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Dispelling myths around cervical cancer screening

By Ruth Ayisi

The story of Mary

Forty-year-old Mary¹ went for cervical cancer screening too late. She had already developed symptoms and cancer had spread to her uterus. The only option was for Mary to have a hysterectomy. But Mary, who had been trying to start a family for 10 years, could not accept this. Last November, she died. Her story is common in Malawi.

Background

Cervical cancer, caused by certain strains of the human papillomavirus virus (HPV), is one of the most preventable and treatable forms of cancer. Some high-income countries are even heading towards cervical cancer elimination in the next decades.

Although every girl or woman who is sexually active will become infected with HPV, most strains are benign and will not harm people with healthy immune systems. Even if the strain develops into cervical cancer, it can be treated if the cancerous cells are detected early and managed well. The main treatment at this stage would be cryotherapy – the freezing of the abnormal cells so normal ones can grow back.²

Yet cervical cancer is still the fourth most common cancer among women globally. There were about 604,000 new cases and 342,000 deaths in 2020.³ An estimated 90 per cent of those new cases and deaths worldwide were in low- and middle-income countries.⁴

Cervical cancers rates are even increasing in some sub-Saharan African settings.⁵ All but one of the 20 countries with the highest caseload of cervical cancer in the world are in Africa.⁶ This is mainly due to inadequate screening and treatment services for precancerous lesions, late diagnosis, limited access to timely and quality treatment, and high HIV prevalence.⁷

Many studies show a strong link between HIV and cervical cancer. According to the World Health Organization (WHO), women living with HIV are six times more likely to develop cervical cancer compared to women not living with HIV.⁸ A Lancet study (2020) found that in Southern Africa, over 60 per cent of women with cervical cancer were also living with HIV.⁹ In addition, a study in Botswana of women living with HIV who also had a cervical cancer diagnosis were more likely to die from cervical cancer compared to women without HIV infection even after adjusting for relevant variables, such as disease stage.¹⁰

1. Not her real name

2. <https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/other/cryotherapy>

3. <https://www.who.int/news-room/fact-sheets/detail/cervical-cancer>

4. *ibid*

5. Estimates of the global burden of cervical cancer associated with HIV. Stelze D et al., 2020.

6. <https://www.afro.who.int/health-topics/cervical-cancer>

7. *ibid*

8. <https://www.who.int/news-room/fact-sheets/detail/cervical-cancer>

9. Stelze D et al. Estimates of the global burden of cervical cancer associated with HIV. 2021; 9 e161-69

10. Dryden-Peterson S et al. HIV infection and survival among women with cervical cancer. *J Clin Oncol* 2016. 34: 3749-57

Data Box

Many studies show a strong link between HIV and cervical cancer.



Over 60%

of women with cervical cancer were also living with HIV in Southern Africa.

A Lancet study (2020)



About 1.72 million

adolescents (15-19 years) are living with HIV in the region, **representing 60 per cent** of the global total.



Malawi

has one of the world's highest HIV prevalence rates with an estimated **10.7 per cent of adults aged 15-49** living with HIV, that is around **2 million people**.

In 2020, the World Assembly adopted a global strategy towards eliminating cervical cancer as a public health concern. The strategy recommends a comprehensive response to cervical cancer and control; this includes community education, social mobilization, vaccination, screening and treatment and palliative care.¹¹

In light of the association between cervical cancer and HIV, cervical cancer prevention and treatment programmes in the eastern and southern African region need to address the relatively high HIV prevalence rates. Yet despite huge progress in addressing HIV in the region, the HIV prevalence rates continue to be high compared to the rest of the world. About 1.74 million adolescents (15-19 years) are living with HIV in the region, representing 60 per cent of the global total. Furthermore, of particular concern especially in light of the cervical cancer research, adolescent girls and young women (15-24 years) comprise 26 per cent of all new HIV infections in the region.¹²

This case study highlights recent efforts to mobilise girls and women in remote rural areas in Malawi for early cervical cancer screening, which is one of the most effective ways to prevent cervical cancer.

