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'WORSE THAN HIV' OR 'NOT AS SERIOUS AS OTHER DISEASES'? CONCEPTUALIZATION OF CERVICAL CANCER AMONG NEWLY SCREENED WOMEN IN ZAMBIA

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Abstract

Invasive cervical cancer is the second most common cancer among women worldwide, with approximately 85% of the disease burden occurring in developing countries. To date, there have been few systematic efforts to document African women's conceptualization of cervical cancer after participation in a visual inspection with acetic acid (VIA)-based "see and treat" cervical cancer prevention program. In this study, conducted between September, 2009-July, 2010, focus groups and in-depth interviews were conducted with 60 women who had recently undergone cervical cancer screening at a government-operated primary health care clinic in Lusaka, Zambia. Interviewers elicited participants' causal representations of cervical cancer, associated physical signs and symptoms, perceived physical and psychological effects, and social norms regarding the disease. The lay model of illness causation portrayed by participants after recent exposure to program promotion messages departed in several ways from causal models described in other parts of the world. However, causal conceptualizations included both lay and biomedical elements, suggesting a possible shift from a purely traditional causal model to one that incorporates both traditional concepts and recently promoted biomedical concepts. Most, but not all, women still equated cervical cancer with death, and perceived it to be a highly stigmatized disease in Zambia because of its anatomic location, dire natural course, connections to socially-condemned behaviors, and association with HIV/AIDS. No substantive differences of disease conceptualization existed according to HIV serostatus, though HIV positive women acknowledged that their immune status makes them more aware of their health and more likely to seek medical

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attention. Further attention should be dedicated to the processes by which women incorporate new knowledge into their representations of cervical cancer.

Keywords

Zambia; cervical cancer; mass screening; HIV; social representations; access to care; retention into care; women; stigma

INTRODUCTION

Invasive cervical cancer is primarily caused by persistent infection of the uterine cervix with oncogenic subtypes of human papillomavirus (HPV) (Bosch et al., 2008). With an annual incidence of 533,000 cases, cervical cancer is the second most commonly diagnosed cancer in women worldwide (Arbyn et al., 2011). To mitigate this public health problem in developing countries, where approximately 85% of the disease burden occurs (Ferlay et al., 2010), important efforts have been made over the past 15 years to develop simple and affordable screening strategies that rely on non-cytological modalities of cervical abnormality detection (Blumenthal et al., 2005; Sankaranarayanan et al., 2004).

Effective cervical cancer prevention programs are especially needed in the eastern and southern regions of sub-Saharan Africa where disease incidence and associated mortality rates are among the highest in the world. In these regions, however, efforts to reduce the burden of cervical cancer through secondary prevention programs are even more challenging due to the HIV pandemic. Women coinfectd with HPV and HIV are at considerably higher risks of high-grade cervical precancerous lesions (De Vuyst et al., 2008) and failure of treatment for these lesions (Tebeu et al., 2006). In HIV-infected women, progression to cervical cancer is not consistently affected by antiretroviral therapy. Finally, disease diagnosis is frequently made before age 30—some 10 years earlier than is typical in HIV-uninfected women (Clifford et al., 2005; Frish et al., 2000). Consequently, general recommendations by the World Health Organization for a single screening visit between 30–39 years of age (Alliance for Cervical Cancer Prevention, 2009) are likely to be of limited benefit to many HIV-infected women on antiretroviral therapy who might now live long enough to develop cervical cancer (De Vuyst et al., 2008). Instead it appears that HIV-infected women will need to be screened at regular intervals from a young age, possibly as frequently as once a year, and monitored closely for post-treatment recurrence of lesions (De Vuyst et al., 2008; Omar et al., 2011).

People from all cultures have understandings of illnesses that are in part personal and in part shared among members of their community (Pierret, 2003). Largely based on intuitions, private experiences, local history and current social circumstances, these understandings, or lay models of illness, can be seen as representing “what feels right” about a health condition for a person or a group of persons at a given time. In response to the continuous exposure to new information and experiences, each model constantly evolves in terms of scope and sophistication. From a public health perspective, lay illness representations are known to strongly influence people's perceptions of personal risk, as well as their interpretations of symptoms, and their help-seeking behaviors (Pierret, 2003; Petrie & Weinman, 2006, Lipworth et al., 2010). More generally, lay models of illness have multiple functions in daily life, such as ascribing personal meaning to illness, helping maintain or restore emotional balance, assigning responsibility for suffering, and regulating interpersonal relationships amongst those affected and members of their social network (Pierret, 2003). Recent publications on representations of cervical cancer in high-income countries are dominated by discussions of women's reactions to the increasingly publicized notion that cervical

cancer is caused by a sexually-transmitted virus (Szarewski, 2011). Now, as in the past, (Kavanagh & Broom, 1997), cervical cancer evokes images of loss of control, impaired body, blemish and death. In Europe and the U.S., however, women who test HPV-positive more frequently struggle today to place these screening results in the context of their personal life and relationships (Szarewski, 2011). Women in monogamous relationships, in particular, express disbelief, anxiety, shame and anger as to how they might have acquired a sexually transmitted infection they associate with promiscuity.

