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“It is big because it’s ruining the lives of many people in Malawi”: Women’s attitudes and beliefs about cervical cancer

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ABSTRACT

Adoption of routine cervical cancer screening in Malawi is very low, even though it has the highest cervical cancer burden in the world. We performed a multi-level assessment of Malawian women’s knowledge and perceptions of cervical cancer risk and screening. Using the Multi-Level Health Outcomes Framework, we conducted interviews with 60 adult Malawian women aged 18–62 at facilities with cervical cancer screening. Eligible participants were recruited regardless of HIV status or history of screening, and asked about their experiences with cervical cancer disease and screening. Interviews were audio recorded and a theory-informed codebook was developed. Analysis focused on thematic differences across groups by age, HIV status, and screening history. Half of the sample (n = 30) had either never been screened for cervical cancer or were at the facility for their first-ever screen. Most women said that cervical cancer is dangerous, and many knew someone affected. Many women spoke about the importance of screening for prevention of cancer. Risk factors were generally well-understood, including increased risk with HIV, although this was misunderstood by some HIV-negative women to mean they were not at risk. Social networks were identified as a key determinant of screening, and gender issues were likewise highly salient. Despite high knowledge levels about cervical cancer, there remain significant challenges to improving screening, including interpersonal and system-level barriers. Future work should strengthen service delivery, target social networks and intimate partners, and develop targeted communication strategies for HIV-positive and -negative groups, especially in high-burden settings.

1. Introduction

Cervical cancer is a major cause of disease and death in many low-income countries. Prevention strategies have effectively reduced the burden in high-income countries, and this has caused a highly inequitable global distribution of disease: “cervical cancer is not a disease of the past – it is a disease of the poor” (Knaul et al., 2019). Malawi has the highest age-standardized cervical cancer incidence and mortality in the world (Bray et al., 2018): 72.7 cases per 100,000 women, and 53.9 deaths per 100,000 women (in the United States, there are 6.4 cases and 1.8 deaths per 100,000 women) (Bray et al., 2018).

Some studies indicate that fewer than 10% of Malawian women have ever been screened for cervical cancer (Gakidou et al., 2008; Reddy et al., 2014). Additionally, since women with HIV are at higher risk for cervical dysplasia and progression to invasive cancer (Dryden-Peterson et al., 2016; Franceschi and Jaffe, 2007), Malawi’s high HIV

prevalence (approximately 12% of adult women are HIV-positive) (National Statistical Office Malawi and ICF, 2017; UNAIDS, 2017) presents another risk factor (Cubie et al., 2017; Reddy et al., 2014).

Malawi utilizes a single-visit “screen and treat” strategy for secondary prevention of cervical cancer (Ministry of Health Malawi, 2014; The Government of Malawi Ministry of Health, 2017; World Health Organization, 2013): women are examined for precancerous lesions using visual inspection with acetic acid (VIA), and eligible lesions are removed immediately (women with more advanced disease are referred for specialty care). The global health development assistance community has recently increased its investments in cervical cancer prevention in Malawi (GAVI, 2019; PEPFAR, 2018).

The scale-up of cervical cancer prevention programs in Malawi presents a new opportunity to strengthen our understanding of what women think, believe, perceive and experience about cervical cancer and “screen and treat” programs. Previous qualitative studies with

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Malawian women have found low awareness about cervical cancer risk, low perceived susceptibility, and many misconceptions about the role and process of screening (Fort et al., 2011; Hami et al., 2014; Ports et al., 2015). A more recent (2016) quantitative survey in Malawi suggested increased knowledge about the efficacy of “screen and treat” and an evolving understanding of risk factors, as compared to prior studies (Maree and Kampinda-Banda, 2018). Literature reviews have identified similar determinants of cervical cancer screening in low- and middle-income countries (knowledge about the disease and efficacy of screening and treatment, perceived severity and susceptibility) (Adewumi et al., 2019; Black et al., 2019; Chan et al., 2015; Chidyaonga-Maseko et al., 2015; Lim and Ojo, 2017; McFarland et al., 2016). Some of these themes have not been identified in the literature from Malawi, including interpersonal influences and spousal support; nor the intersection of cervical cancer and HIV, despite the unique challenges and opportunities these dual epidemics may present. The goal of this study was to explore Malawian women’s perceptions of and experiences with cervical cancer disease and screening, using a theory-informed qualitative design.

