nelly Madegwa



Through the blinds, a dull gleam illuminates the room. The tension in my shoulders begins to dissipate as I sit down to go through a pre-counseling session before my pap smear. I made the decision of having the test done early this year, though it's taken months to actualize it. I have made two appointments and cancelled them both. The first time was because I hadn't timed the appointment correctly - you are supposed to have a pap smear about two weeks after the start of your last period and I wasn't in that time frame. The second time I just couldn't go through with it; having gone through sexual assault in the past, the test was intimidating and I was afraid to stir up old ghosts.

For months I was trapped by indecision. From what I had read about the pap smear tests, there is nothing graceful about it, but I knew it was important to have it done. Finally I showed up for my third appointment.

I was oblivious of my vulva until the age of 20; I mean, I knew it was there but I really didn't think about it, or my reproductive system in general, except through feelings of shame. In school we are taught about our reproductive system but usually teachers just want to get through the material and don't want to answer questions, and so becomes relegated to a kind of blurry knowledge - sort of familiar yet without certainty.

That year I was 20, a friend shared a TED talk video and something the speaker said stuck with me, (I'm paraphrasing) *women always feel they owe someone their beauty, their sexuality and body, but they never own it; we are the stewards of our bodies, not its beneficiaries* - a truth I could identify with. I wanted to reclaim that for myself and I had to start somewhere. But I had many layers to shed - the fear, and shame, most of it irrational, that my body, my vulva especially, was somehow gross and shameful. This is a reality for many, if not most women. These fears were heightened by the fact that I had been sexually assaulted some time in the past.

When I was setting up the appointment for the third time, I made sure I was very specific that my preference was a female medical officer, though I did not divulge why and they assured me that it's okay. I got to the hospital just a few minutes past noon, though I was up way earlier. I had spent most of that morning juggling between thoughts like *does my vulva look right* and *am I really ready to have a stranger look at it*. The sun was blazing that morning as I walked to the hospital, which made the walk seem even longer; a part of me wanted to back out, but somehow I made it there - anxiety, nerves and all.

In the waiting room, a medical officer asked me what brought me in, and when I told her I wanted a pap smear she seemed startled, but quickly cloaked it with a smile. She explained that women my age rarely voluntarily come for screening unless when mandated by a doctor. There was no queue ahead of me so I walked into the doctor's office. After the usual introductions she also asks me if I have been referred by a doctor. I tell her I haven't, but she doesn't make a big deal about it. She goes on to brief me on the things I need to know - a pap smear is not a test for cancer but a test that can detect abnormal cells that could result into cervical cancer. So if abnormal cells are detected, then they could be treated to prevent cancer from developing.

I am led to a space behind a curtain and asked to lie down. The doctor puts a pillow behind my back and tells me to place my feet on peddle-like structures so that my legs are raised and apart. I'm telling you, there is no more vulnerable position for a woman than on her back with her legs open, and this reality sinks deep even as I try to find something to focus on to distract myself. I have this powerful desire to run away, or to disappear.

She says it will be *just uncomfortable* - the famous phrase doctors use to understate pain. She gets the speculum, the device they insert into the vagina in order to view the cervix and keep it open. She tells me a cotton wool-tipped brush will then be used to collect cells from the inside the opening of the cervix. The cervix connects the vagina and the uterus; its function is to produce cervical mucus that changes in consistency during the menstrual cycle to prevent or promote pregnancy. It also acts as a physical barrier between the vaginal canal and the uterus.

*Are you ready?* she asks. Of course I wasn't, but what can one say at that moment? I had come this far. I know doctors and nurses have seen it all, yet this does little to abate my nerves. I focus on my breathing to relax the muscles; she says this will ease the discomfort. I mention the assault just as she is about to insert the speculum. She empathizes, promises to be gentle and tells me to forgive and forget. I start thinking about that, forgiving and forgetting, and while engrossed in my thoughts I barely notice when she starts inserting the speculum. She's patient and gentle though it all. I keep apologizing what the waves of anxiety hit me; she listened to me and made me feel very safe. When it is all over she tells me that there can be three results - "normal" which means negative for abnormal cells, "inadequate" meaning the cells could not be viewed and so another sample is required within a period of three months, and "positive" to indicate presence of abnormal cells which could be mild, moderate or severe.