To date, few systematic efforts have been undertaken to document African women's lay representations of cervical cancer and to study the potential influences of these representations on cervical screening behavior (Szarewski, 2011). Publications on the topic suggest that many African women either have little awareness of the disease or express perceptions that depart markedly from the biomedical model in terms of causal attributions and risk perception (Francis et al., 2010; Gichangi et al., 2003; Mangoma et al., 2006; McFarland, 2009; McFarland, 2003; Nnodu et al., 2010). A greater understanding of local conceptions of cervical cancer is particularly needed to understand what might motivate HIV-infected African women to remain in preventive cancer care after having been screened for cervical abnormalities for a first time, and, more generally, to inform development of screening promotion messages that are culturally appropriate and make sense to the general population.

In Zambia, estimated age-adjusted cervical cancer incidence is 52.8 per 100,000 annually (Ferlay et al., 2010). HIV prevalence among women 15–49 years is extremely high, at 16.1% nationally and 23.1% in the capital of Lusaka (Joint United Nations Programme on HIV/AIDS, 2010). In response to this crisis, the Zambian Ministry of Health, in collaboration with the University of Alabama at Birmingham-Center for Infectious Disease Research in Zambia, launched a cervical cancer prevention program in 2006 that introduced VIA-based “see and treat” prevention services within twelve existing primary health care facilities in Lusaka and linked them with concurrent HIV treatment and prevention services (Mwanahamuntu et al., 2009). As of 2011, a total of 58,000 women had been evaluated using VIA see and treat methods in clinics where cervical screening was offered (Mwanahamuntu et al., 2011). The present study was conducted at one of the primary care clinic sites, in parallel with a population-based survey of barriers to screening (Chirwa et al., 2010). Our study employed qualitative methodologies to: 1) characterize the illness entity, if any, that Zambian women, newly screened for cervical cancer for the first time, labeled as “cervical cancer”; 2) describe the attributes that these women attached to their representations of the disease; and 3) evaluate the implications of these representations in terms of cervical screening organization and promotion.

METHODS

Study Design

To elicit detailed perceptions of cervical cancer held by Zambian women newly screened for cervical cancer, we employed a descriptive and qualitative design utilizing focus group discussions (FGD) and in-depth interviews (IDI). Data were gathered through a descriptive inquiry approach which seeks to comprehensively depict a phenomenon of interest using the direct language of the participants, with low-level interpretation by the researchers (Sandelowski, 2000). This approach is suitable here in that women were able to describe their perceptions of disease causation and manifestations in the context of their lives and experiences.

FGD employ group interview techniques to gain access to the means in which small lots of individuals chosen for their homogeneous characteristics discuss a topic of interest in their

own words (Green, 2004). In this study, FGD were used to collect broad points of view on cervical cancer from Zambian women who shared the same cervical screening history, language, and HIV status. Participants were asked to describe their perceptions about cervical cancer and its manifestations, course and consequences (both physical and psychosocial). Participants were also asked how serious they considered cervical cancer to be compared to other diseases that affect women; whether they felt personally at risk; and how to avoid getting the disease. (See Table 1 for sample questions from FGD). For each group, e.g., Bemba, Nyanja, HIV+ women, a second FGD was held in order to validate findings of the initial discussion using member checking techniques.

Semi-structured interviews give each respondent substantial control over which topics to discuss and to what degree (Corbin and Morse, 2003). In this study, we used IDI to provide motivated respondents with an environment where they might feel more comfortable discussing personal issues and potentially sensitive topics.

Research ethics committees from both the University of Alabama at Birmingham and the University of Zambia approved the research protocol.

Study sample

The decision to conduct 6 FGD consisting of 10 women each and 10 subsequent IDI was made following discussions with the Zambian team members, who, based on their experience in conducting similar qualitative research studies, held the conviction that theoretical saturation, or the point at which no new information is presented, could be reached with 60 women.

