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Title

Understanding the role of embarrassment in gynecologic screening: A qualitative study from the ASPIRE cervical cancer screening project in Uganda

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Abstract

Objective: To define embarrassment and develop an understanding of the role of embarrassment in relation to cervical cancer screening and self-collected HPV DNA testing in Uganda.

Design: Cross-sectional, qualitative study using semi-structured one-to-one interviews and focus groups.

Participants: Six key-informant health workers and 16 local women, purposively sampled. Key informant inclusion criteria: Ugandan members of the project team. Focus group inclusion criteria: Woman age 30-65 years, Luganda or Swahili speaking, living or working in the target Ugandan community. Exclusion criteria: unwillingness to sign informed consent.

Setting: Primary and tertiary low-resource setting in Kampala, Uganda

Results: In Luganda, embarrassment relating to cervical cancer is described in two forms. 'Community embarrassment' describes discomfort based upon how a person may be perceived by others. 'Personal embarrassment' relates to shyness or discomfort with her own genitalia. Community embarrassment was described in themes relating to place of study recruitment, amount of privacy in dwellings, personal relationship with health worker, handling of the vaginal swab, and misunderstanding of HPV self-collection as HIV testing. Themes of personal embarrassment related to lack knowledge, age, and novelty of the self-collection swab. Overall, embarrassment was a barrier to screening at the outset and diminished over time through education and knowledge. Fatalism regarding cervical cancer diagnosis, worry about results, and stigma associated with a cervical cancer diagnosis were other psychosocial barriers described. Overcoming psychocial barriers to screening can include peer-to-peer education, drama, and media campaigns.

Conclusions: Embarrassment and other psychosocial barriers may play a large role at the onset of a screening program, but over time as education and knowledge increase, and the social norms around screening evolve, its role diminishes. The role of peer-to-peer education and community authorities on health care cannot be overlooked and can have a major impact in overcoming psychosocial and social barriers to screening.

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Strengths and limitations of this study

Strengths
○ This study is unique in the qualitative evaluation of the specific role of embarrassment in cervical cancer screening in Uganda. ○ The study also provides a novel comparison between a group of women who have had previous education on cervical cancer screening compared with those who have not.
Limitations
○ The research team was limited in its ability to explore the perspective of all ethnic groups in the target community. ○ The focus group format may have been prohibitive for the most embarrassed women to participate.

Introduction

Approximately 233,700 women die in the developing world per year from cervical cancer which is largely preventable through screening and treatable in the early stages (1). In Uganda, 80% of cervical cancer is diagnosed at stage III or IV (2) largely due to a lack of screening infrastructure. With HPV emerging as a more sensitive screening test for cervical cancer, there are opportunities for Low and Middle Income countries (LMIC) to employ this technology to prevent cervical cancer morbidity and mortality (3). Screening programs in the developed world have made strides in increasing screening uptake (4) and recent advances such as high-risk Human Papillomavirus (hrHPV) DNA testing have improved screening among the most difficult-to-reach women (5–7). The HPV vaccine is currently being offered for primary prevention in young women but the benefits will not be realized for many years to come.

Screening remains the best option for prevention and yet in LMIC, and Uganda specifically, cytologic (Papanicolau smear) screening programs are cost-prohibitive, resource-intensive, and not widely available (8). These barriers to screening, in addition to barriers of misinformation, access, psychosocial burden, and lack of reliable treatment options make screening uptake highly challenging. If the new technologies of hrHPV DNA testing or HPV vaccination are to have any impact, a better understanding, and renewed focus on understanding a woman’s motivation for screening is essential.

A significant cervical cancer screening barrier cited by women in both the developing and developed world is embarrassment (9–15). Embarrassment in gynaecologic screening is a well-known, but ill-defined phenomenon. From screening for sexually transmitted infections to cervical cancer, many women cite embarrassment as reason for not participating in screening (4,6,7,9–12,14–24) yet little is known about the specfic components of screening that are most embarrassing and the wider impact this has on screening uptake and adherence. Some studies discuss lack of privacy, discomfort with sexuality, fear of judgement, and religious rationale as contributors to embarrassment (7,9,16,25). Embarrassment is commonly viewed as a static psychosocial barrier with little discussion on how it can evolve and dissipate. With such strong psychosocial barriers to screening, it follows that compliance with future testing or initiating screening at all, may be threatened.

Context and Setting

The ASPIRE (Advances in Screening and Prevention in Reproductive Cancers - http://www.aspireafrica.ca/) project was created to fill the gap in early detection and treatment of cervical cancer in Uganda. To date, this collaboration has conducted a baseline survey to explore the acceptability of self-collected HPV DNA testing and attitudes towards cervical cancer screening (26,27). As well as, a feasibility study enrolling 200 women and taking them from HPV swab self-collection to colposcopy and treatment (28).

The key results from the initial phase of the ASPIRE assessment of 300 women in a low-resource community in Uganda showed that embarrassment was cited as significant barrier to self-collection (26). Of those unwilling to collect a swab, 36% reported they would be embarrassed to collect a swab at home. In contrast, of those willing to collect a swab, 2% reported that they would be embarrassed to do so. Embarrassment to collect the swab at home was a significant negative predictor for participation (AOR 0.09 95% CI: 0.03-0.29) (26).