2. Methods

Theoretical framework: We use the Multi-Level Health Outcomes Framework (MHOF; previously Health Behavior Framework) to examine how cervical cancer screening behavior is affected by patient-level factors, including knowledge and beliefs (about cervical cancer, susceptibility, efficacy of screening), barriers and facilitators, and cues to action (Fig. 1) (Bastani et al., 2010). The MHOF takes a socio-ecological perspective and synthesizes common health behavior, outcomes, and implementation science constructs – to consider the range of factors that may affect health behaviors, although the framework acknowledges that, practically, a single study will generally focus on only a subset of model factors. The MHOF situates the individual-level factors explored here within a broader context that likewise influences health behaviors and health outcomes. The MHOF has been used for formative research, instrument development, and intervention design targeting diverse groups in varied contexts, including previous research in liver cancer (Bastani et al., 2010), breast cancer (Bastani et al., 1999), and

colorectal cancer (Bastani et al., 2001).

Participants: We collected qualitative data by interviewing Malawian adult women (18 years of age and older) about their opinions and experiences with cervical cancer disease and screening. To understand the experiences of women who participate in “screen and treat,” we conducted interviews immediately following this service; and to capture the perspective of a broader cross-section of women (including those who have never been screened), we interviewed women visiting the facility for other types of care. Women in this latter group were only eligible if they had heard of cervical cancer, as we wanted to interview women with some awareness of the disease. We used convenience sampling for both, and enrolled all eligible and willing women until meeting the desired sample size of 10 women in each group, per facility. After being assessed for eligibility, women were given an opportunity to ask questions before providing oral informed consent to participate in an interview. Data were collected anonymously. The interview guides included semi-structured open-ended questions that reflected constructs of the MHOF.

Study sites: We conducted interviews with women at three health facilities in Central Malawi that have implemented “screen and treat” using thermocoagulation since 2015. Interviews were conducted between November 2018 and January 2019.

Data collection: Interviews were conducted by Malawian staff highly experienced in qualitative data collection methods. The interviewers were female, and received specific training for this project that included an overview of cervical cancer disease and prevention, and extensive training and pre-testing with the interview guides for this study. Based on pilot testing of the interview guide, we made small adjustments to clarify language (for example, to ensure that words like “screening” and “cervix” were accurately communicated). The interviews were conducted in Chichewa (the local language) and lasted on average 26 min (median 24 min, range 15–55 min). The interviews were conducted in-person, and with the participant’s consent, all interviews were audio recorded. At the end of the interview, participants were given an opportunity to ask questions and provide any additional comments. Participants were given 1500 Malawi kwacha (approximately US\$ 2) for their participation in the study.