On recruitment days, peer educators referred potentially eligible women presenting at the clinic to study team members. To be eligible for the study, women had to be local residents, 18–49 years of age, eligible for VIA screening (Parham et al., 2006), willing to undergo a pelvic examination, and conversant in either Bemba or Nyanja, the two local languages most commonly spoken in Lusaka. Interested women were given date/time reminder cards to come back to the clinic for the FGD. Following informed consent, HIV serostatus was documented for all women based on medical record information.

Study setting

The research was conducted at the Kanyama clinic, located on the outskirts of Lusaka, the capital city of Zambia (population approximately 1.5 million). Kanyama is a poor and densely populated peri-urban settlement with an estimated population of more than 150,000 inhabitants (Zambia Ministry of Health, 2008). The area is situated in a flood prone area bordering Lusaka's largest outdoor commercial market. The social environment is characterized by high unemployment, makeshift housing, and inconsistent utility services (Zambia Ministry of Health, 2008).

Kanyama clinic is one of 25 health centers managed by the Lusaka District Health Management Team under the authority of the Ministry of Health. The clinic provides general outpatient services, including HIV, tuberculosis, antenatal, and pediatric health care. By late 2006, Kanyama clinic was dispensing ART to nearly 3,000 patients (Koethe et al., 2010).

VIA screening procedures

At Kanyama clinic, the cervical screening program is managed by a specially trained nurse, assisted by a small team of volunteer, lay peer educators who provide promotional talks on cervical health and circulate through the clinic daily to invite women for screening

(Mwanahamuntu, et al., 2009; Pfaendler et al., 2008). Core educational messages conveyed to women include the following: any woman who has had sexual intercourse is at risk for development of HPV-induced lesions which could lead to cervical cancer; the disease has an early stage and a late stage; in its earliest stage, there are no symptoms; the purpose of cervical screening is to detect the problem before it becomes cancer.

Eligible women choosing to undergo screening are seen by the nurse who takes a brief clinical history. Following a complete gynecological examination, the nurse visually inspects the patient's cervix after application of dilute 3% acetic acid. A picture of the visualized cervix is captured using a commercial-brand digital camera connected to a monitor for enhanced visualization, documentation and quality assurance purposes (Parham et al., 2010). Women diagnosed with aceto-white lesions are offered immediate treatment with cryotherapy, as appropriate, or referred for further gynecological evaluation at the local tertiary care center – University Teaching Hospital ((Mwanahamuntu, et al., 2009; Pfaendler et al., 2008).

Focus group discussion procedures

Women were grouped according to language preference (Bemba versus Nyanja). Separate FGD were held based on HIV status (positive versus negative, unknown or undisclosed) assuming that women who disclose their HIV positive status might have different experiences with the local health care system and, possibly, unique perceptions in association with their increased risk for cervical cancer. Each of the FGD included 10 women and lasted 1–2 hours. All discussions were held in private rooms within the clinic and were conducted by Zambian staff experienced in qualitative data inquiry and trained specifically for this protocol. A moderator asked the pre-scripted, open-ended questions to the group, encouraged balanced group discussions, and used probes to clarify any unclear or unresolved statements; in parallel, an observer documented the general atmosphere, group dynamics, and individuals' non-verbal cues. With women's permission, each discussion was recorded using a digital recorder for transcription and translation purposes.

In-depth interview procedures

Once all FGD were transcribed, translated in English and initially reviewed for emergent themes, the research team gathered to compile a list of topics and findings to be further explored, where possible through IDI (see examples of interview topics in Table 1). All women who participated in the FGD were asked to consider participating in an IDI to further discuss themes elicited during FGD or debate new topics. Women who agreed were given an appointment reminder card to return for the interview. Upon her return, after obtaining written consent, each woman was escorted to a private room in the clinic along with an interview moderator and observer/recorder who conducted each of the interviews. Pre-scripted, open-ended questions centered on priority FGD themes were drafted prior to the conduct of the interviews, though interviewers were instructed to allow respondents to dictate interview dialogue. Each interview lasted no more than 2 hours. Interview procedures matched those used for FGD, with regard to transcription and translation.

Data Analysis

For qualitative descriptive studies, qualitative content analysis is the method of choice (Sandelowski, 2000). With this iterative technique, the role of the researcher(s) is to organize and summarize the informational contents of the data through formulation of categories, themes, and patterns. English translations of verbatim FGD and IDI transcripts were used as the primary data. Three investigators (2 U.S.-based and 1 Zambian-based) independently coded and sorted the data using QSR Nvivo 8.0© software. The team then met (by phone and in person) to discuss their independent coding schemes and reach

consensus of dominant themes. A fourth U.S. investigator was used to adjudicate any disagreements amongst the research team as to the final coding scheme.