The test results were negative, and that was not the only thing I was thankful for. I was grateful for having such a patient and understanding doctor, she made me feel comfortable to ask questions and

it never felt like a fuss to her.

According to GLOBOCAN 2018, Kenya has a population of 13.45 million women aged 15 years and older who are at a risk of developing cervical cancer. The current estimates indicate that every year 5,250 women are diagnosed with cervical cancer, and 3,286 die from the disease. Cervical cancer is rated as the second most frequent cancer among women in Kenya, and leading cancer among women between ages of 15 and 44 years. About 9.1% of women in the general population are approximated to harbor HPV-16/18 infections. The human papillomavirus accounts for 99.7% of all cervical cancer and HPV is sexually transmitted. But it is treatable and can be vaccinated against thus greatly reducing incidence of cervical cancer. The current estimates are that only 12% of the population at risk have gone through screening and contributes greatly to the high mortality rate. Screening allows for treatment in the asymptomatic precancerous stage; early treatment is highly effective. At the advanced stage - when most diagnoses in Kenya are done - treatment is difficult and expensive, the chances of cure are low.

In my native language, there is no word for cervix; even the words that do exist for the female reproductive system have been sexualized making it clear that the female body is seen from a male gaze. Women too have internalized this objectification; the language used in reference to the vagina or vulva is made to seem vulgar making it a very uneasy conversation to have with someone who is not literate. Even for those who are educated, it is still uncomfortable as we are taught to regard parts of our bodies as 'bad manners'. We grow up embarrassed, fearful and ashamed of ourselves and at no point is there a shift to include these parts of our bodies in conversations, even as we mature.

Language is extremely important especially when you need people to focus on a particular issue. The flippant way the female reproductive system is regarded is a huge problem. There is also the culture of how slow or apprehensive we are about prevention mechanisms, which include medical checkups. We have been socialized to only go to health facilities when you are feeling unwell and so if you consider yourself healthy, most of us think it is unnecessary to go for a screening. But the reality is that a checkup could save your life, as most of the life-threatening diseases when detected in asymptomatic stages can be treated and cured.

For women especially, our bodies remain mysterious, with some parts regarded as gross, leaving us anxious about how we look in them rather than how we feel in them. You will think with a generation that grew up with the wave of body positivity and empowerment, the percentage of women between the ages of 25-35 years going for screening will be the highest; sadly the opposite is true.

Any woman who has ever had sexual intercourse is eligible for an annual pap smear; the target population for screening is women aged 25 to 49 years. Older women aged 50 - 65 years are still at risk of cervical cancer and can therefore receive screening every five years, according to Kenya National Cancer Screening Guidelines 2018. The success of a screening program depends on its achieving adequate coverage, in this case of 70% of women nationally. But a majority of women I talked to had no clue where these services are being offered or what the costs are. As I was preparing for my pap smear I discovered that the tests are available in all public health facilities at no cost, though I was very fearful of getting the test done in a public hospital due to the disrepute of services rendered.

The truth is you do not wake up one day and suddenly have a new appreciation for your body. It is a process and some of your perceived flaws would probably never go away; it is only when you embrace them that they stop lurking in the shadows and consuming you. You might think you are alone in battling insecurities, but we all go through it. The wall that goes up in the fight against screening for cervical cancer will come down when we overcome perceptions and attitudes about

our bodies.

The test is definitely one of the least preferable things I have done, it was anxiety inducing and uncomfortable. But I would do it again because I know those few minutes could save my life. There are so many ways to make the test easier, you could go with a friend to hold your hand, ask for a smaller speculum to be used, or a plastic instead of a metal speculum. You could speak up when is too uncomfortable or painful, have a session before you have the test and have your concerns addressed, bearing in mind no concern is too silly or small. Ultimately we have to re-examine our relationship with our bodies, so that women can stop dying of ignorance and fear.

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