Data analysis: All audio recordings were transcribed and translated

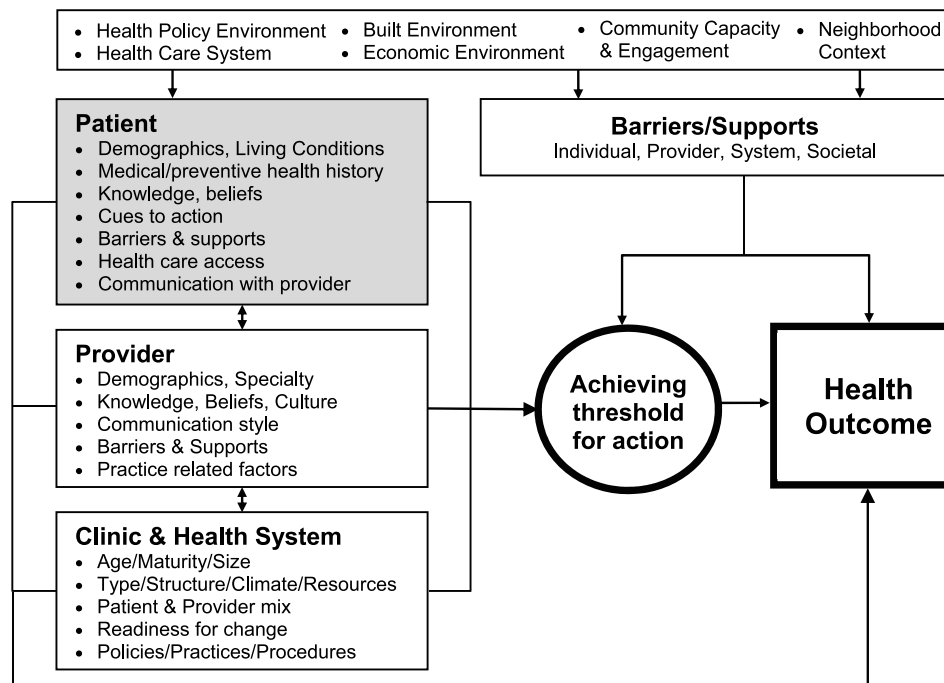


Fig. 1. Multi-Level Health Outcomes Framework (MHOF) with study-specific constructs highlighted in grey.

to English by an experienced team of bilingual (Chichewa-English) translators. A codebook was developed based on MHOF constructs, and emergent codes were added as the codebook was pilot tested on several transcripts. Two authors (CM and PK) refined the codebook through three rounds of iterative coding, and when high inter-rater agreement was reached, each independently coded a subset of the transcripts using NVivo software (QSR International, v11).

Analysis focused on constructs within the “Patient” domain of the MHOF. After coding the transcripts, text within each domain was read for the identification of sub-themes; we then looked for similarities in respondent demographics within each of these sub-themes – primarily, whether the respondent had experience with cervical cancer screening (the label “screening-inexperienced” was used for women who had never been screened and those who were screened for the first time that day), her self-reported HIV status, and her age.

Ethical review: This study was approved by the Institutional Review Board at the University of California Los Angeles and the Malawi National Health Sciences Research Committee.

3. Results

We conducted interviews with 60 women. No potentially eligible participant was excluded due to not having heard of cervical cancer. The average age of respondents was 39 years (Table 1). Approximately half of women in the sample (n = 32, 53.3%) reported being HIV-negative, while 41.7% were HIV-positive (n = 25), and 3 women did not disclose their status. Only 13 women (21.7%) said they had never been screened for cervical cancer, and 17 women (28.3%) were at the facility that day for their first-ever cervical cancer screen; approximately one-quarter of these screening-inexperienced women (n = 8) were HIV-positive and on ART. Half of the sample (30 women) reported having been screened for cervical cancer at least once previously. Two respondents spoke of being screened annually, and they both reported being on ART.

Approximately half of the respondents said they had first heard of cervical cancer within the last 5 years (n = 31), and half of these women (n = 14) were HIV-positive. Ten women said they had first heard within the last year, and most of these women were HIV-negative (7 women). The most common sources for learning about cervical cancer screening for the first time were the radio (mentioned by 25 women) and the health facility (mentioned by 24 women). Thirteen women said they had heard through word of mouth, and some women also cited other sources, such as church (mentioned by 4 women), school, and announcements in the village.

3.1. Knowledge and beliefs

When asked whether they felt that cervical cancer was a dangerous

disease, most women responded in the affirmative. The most prevalent reason was because of the risk of death, and this was mentioned by women both experienced and inexperienced with screening. Put simply: “Cancer kills, and it’s very dangerous” (54, on ART, twice screened).