RESULTS

Of 66 eligible women referred to study team members between September 2009 and July 2010, 60 (20 Bemba speakers, 20 Nyanja speakers, and 20 self-reported HIV+ women) participated in 6 FGD and 10 IDI (5 women refused to participate and 1 missed her appointment). Since theoretical saturation was reached as predicted, data collection was concluded after the tenth individual interview. Key findings are summarized in Table 2. Although categories were initially created inductively, it soon became evident that they closely matched Leventhal's categories of illness identity, causes, controllability and consequences (Leventhal, Meyer, & Nerenz, 1980); results are therefore presented using this latter classification.

Identity and manifestations

Among our cohort of women who had been recently exposed to screening promotion messages and who subsequently decided to undergo screening, cervical cancer was clearly seen as a recognizable disease, typically referred to in the community either using the English term “cervical cancer” or various Nyanja/Bemba colloquial metaphors pointing to “diseases of the female private parts”. Participants could not identify any Nyanja/Bemba term widely accepted as having a precise, ascribed meaning of “cervical cancer”. Descriptions of the disease by respondents typically included elements of medical knowledge, but in various amounts and expressed with variable levels of confidence.

In line with the core messages of the peer educators, the most common perceived physical symptom of cervical cancer was bleeding, either as prolonged menstruation or as a spontaneous occurrence: “This cancer gives women prolonged periods which do not finish. And others will have the periods for a few months then they will stop and start again after some months (*Bemba speaker*)”. “[Postmenopausal women] will start having periods all over again (*Nyanja speaker*)”. Other vaginal symptoms were reported, including sores or a rash on the vagina, discharge, itching, and vaginal odor. Pain and/or bleeding during intercourse were suggested by several women as symptoms of the disease. Women also described stomach pain, weakness, and pain throughout the body as common disease manifestations: “Generally one gets weak, you experience a backache, legs paining and generally the whole body is in pain (*Bemba speaker*)”. Several women mentioned that a unique characteristic of cervical cancer is its long latency period: “When you are infected with cervical cancer, it takes long to notice...about four to five years before you know that you have the disease (*HIV+ Bemba speaker*)”.

Respondents strongly associated cervical cancer with HIV/AIDS, pointing out that a widely held belief in the community is that if a woman tests VIA positive when screened for cancer of the cervix, then she also has HIV:

A lot of people think when you come for [VIA cervical] screening then you are HIV positiv...because in the community, cancer is associated with HIV/AIDS. So a lot of women fail to come for screening for fear of being found with cancer lesions because it means they are HIV positive (*Nyanja speaker*).

Another stated, “Some women fear because they say that if anyone has cervical cancer then they have AIDS” (*Nyanja speaker*).

Perceived causes

When asked to cite causes of the disease, women offered a variety of explanations. The most common reason given was the use of traditional herbs or medicines which, according to respondents, are used to make sexual intercourse more pleasurable for male partners: “Herbs we put in the porridge to make our body temperatures rise so that a man can enjoy sex with us and the herbs that we insert into the vagina to tighten it [cause cervical cancer]” (*Bemba speaker*).

The second most common cause of cervical cancer offered was having multiple sex partners, as indicated by comments such as “I have heard...cancer of the mouth of the womb comes through having sexual intercourse with men” and “[cancer] comes about if a woman is having sex with different men because the sperms of men mix and this brings cancer”. Women often used the term “promiscuous” when describing those with multiple sexual partners. Consistent with the peer educator message, some respondents mentioned that the disease is caused by a sexually transmitted virus:

What I know is that there is a virus called HPV which comes from men, which gives a disease to men, but as for women it goes and stays just at the mouth of the womb, so if a woman doesn't go for screening it turns into cancer. (*Bemba speaker*)

Several women noted that men, though responsible for transmitting HPV virus to women, could not be affected by the virus itself. As one woman said, “...there is a virus called HPV which comes from men, but it does not give cancer to men only to women (*Nyanja speaker*)”. Some women suggested that having sex during menstruation or early parity could cause the disease.

A very different facet of the relationships between men and women was also offered as an explanation for cervical illness among women, namely, that a woman who began to experience prolonged menstrual periods or bleeding may become convinced that another woman is bewitching her (using sorcery) to try to steal her husband:

...let's say the husband has a girlfriend and the girlfriend did some black juju so that the woman can be experiencing prolonged periods, then the man will not be going to the wife. So then girlfriend is going to have the man” (*Nyanja speaker*)

In this case, women would most likely choose to see a traditional healer in order to mitigate the effects of witchcraft.