Malawi has one of the world's highest cervical cancer

incidences with an age-standardized rate

(ASR)¹³ of 75.9 per 100,000.¹⁴ The median survival period from the time of a cervical cancer diagnosis is 10 months.¹⁵ This translates into the highest mortality related to cervical cancer, with 51.5 deaths per 100,000 every year. This is twice the rate in Eastern Africa (28.6 deaths per 100,000 every year) and seven times the global rate (7.3 deaths per 100,000 every year).¹⁶ Malawi also has one of the world's highest HIV prevalence rates with an estimated 10.7 per cent of adults aged 15-49 living with HIV, that is around 2 million people.¹⁷

Research in the past has suggested that myths, fears and male attitudes are among the main barriers to cervical cancer screening in Malawi. Men are reluctant to allow women to be screened for cervical cancer, particularly if the health worker is male. Moreover, many women are scared as they hear rumours that the screening is painful and dangerous involving large instruments that could cause infertility. Other women are discouraged as they hear that health workers are sometimes impatient and also, due to the workload, send women away telling them to return another day for the cancer screening service.¹⁸

11. <https://www.who.int/news-room/fact-sheets/detail/cervical-cancer>

12. UNAIDS 2021 Estimates. <https://aidsinfo.unaids.org/>

13. The age-standardized rate is a rated mean of the age-specific rates where the weights are taken from the population distribution of a standard population. It is calculated by dividing the total number of expected cases by the total population size.

14. The median survival rate refers to the length of time from the date of diagnosis that half of the patients diagnosed with cervical cancer are still alive.

15. Keliya Msyamboza et al. Cervical cancer screening uptake and challenges in Malawi from 2011 to 2015: 2016 retrospective cohort study. 16; 806.

16. <https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-022-12547-9>

17. UNAIDS 2021 Estimates. <https://aidsinfo.unaids.org/>

18. <https://doi.org/10.1016/j.pmedr.2020.101093>

Creating demand for cervical cancer screening

In 2018, four UN organizations, in partnership with the Swedish International Development Cooperation Agency (Sida), launched the 2gether 4 SRHR four-year programme¹⁹ to improve integrated sexual and reproductive health and rights (SRHR) in eastern and southern Africa. For women and girls, this means accessing cervical cancer screening on the same day as they access a package of other quality SRH services, including family planning, HIV testing and, if needed, services for gender-based violence (GBV).

As part of this programme, the Ministry of Health collaborated with two non-governmental organizations – the Coalition of Women Living with HIV/AIDS (COWLHA) and the Coalition for the Empowerment of Women and Girls (CEWAG) – to reach girls and women (aged 15-49) with cervical cancer screening in remote rural communities in the districts of Mangochi, Nkhatabay and Mulanje.

“We engaged traditional and religious leaders as they have a powerful voice, creating an enabling environment and pushing up demand for cervical cancer screening,” says Edna Tembo, the Executive Director of COWLHA.

Outlining the process of the mobilization campaign, Edna Tembo, the Executive Director of COWLHA, said they first involved high-level government officials from the Department of Reproductive Health and then set up an advisory committee of eight women living with HIV. Afterwards, the advisory team had meetings with the District Health Committees and District Executive Committees. From there, they visited the rural communities where the team met with Area Development Committees which comprise of the chiefs and the councillors in the districts.

As shown in previous research, initially the team found the main obstacles to overcome were myths, fears, male attitudes and the distance to the health centre. The team also found that men were reluctant to allow women to be screened for cervical cancer, particularly if the health worker was male. Additionally, as in previous research, many women were scared as they heard rumours that the screening was painful and dangerous involving large instruments that they thought could cause infertility.²⁰ The women had also been discouraged as they heard that health workers sometimes sent women away telling them to return another day for the cancer screening service. In addition, the men argued that they felt prostate cancer was being ignored. The team explained that this campaign was focussing on cervical cancer others will take up prostate cancer, and they explained what cervical cancer is, what the women will experience and the benefits of the screening.

The team used a selection of the most appropriate communication materials for the rural communities which had already been developed by the Ministry of Health.