Almost one-third of respondents (n = 18) mentioned knowing a friend or family member who had cervical cancer, and some respondents spoke about the prevalence of cervical cancer in Malawi as reinforcing their opinion of its severity: “It is big because it’s ruining the lives of many people in Malawi” (30, HIV-, once screened).

Women discussed their susceptibility to cervical cancer. Some HIV-positive women acknowledged that they are at increased risk; this was reported only among women experienced with screening, and primarily among women over age 40. Inversely, some HIV-negative respondents spoke about how exposure to information about cervical cancer had corrected previous misconceptions [“I thought I was safe since I am not HIV positive” (33, HIV-, first time screened)]. A few respondents said they felt susceptible to cervical cancer because it is widespread [“Cancer is an epidemic and cannot be avoided” (30, HIV-, once screened)].

Respondents commonly spoke of risk factors for cervical cancer, and sexual transmission was the most commonly mentioned, particularly among women experienced with screening. Women spoke of the importance of reducing multiple sexual partnerships:

“We should abstain because sleeping with many men is one way of getting this disease. We should be satisfied with the man that we have.” (59, HIV-, twice screened)

Male circumcision, male hygiene, and use of vaginal herbs for sexual pleasure were mentioned by several respondents as associated with cervical cancer risk. Several women also spoke about how their husbands’ sexual behavior would affect their own cancer risk:

“Since they say men can transmit the virus after having multiple partners, that is where my worry is – that my husband may be the one to transmit the virus.” (55, HIV-, never screened)

3.2. Cues to action

Women who were being screened for the first time were asked why they had decided to get screened that day. Some women mentioned wanting to know their “cancer status,” among HIV-positive women, this motivation seemed tied to their perception of susceptibility:

“Many women are dying of cervical cancer, so I came so that I should know my status on cancer.” (41, on ART, first time screened).

Several women mentioned feeling at risk – either due to specific symptoms (primarily abdominal pain, as well as amenorrhea), or risk factors (e.g., partner infidelity or a family history of cervical cancer). Another common source of motivation for screening was urging from friends or family. Some women spoke of accompanying a peer for screening:

“On Monday, a neighbor asked me if I have screened for cervical

Table 1
Characteristics of the study population (n = 60), stratified by screening history.

	Full sample (n = 60)	Never screened (n = 13)	First-time screeners (n = 17)	Women screened at least once before (n = 30)
Age	Mean: 39 Median: 40 Range: 18–62	Mean: 40 Median: 39 Range: 20–56	Mean: 38 Median: 39 Range: 18–56	Mean: 40 Median: 41 Range: 21–62
HIV status	n = 32 (53.3%)	n = 8 (61.5%)	n = 10 (58.8%)	n = 14 (46.7%)
Negative	n = 25 (41.7%)	n = 3 (23.1%)	n = 6 (35.3%)	n = 16 (53.3%)
Positive	n = 3 (5.0%)	n = 2 (15.4%)	n = 1 (5.9%)	n = 0
Undisclosed				
Screening frequency	n/a	n/a	n/a	
Once				n = 15 (50%)
Twice				n = 9 (30%)
Three times				n = 2 (6.7%)
Four times				n = 2 (6.7%)
Annually				n = 2 (6.7%)

cancer... She told me that she was afraid, and I encouraged her that we should go and get screened. I came with her, so that we should get screened and know the truth.” (53, HIV-, first time screened)

It was common for women to encounter multiple cues to action for their first-ever screen, and many mentioned that their final decision to get screened was motivated by community-based announcements with specific information about services offered at a certain time and place.

“The campaign announcing about cervical cancer made me realize that there is an opportunity for me to get screened.” (33, HIV-, first time screened)

Women who had never been screened were asked if they had plans to be screened in the future. All said that they planned to be screened; the most common reason was to know one’s status (“Because I want to know how I am” [23, on ART]). A few women cited concerns about specific symptoms (“I wish to be screened because sometimes I have stomach problems” [26, HIV-]), and several mentioned the importance of screening as a regular health maintenance practice.