Along with sexual activity, family planning, e.g., the use of birth control pills and condoms, was described by several women as a cause of cervical cancer. Some women said that use of the pill “over a very long time” was the cause of the disease in women. Others attributed it to the use of condoms: “What I have also heard is that condoms bring problems to the cervix, and one can have cancer because of using condoms” (*Bemba speaker*). One woman offered, “...they [men and women in the community] say the medicine put on condoms brings about cancer” (*Nyanja speaker*). According to our respondents, there seemed to be a considerable amount of fear and distrust in the community surrounding contraceptive use. Besides the deleterious effect of condoms, injury to the cervix via direct physical or chemical means was identified as causes of the disease. Bathing practices, in particular, were often cited. Among these, the act of a woman touching the vagina with her fingernails while bathing, causing abrasions, was most commonly mentioned: “At the same time the nails from your fingers can cause bruises inside as you wash, some of these bruises do not heal and eventually turn into cancer” (*Bemba speaker*). Another common perception was that dirt from a woman's hands while bathing would damage the cervix and lead to disease, including cancer:

But the finger leaves dirt inside, sometimes you may have a sore inside and as such the dirt from the finger can be accumulating on the sore...the dirt from the finger remains in the womb and over some period of time a woman starts to develop complications and diseases. (*Bemba speaker*)

Several women explained that the use of soap could lead to cancer, “I also heard that bathing with very strong bath soaps can put a woman at risk [for cervical cancer]” (*Nyanja speaker*). Similarly, the use of baby powder was mentioned as a risk factor for cancer, and so were using dirty or “rusty” water when washing the vagina, and wearing wet underwear or wet clothes.

Finally, practices of using commercial and noncommercial absorbents during menstruation carried a perceived risk of affecting the cervix and causing cervical cancer. These included inserting tissue, cotton wool, or tampons into the vagina during menstruation. As one woman remarked, “I have also heard that cotton wool gives cancer. If you are using cotton wool during menstruation, if the cotton wool gets inside it gives cancer (*Bemba speaker*)” or, in the case of tampons:

There are those who use tampons. When the blood is coming out, the tampons stops the blood from coming out, as a result the blood remains inside, this also causes problems. The blood that remains inside remains sterile and this brings cancer (*Bemba speaker*).

Controllability

Given that many women attributed cervical cancer both to the effect of objects or substances coming into direct contact with the vagina and to “promiscuity”, when asked how to avoid the disease, women commonly stated that to avoid the disease was to refrain from putting anything into the vagina and to avoid having sex with “a lot of men”. Although several women suggested that using condoms can cause cervical cancer, one respondent said that it was necessary to use a condom during sexual intercourse and another asserted that the use of condoms lessened the risk of disease.

Three women mentioned the importance of coming to the clinic for cervical screening even in the absence of symptoms. One respondent said that women should get screened as soon as they begin to feel symptoms. When asked whether women understood that a positive screening result is not necessarily indicative of cervical cancer, respondents said that “some, but not all women” understood and made the distinction between pre-cancerous lesions and malignancy.

In response to the question “What might a woman do if she thought she had [cervical cancer]”, participants disagreed considerably as to whether women would come to a health clinic for screening or go to a traditional healer. One respondent described this dilemma:

And [women] start to feel scared and start thinking of going to traditional healers. Others just think of coming straight to the hospital, but others it takes time to convince them to come to the clinic and it is also difficult to share with your husband about the disease or tell him the problem that you have. Mostly we keep the problem to ourselves (*HIV+ Bemba speaker*).

Many women attributed increased education and awareness as a reason to visit the clinic versus a traditional healer:

Without people knowing about cervical cancer, people long ago used to go to traditional healers...since people have started knowing that this is cervical cancer and have knowledge about it, and they have started coming for screening. People in

the past used to stay with the disease for a long time before going to the hospital to seek help (*HIV+ Bemba speaker*).

No woman spontaneously mentioned being aware of the recent opening of a modern oncology center at the Lusaka University Teaching Hospital, a medical unit providing radiation and chemotherapy. This was widely perceived as an incurable disease and viewed as fatalistic, as summarized by one woman:

There is so much fear surrounding cancer because most women know that it cannot be treated. When one starts having prolonged periods, backaches and the whole body pain, what comes to their minds is death because there is no way to be treated (*Bemba speaker*).