The following are samples of the messages delivered to the community:

Early detection saves lives.

If you live with HIV you are at higher risk of cervical cancer and you must screen every years.

If you are not living with HIV, screen every three years.

Don't fear screening.

Men support your women to go for screening.

If you are a girl aged 9-13 years get an HPV vaccine.

19. 2gether 4SRHR programme brought together the expertise of four UN agencies – the Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Population Fund (UNFPA), the United Nations Children's Fund (UNICEF) and the World Health Organization (WHO)

20. <https://doi.org/10.1016/j.pmedr.2020.101093>

The team agreed that the HIV support groups in the communities should play a pivotal role in mobilizing women living with HIV, particularly COWLHA support groups. COWLHA has a huge reach throughout the country and in 2019, COWLHA had a membership of 34,000 women living with HIV across every district in the country. Moreover, the network has mobilised children and adolescents aged 9-19 years who live with HIV to form networks in two districts. Those who are under 12 years of age can also meet at the hospital where they can join clubs, providing another opportunity to mobilise young girls for the HPV vaccines as well. Studies in the past have shown how crucial networks are to mobilising women and girls for cervical cancer screening.²¹ Taking into consideration the reach of the support groups, the team devoted time to train the support groups on communication techniques and encouraged them to work together with the chiefs to mobilise their members.

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The use of a variety of communication means was also important and needed to be innovative particularly during the COVID-19 pandemic. During the first wave of COVID-19, messaging was carried out using a public address system to avoid close gatherings. Once the COVID-19 infections subsided, the community members would gather and the team used flip charts during their talks and distributed posters to be put up in key places such as the chief's offices/homes, community centres and the local school. Sometimes, health workers brought with them the speculums and the torches used during the procedures to dispel the rumours about the size of the instruments.

Although women soon were convinced about the benefits of screening, many were reluctant to visit the health centres in case they caught COVID-19. So CEWAG organised health workers to travel to the communities to carry out screening. The evening before the health workers arrived, the traditional leaders used public address systems to mobilise the communities, and on the day they organized spaces to host the screening, such as in schools and offices.

The results and challenges

The number of women and girls being screened for cervical cancer in the target districts gradually increased. For example, in 2019, a total of **2,126 women and girls** were screened for cervical cancer which in 2020 went up to **9,910** and in 2021 rose to **10,694**. Those women and girls who tested positive for cervical cancer, if in the early stages, were treated at the health facility, and the others were referred to the district hospital. **For example, in 2021, out of the 10,694 girls and women girls who were screened, 2,029 were positive of whom 268 were treated at the health facility.**

There were several challenges identified. For example, in some health centres, there was a shortage of instruments for the screening and some rural health centres had only one health worker trained in cervical cancer screening which was inadequate to meet the increased demand. Also, in some cases, there was weak coordination between the health facilities and the district hospitals which meant some referrals were not followed up.

21. Moucheraud C. et al., 2020. Preventive Medicine reports (2020) 101093. "It is big because it's ruining the lives of many people in Malawi": Women's attitudes and beliefs about cervical cancer. Elsevier.

Recommendations and conclusion

There were several recommendations including the need to strengthen the health systems, in particular the referrals, provide cervical cancer screening training to more health workers and ensure that health workers take time to explain the procedures.

Bringing cervical cancer services to women in remote areas is important to reach women living far from the health facilities. They would no longer have to leave their children and/or their farms or small businesses unattended and lose vital family income. Although resources for these mobile clinics are limited, some health workers said that they could carry out the cervical cancer screening while performing other outreach activities, such as vaccinations.

Overall, the main success of the project was the sensitization of the influential chiefs and other traditional leaders who mobilized the population and

assisted in dispelling myths and fears as well as the involvement of the HIV support groups.

Beatrice Mateyo, the Executive Director of CEWAG sums it up:

“I think it was a great success. Following the sensitisation, the chiefs said they would be champions for cervical cancer screening and carry out awareness in the community. Also, working closely with COWLHA support groups in the communities was effective as these groups are influential and permanent structures there.”