3.3. Barriers and supports

Many women spoke about the importance of early intervention to mitigate the danger of death (i.e., screening to identify disease before it has progressed, and therefore being able to access treatment). This was mentioned by respondents of different ages, HIV status, and screening history – including women who have never been screened:

“If they test you and find that you have cancer, they do cryotherapy to kill the cancer cells. But when you are late and the cancer has spread, it has no cure because it destroys the body inside so you die anytime.” (47, on ART, never screened)

Screening-experienced women spoke about how screening alleviates stress and uncertainty related to cervical cancer; and several women spoke about how being screened for the first time altered this perspective:

“At first I used to think it was a big issue before I got screened. But now that I got screened it is lighter because now I know about my health status and where my future is.” (53, HIV-, first time screened)

Many respondents said they had heard rumors that screening is painful and/or dangerous and that this had deterred them; this was common among screening-inexperienced women:

“I heard that they insert a metal instrument with an appearance of a duck mouth, and it hurts, and when you come back from the screening you can’t sit. But then I realized that listening to other people will not help me, and here I am able to sit after being screened, I am not even in pain.” (56, HIV-, first time screened)

Additionally, issues of modesty were mentioned as a barrier by women of all backgrounds (screening-experienced and -inexperienced women, regardless of ages or HIV status):

“It’s so hard for a woman to undress for a man. It’s different from labor when you are in pain and you just want to get helped. This is a different case - you are okay, so for you to undress for a man, most women see it as a wrong thing.” (39, HIV-, once screened)

Some women also mentioned that their husbands were not supportive of screening, due in part to these modesty concerns or general beliefs about gender norms and decision-making. There were also concerns about the lesion removal technique – including about the recommended 4-week period of abstinence, and rumors that treatment leads to infertility:

“After I was told that I have cancer signs and that they need to treat, I went back home and people started saying that I will never again have any more children and that they have seen people who have been treated from lesions but they never gave birth again. My husband got scared and he asked around to see whether that is true or not. Most responses told him that it’s true so yesterday he came back home and said our marriage is over.” (23, HIV-, once screened)

In other cases, women mentioned the importance of support from their husbands:

“Going with your husband to screen for cervical cancer is not wrong... If you are found VIA positive and your husband is there, you help each other pass through the hard times.” (50, on ART, annual screener)

Women also spoke of the distance and cost of reaching the health facility as a barrier to screening; long wait times and supply shortages; and ill treatment by health care providers that discouraged them:

“Doctors should talk to us politely. Because sometimes they get tired and they shout... that demotivates a lot of women from getting screened for cervical cancer.” (31, HIV-, never screened)

“A doctor at [X Hospital] told me that the process is scary, in a way that scared me so that I should not go get tested.” (23, on ART, never screened)

4. Discussion

Reflecting the high prevalence of invasive cervical cancer in Malawi, women who were interviewed for this study saw cervical cancer as dangerous and common – and many had lost friends or family members to cervical cancer. Knowledge of the disease was universal, and women were well-informed about its source as a sexually-transmitted virus. Although half of the respondents were screening-inexperienced (never screened or screened for the first time that day), all women understood the benefits of screening and the importance of identifying problems early, before cervical cancer has progressed. When compared to earlier studies, this and another recent study from Malawi (Maree and Kampinda-Banda, 2018) suggest trends of increasing knowledge about cervical cancer and a heightened sense of susceptibility (Fort et al., 2011; Hami et al., 2014; Ports et al., 2015).