Another woman added, "Others think it's all over, they are about to die because cancer has got no cure. This disease can't be cured, and so they start sharing their properties saying they will die at any time" (*Nyanja speaker*). This belief was conveyed in every contact with women and was thought to be one of the main reasons that women avoid cervical screening. As one participant noted, "Others fear to come to the hospital, saying that if I am screened I will know the disease, so they prefer to stay at home. They fear to know their problem because they feel they cannot live with it (*Bemba speaker*)" One woman described cervical cancer as, "...worse than HIV".

Not all women, however, shared this opinion about the severity of cervical cancer. For instance one woman felt that "it is not as serious as other diseases", while another commented, "Yes, but it is curable. I am not sure it is as serious as other diseases" (*HIV+ Nyanja speaker*). One woman offered both points of view, stating, "It depends on the mind of the person, some do not take it seriously because you do not experience any pain in the early stages, while others take it serious" (*Nyanja speaker*). Given the common absence of discrimination between precancerous lesions and cervical malignancy, it was unclear whether these women had in mind the cure of precursor lesions discovered through screening or invasive cancer.

Physical, psychological and social consequences

When asked to describe the physical consequences of the disease, women most commonly provided answers directly related to fertility and the ability to conceive: "This disease spoils your womb severely and sometimes you may not have children because of this disease". Another woman stated, "This is a disease which comes about when the womb is spoiled, then it turns into cancer (*Bemba speaker*)". Beyond affecting the uterus directly, women spoke of other long-term effects: "[Cervical cancer] spreads throughout the body, can cause madness, and eventually you die" (*Nyanja speaker*).

Women were also asked to discuss possible psychological effects of cervical cancer. As previously noted, fear of death from cancer was the most common concern described by women. Other psychological consequences of being diagnosed with the disease included feelings of hopelessness and anxiety. These emotions had a direct link in women's minds as to whether one would seek cervical screening. One woman stated, "...some [women] are scared because there are beliefs that when you are found positive with cancer, it has no cure, so they even fear to go for screening, instead they choose not to know so they are not depressed" (*HIV+ Bemba speaker*). Another felt, "You are never calm when they find you with a problem. You are always worried knowing it has no cure (*Bemba speaker*)". Of note, one woman described the difficulty in dealing with a positive VIA screening result when compounded by HIV+ status:

The most depressing thing is when you are already HIV+ then you [are] also told that you have cancer, it feels so bad. We are scared because we don't know how cancer can be cured, this brings much fear and it feels so bad (*HIV+ Nyanja speaker*).

DISCUSSION

Formulating effective health education and communication strategies is of crucial importance for successfully promoting cervical cancer prevention programs and motivating women diagnosed with a precancerous lesion to remain in follow-up care after treatment. As programs for non-cytological cervical screening expand in low-resource settings, an essential first step toward framing relevant and ethical program promotion interventions is to develop an understanding of women's lay conceptualizations of cervical disease in each target population.

Findings from this study of Zambian women who accepted a cervical screening invitation have important implications for public health experts and policy makers striving to maximize population benefits and minimize possible adverse consequences of cervical screening programs in Africa. Five years after launching a cervical cancer prevention program all participants provided illness descriptions that overlapped substantially with the program's core promotional messages and were familiar with "cervical cancer." However, participants also held a wide range of lay perceptions about the disease, its causes, its consequences, and ways of reducing personal risk. Some of these views were unique; others were shared by women attending cervical screening in other African countries (Gatune & Nyamongo, 2005; Mangoma et al., 2006; van Schalkwyk, et al., 2008; Wood et al., 1997).

As often reported in resource-limited settings where the local health system has long been ill-equipped to provide effective cancer care, most study participants held fatalistic views of cervical cancer. Typically the condition evoked images of pain, imminent death, fear, hopelessness and depression. In this group of women who had all witnessed profound suffering from HIV/AIDS around them, and who may personally be infected with HIV, cervical cancer was commonly described as the ultimate dreadful illness—a condition "worse than AIDS" over which women have no control. Not all participants shared this somber representation, however. Accounts from several women suggested that they were in the process of revising their perceptions of cervical disease. They questioned the notion that cervical cancer was more serious than other diseases—always leading to death—and seemed to view screening as a means to gain control over cancer. For these women, coming to the screening clinic was considered to be a sign of education and modern thinking. This finding is encouraging because fear of cancer is known to be associated with self-defeating forms of coping (e.g., "preferring not to know"), delay in seeking information from relatives and friends, and delay in seeking care (Lipworth et al., 2010).