The objectives of this study are to define embarrassment in Uganda and develop an understanding of the role of embarrassment in relation to cervical cancer screening and self-collected HPV DNA testing. In addition, the aim is to determine viable solutions to overcoming barriers to embarrassament specifically and to cervical cancer screening overall. This study was designed to better understand embarrassment as a barrier to screening with the hope of informing the development of a prospective study investigating community-based HPV self-collection.

Methods

We conducted key stakeholder interviews with the Ugandan ASPIRE research team which included members of the Department of Obstetrics and Gynecology at the local tertiary hospital, Nurses from the local health unit, and community health workers in the target community. This method was used to obtain an initial framework to understand embarrassment in Uganda. We subsequently conducted three community focus groups to further develop these ideas. The community focus group discussion guide was developed using peer-reviewed research articles on key barriers and facilitators to cervical caner screening (9,20,29–32) and discussion points generated within the ASPIRE key stakeholder interviews (Box 1). This methodology was used to incorporate local knowledge and cultural practice with current peer-reviewed knowledge. All participants signed informed consent and their confidentiality was ensured. This study received ethical approval from the local university in Uganda and the partner University in Canada.

Box 1. Focus Group Discussion Guide

Items included in the focus group topic guide
(1) Definition of embarrassment with regard to cervical cancer
(2) Implications of embarrassment on cervical cancer screening and treatment

(including HPV self-collection) (3) Overcoming embarrassment (4) Other barriers to cervical cancer screening (5) Perception of cervical cancer (6) Evaluation and future directions for the ASPIRE project
Items included in stakeholder consultation
(1-6) of the focus group topic guide (7) Focus group methodology (8) Focus group data analysis

A subset of key stakeholders participated in the focus groups to facilitate discussion. Local women were invited to participate through a purposive sampling lead by the ASPIRE community health workers (33). We recruited women between the ages of 30-69 who live or work within the target community in Uganda. Using the rich knowledge of the ASPIRE community health workers, we sought information rich participants who would be willing to share their views. We recruited a total of 16 women to attend 3 focus groups. The first focus group was comprised of 8 previous participants in the ASPIRE project. The second focus group was comprised of 8 women naïve to the ASPIRE project. The third focus group was conducted with all 16 women to review results, disseminate the findings, and seek clarification on any underdeveloped ideas. This recruitment strategy was specifically chosen to capture diverse perspectives from an experienced group and a naïve group. We hypothesized that the ASPIRE-experienced group would describe less embarrassment than the ASPIRE-Naive group. The community health workers involved in the project acted as focus group facilitators and the ASPIRE project coordinator (DB) assisted in translation and cultural interpretation of the results. Transcription and thematic analysis was undertaken following each focus group, with the goal of generating new ideas for discussion in subsequent groups. The topics were flexible and driven by the focus-group participants, in keeping with the foundation of qualitative research (34).

Data collection and Analysis

All stakeholder interviews and focus group discussions were audiotaped and transcribed by the primary researcher (FT) and Luganda translator (DB). Workshops were undertaken in Luganda and English. The English portion of the audiotape was transcribed. The Luganda translator reviewed the audiotape and written transcript to verify appropriate translation and content. During the second review, the translator also assisted as cultural liaison to ensure that the data correctly reflected the Ugandan cultural context. A thematic analysis was undertaken after the each focus group and the code structure was was refined with each analysis.

A final thematic analysis was undertaken at the conclusion of the three workshops by FT and the data was presented to the participants at a final meeting to ensure that the content was correct and reflective of the intentions of the group (35). The coding structure was developed using grounded theory and content analysis (36). A second independent thematic analysis was undertaken by MS to enhance inter-rater reliability (37) and to ensure that all themes were internally convergent and externally divergent, meaning that categories were structured so that they were internally consistent, but distinct from one another. (38) Following the development of the code structure, a framework analysis was undertaken using the Health Belief Model (39). This framework has been utilized in understanding screening behaviours, preventative actions, illness behaviour and has been well-validated in these settings (20,21,39).

Results

Demographics

Of the 16 women that we surveyed, the average age was 44 years old with a range between 30 and 57. The majority of women were married (50%) and had attended primary school with or without some secondary education (75%). Eighty-eight percent worked outside and the home, lived in the target district in Kampala, within 30 minutes from the health centre (Table 1).

Table 1.