Paralleling a broader literature from sub-Saharan Africa, we identified several barriers that may be contributing to the disconnect between high knowledge and low uptake of screening (Getachew et al., 2019; Lieber et al., 2019; Olubodun et al., 2019) including hesitations due to rumors about dangers and discomforts. Those who overcame this barrier expressed eagerness to educate their friends and community members about their experience. Some first-time screeners said they came to be screened that day because they accompanied a friend or neighbor. Other studies from sub-Saharan Africa have similarly identified the importance of interpersonal relationships for promoting cervical cancer screening (Gatumo et al., 2018; Huchko et al., 2019; Nyambe et al., 2019), which suggests an important potential area for intervention. Participants articulated benefits of screening –the importance of early detection and the psychological relief of knowing one’s status – that may be appropriate messages for interventions.

Health system strengthening is a necessary accompaniment for any cancer control strategy in a low-resource setting like Malawi (Chidyaonga-Maseko et al., 2015; Finocchario-Kessler et al., 2016) and health system factors were highly relevant determinants of screening in this population – both positive (as a source of information about screening in this population) and negative, such as long travel and wait times, poor treatment by health workers, and shortages of screening supplies.

A key benefit of the MHOF is its articulation of the distinct roles of mutable and immutable constructs: mutable factors are amenable to intervention, while immutable factors (like patient age or demographics) can inform the targeting or tailoring of interventions. Our study adds to the relatively small literature about HIV-positive women’s experiences undergoing cervical cancer screening (Finocchario-Kessler et al., 2016; White et al., 2012). Taken together, these data suggest ways in which HIV status may intersect with attitudes toward cervical cancer: HIV-positive women cited their increased risk for cervical cancer disease, and some first-time screeners who were HIV positive mentioned this as a cue to action. On the other hand, some women said they felt less susceptible to cervical cancer because they are HIV-negative. Future work might seek to develop unique messages for HIV-negative women that clarify their cervical cancer risk.

Our study adds new evidence to the nascent literature about the importance of male partner involvement in cervical cancer screening

programs, and suggests ways to target interventions to both men and women in order to ease communication between partners, reduce misconceptions, and improve uptake of screening (Adegboyega et al., 2019; Adewumi et al., 2019; Chidyaonga-Maseko et al., 2015; Lim and Ojo, 2017; Manga et al., 2019; Ragan et al., 2018). This study identified important information related to gender and sexuality, including concerns about examinations by male doctors, lack of spousal support for screening and/or lesion removal, concerns related to fertility and childbearing, and sex-related risk behaviors.

Some limitations should be noted. First, all participants were recruited from health facilities with established “screen and treat” programs, so these results should be interpreted in the context of access to cervical cancer services and may not generalize to environments without such services. Availability of “screen and treat” is far from universal in lower-resource settings; per the Malawi National Cervical Cancer Strategy, there are 129 VIA sites in Malawi, of which only 32 offer lesion removal (The Government of Malawi Ministry of Health, 2017). (For context, there are approximately 1000 health facilities in Malawi (Ministry of Health Malawi and ICF International, 2014).) Additionally, the sampling strategy resulted in a respondent pool with an above-average HIV prevalence (the cervical cancer screening program is funded by PEPFAR, and therefore is implemented at HIV treatment sites, and this constituted the sampling frame for our study). Second, responses may be subject to reporting bias, including recall bias (if more dramatic incidents like negative experiences are recalled more readily) and social desirability bias (if women feel pressure to say certain things, e.g., about perceived severity of cervical cancer). All interviews were conducted by highly experienced and well-trained Malawian research assistants, and we tried to mitigate these sources of bias by thoroughly probing all responses and establishing a good rapport with participants. Lastly, we did not collect additional socio-demographic information on respondents so cannot compare findings along such dimensions.

Interventions to improve screening coverage have largely focused on increasing knowledge and expanding service availability. Cancer control researchers, practitioners, and policymakers should augment these efforts with interventions targeting other factors that may play a crucial role for women, such as engaging social networks and educating and including spouses/partners in the screening process. A comprehensive, multi-level approach will be needed if we want to make substantial gains in reducing the burden of cervical cancer in the most-affected countries worldwide.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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