Nonetheless, identifying and treating cervical lesions while they are precancerous and asymptomatic is the essential premise upon which cervical screening is based. Therefore, one of the core educational messages provided to women as part of the screening program is that because precursor lesions and very early stages cervical disease can be present in the absence of symptoms, women should be screened even if they feel well. In our study, evidence of retention of this message was mixed. As with cytological screening in other settings (Agurto et al, 2004; Ogedegbe et al., 2005; Wood et al., 1997), VIA was not consistently conceived as a screening test and a way to prevent cervical cancer, but rather a diagnostic procedure that women experiencing symptoms evocative of cervical illness would consider undergoing, in hopes of being reassured that they do not have the disease. A challenge for screening programs moving forward is to strengthen how they convey the notion that the best time to undergo VIA screening is before symptom occurrence.

In this study, causal attributions were dominated by physical and chemical damage to the female genital organs, by infringing upon the limits of acceptable sexual and relational behaviors, and by meddling with reproductive matters. As in other parts of the world, lay causal representations partially overlapped with the biomedical causal model. Most women saw a possible causal relationship between having many sexual partners and cervical cancer, explaining the disease as being sexually transmitted. A handful of women specifically attributed the illness to HPV infection. Although women sometimes attributed symptoms of genital infection to cervical cancer and appeared ready to integrate HPV in their existing causal framework, possibly as a new source of trauma to the female genital organ, they never explicitly described HPV infection as being a sexually transmitted infection (STI). Similar findings about the reluctance of using the label of STI when referring to cervical cancer have been reported in various settings (Waller et al., 2005; Wood et al., 1997).

Sexual activity, trauma to the genital organs, and birth control methods are perceived to be dominant causes of cervical disease in multiple cultures (e.g., Latin American culture; Chavez et al., 1995). In many ways, however, the causal explanations formulated by Zambian women departed from those described in other parts of the world. Salient lay causal mechanisms not commonly expressed by our participants included fate, sin (Wong et al., 2008; Ramanakumar et al., 2005; Ratanasiri et al., 2000) or divine punishment (Ashing-Giwa et al., 2004); carelessness and negligence (Goldman & Risica, 2004) ingestion of taboo food (Wong et al., 2008; Ratanasiri et al., 2000); and other lifestyle factors such as stress, physical activity, or smoking (Ashing-Giwa et al., 2004; Chavez et al., 1995). A cause cited by other Zambian women but not noted amongst our participants is lack of routine hygiene (AUTHORS, 2010). Finally, in this study, no woman explicitly indicated that HIV/AIDS is a cause of cervical cancer. Many participants, however, perceived the condition to be the kind of illness that HIV-infected women would get. This finding, also cited by Chirwa and colleagues (2010), is likely to reflect the extremely high prevalence of HIV infection in Lusaka and its effect on the local epidemiology of cervical cancer. In comparison, few women made an explicit connection between HIV infection and cervical cancer in previous qualitative studies conducted in Africa, though women elsewhere did cite fear of HIV testing as a barrier to cervical screening (Gatune & Nyamongo, 2005; Mangoma et al., 2006).

Non-medical options proposed by study participants for preventing the disease were in line with their main lay causal attributions, ranging from refraining from inserting anything into the vagina to limiting one's number of sexual partners. Of note in a community impacted by HIV/AIDS, participants were highly distrustful of condoms and, with the exception of a single respondent, did not see a role for them as a protection against cervical cancer. We did not gather any evidence suggesting that women had awareness of the limited efficacy of condoms for reducing HPV transmission. Instead, women's attitudes regarding condom use may be reflective of multiple concurrent social, cultural, and economic factors. Large family size as accepted fertility norms, resistance from male partners, and lack of female decision-making power have each been associated with low condom use in sub-Saharan Africa (Grabbe et al., 2009; Stephenson et al., 2007).

People are universally concerned with making sense of their illnesses; that is with finding responses to questions such as "why me?" or "why now?" "Common sense" lay causal attributions such as viewing any direct aggressions to the cervix as a potential cause of cervical cancer provides women with a range of possible responses. Cervical cancer is a highly stigmatized disease in Zambia because of its anatomic location, dire natural course, connections to socially-condemned behaviors, and association with HIV/AIDS. It is also difficult for women to manage a health risk, such as HPV infection, that is acquired from men but does not affect men directly. For many women, acknowledging personal risk status

with regard to sexual transmission is therefore fraught with social consequences. Rationalizing the use of “strong soap”, for instance, as the source of the problem may allow them to deflect felt or enacted blame, thus protecting their self-image, social status, and intimate relationships. Similarly, Thomas (2008) has suggested that witchcraft and the idea of being “bewitched” by a husband's mistress or girlfriend may be more socially acceptable explanations than admission of a highly stigmatized disease, and shifts blame away from an individual.

We did not observe marked differences between women's perceptions of cervical cancer according to their HIV serostatus; however, many HIV-infected women appeared more prone to take responsibility in preventing cervical cancer than other women. By analogy with what has been observed among women at high genetic risk for a life threatening disease (Walter et al., 2004), it is likely that HIV-infected women accepted the idea of being “at risk persons”; developed skills to manage uncertainty, and were able to get on with their lives. Whereas these women wrestle with the distressful emotions caused by their personal vulnerability, they might also feel better prepared to receive the news of a cervical lesion compared to the general population.

This study has several limitations. First, we did not systematically assess the extent to which the perceptions expressed by any given woman were shared by the other participants in the study. Due to practical constraints, we interviewed a limited number of women purposefully sampled from one of twelve clinics where VIA cervical screening is performed. This sample of respondents represents only a small proportion of women eligible for screening and does not necessarily reflect the views of the larger population; however, because women were asked to reflect on our questions both personally and as a member of their community, we believe that women conveyed both personal and general perspectives on the topics discussed. Second, we limited our sample to women who underwent screening. Women actively opposed to screening may possess different attitudes or opinions. Finally, women may have given opinions they believed were ‘acceptable’ to the research team, thus introducing social desirability bias in our results.

CONCLUSION

A challenge for program providers is to formulate cervical screening promotion messages that resonate for women and account for the complex psychosocial barriers to screening that they encounter in their daily lives. Our findings, in particular, underscore the need to better understand the mechanisms by which women and their social networks assimilate and combine information from various sources about the natural history of this disease, the mechanism by which screening prevents cervical cancer, and the options that now exist in Lusaka to improve disease outcomes.

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- This study explored the conceptualization of cervical cancer among women screened for cervical lesions in Lusaka, Zambia.
- Illness descriptions integrated local knowledge and elements of promotional messages.
- Some, but not all women expressed being less fatalistic about cervical cancer than in the past.
- Screening was seen as only one of several means to gain control over cervical cancer.
- Illness representations did not differ by HIV status, though HIV-infected women were more assertive in managing their health.

Table 1

Sample questions from group discussions and in-depth interviews held with Zambian women eligible for VIA cervical screening.

Focus Group Discussion & In-depth Interview Questions
<p><i>Identity & manifestations of cervical cancer</i></p> <p>What is cancer of the mouth of the womb^a?</p> <p>What might make a woman think that she has cancer of the mouth of the womb?</p> <p><i>Controllability of cervical cancer</i></p> <p>How can women protect themselves from cancer of the mouth of the womb?</p> <p>If a woman thought she had cancer of the mouth of the womb, what might she do?</p> <p><i>Physical, psychological, social consequences of cervical cancer</i></p> <p>What does cancer of the mouth of the womb do to a woman's body?</p> <p>Are you worried that you may one day have cancer of the mouth of the womb?</p> <p>If you thought you had cancer of the mouth of the womb, would you tell anyone? Why or why not?</p> <p><i>Differences in perceptions between HIV+ and HIV- women</i></p> <p>Would you say that your HIV status makes you more aware of your health than others?</p>

^aLocal terminology for the cervix

Table 2

Summary of findings from focus group discussions and in-depth interviews with Zambian women attending a cervical cancer screening program.

Theme	Women's Responses ^a
Perceived physical manifestations of cervical cancer	Bleeding (spontaneous or prolonged periods) Vaginal discharge Vaginal odor Pain during intercourse Stomach pain Pain throughout the body Sores on vagina
Perceived causes of cervical cancer	Traditional herbs/medicines Multiple sexual partners / virus Lesions to vagina/cervix from fingernails/fingers, soaps, condoms, tampons, etc. Sorcery/witchcraft Strong communal association with HIV/AIDS
Perceived prevention measures for cervical cancer, e.g., "controllability"	Avoid physical and chemical lesions to vagina/cervix Refrain from having multiple sexual partners Cervical screening Condom use
Perceived physical consequences of cervical cancer	Spreads throughout the body Infertility Destroys womb
Perceived psychological consequences of cervical cancer	Fear of death Fear of having cancer Hopelessness, worry, anxiety
Perceived social consequences of cervical cancer	Social stigma

^aNot all responses shown.