Demographic characteristics of focus group participants (n=16)*

Characteristic		*Number of Participants (%)*
Age groups		
	26-30	2 (13)
	31-35	4 (25)
	36-40	1 (6)
	41-45	1 (6)
	46-50	0 (0)
	51-55	5 (31)
	56-60	3 (19)
Marital Status		
	Single	7 (44)
	Married	8 (50)
	Widowed	1 (6)
Education of the participant		
	No schooling or some primary schooling	1 (6)
	Primary with or without some secondary schooling	12 (75)
	Secondary	1 (6)
	Postsecondary	2 (13)

Work outside of home		
	No	2 (13)
	Yes	14 (88)
Live in Kisenyi		
	No	2 (13)
	Yes	14 (88)
Housing		
	Rent	10 (63)
	Own	6 (38)
Religion		
	7th Day Adventist	1 (6)
	Anglican/protestant	4 (25)
	Catholic	5 (31)
	Muslim	6 (38)
Time to walk to nearest health center, min		
	< 30	14 (88)
	30 - 60	2 (13)

* values for some variables do not sum to 100% due to rounding

Perceived Susceptibility

Women perceived themselves to be at low risk for HPV infection, but the HIV screening model influenced perceptions for HPV screening. They could understand the need for HPV screening from their knowledge of the HIV paradigm. For some women, there was a belief that testing was only necessary for sexually active women. Similarly for cervical cancer, women perceived themselves to be at low risk and there was a lack of knowledge regarding the relationship between HPV and cervical cancer. In addition, most people do not seek care unless there are symptoms. One woman highlighted,

> *"For Africans its hard to go to the hospital if you are not sick. You have to actually be sick in bed before you will go for treatment."*

Perceived Severity

Women acknowledged a sense of fatalism regarding cancer and felt that 'knowing their status' would be a situation too difficult to cope with. In addition, they didn't want to worry about the outcome. They felt that worrying would make the disease worse. One woman described,

> *"They don't want to know their [cervical cancer screening] status because if they know their status, they don't see any solution. They will just die, there is no treatment, there is nothing to be fixed. It is like a death sentence."*

Surprisingly, some described that they would rather have HIV because there is a perception that there is an effective treatment, compared to a cancer diagnosis that has no cure.

> *“Nowadays, people say that if someone to gets cancer, at least let her get HIV, than getting cancer, because for HIV there is treatment. but for cancer, there is no treatment.”*

There were also some women who felt that the testing and/or biopsy would actually cause cancer. Some women perceived that before they got a biopsy/test they were healthy and after the test, they were sick, so it must have been the test that made them sick. Women were also concerned about the overbearing cost of cancer treatment in LMIC. Alternatively, those women who had an awareness of HPV perceived that HPV could be treated and this diagnosis was less severe.

Barriers to cervical cancer screening

Barriers to cervical cancer screening and HPV self-collection could easily be divided into barriers inherent to screening in general, barriers related to the use of the HPV swab, and overarching barriers related to the outcomes of the test (Table 2). Our focus group participants felt that cervical cancer screening in general was predicated upon trust in the researchers, adequate knowledge and an awareness of their risk of cervical cancer. One woman felt that a major barrier to screening was the worry that screening would incite, she described,

> *“What if I get my sample. What results will I get? That fear of getting the results, … Am I positive? Am I negative? Really people fear to hear what [results] they will get, so they end up saying, I'd rather not test. I'd rather not collect, so that I may not know any results about what is happening to me.”*

The women had valuable insight into the barriers associated with HPV self-collection. Many women admitted to the initial novelty of the swab and discomfort with inserting items into the vagina as barriers. Women were also concerned of the swab causing infection or injury. For one group, there was significant discussion regarding hygiene and the cleanliness of vaginal discharge. Closely related to this was the associated embarrassment of having to give a swab of vaginal secretions (with a potential smell) to a health worker.

Gender perspective

Interestingly, barriers that were not endorsed included spousal permission and cultural beliefs, practices, and norms. When questioned, women were universally in support of screening whether they had spousal permission or not. One woman alluded to the mistrust and lack of communication within marriages as a source of HPV risk and as a result felt strongly about the importance of screening.

> *"You have to take care of your life. You can't say that my husband refused me to go for testing. It is not his life, its mine. You have to protect your life."*

> *"These men, they always go for treatment. Like an example for HIV. they test and they are positive. They start the treatment without telling their wives, so he keeps on going for treatment, when the wife doesn't know anything. So everyone is concerned about his or her life."*

Women in Kisenyi also described cultural practices that normalized the insertion of items into the vagina. Not all women endorsed this activity, but some women reported inserting herbs to widen the birth canal during the later stages of pregnancy, which provided some women a comfort with their genitalia.

> *"I don't think it has to do with shyness, because women they actually douche, they use herbs for all sorts of things. Even when they are pregnant, they use herbs, it is in most of cultures here, particularly in central Uganda, you use herbs to enlarge your birth canal to make sure you don't get an episiotomy."*

Table 2. Health Belief Model Framework Analysis

Health Belief Model Parameter	ASPIRE Respondents	
	HPV Self-Collection	Cervical Cancer
Perceived Susceptibility	Perceived risk is low Testing will cause the disease Screening is only necessary for sexually active women	
	HIV education model increases risk awareness	Limited knowledge of link between HPV and cervical cancer
Perceived Severity	HPV can be treated	Cervical cancer is a death sentence Cervical cancer treatment is expensive No cure for cancer Would rather get HIV than cervical cancer
Perceived Benefits	Early detection Treatment availibility Protecting yourself	Some treatment may be beneficial
Perceived Barriers	Lack of time Lack of knowledge Mistrust of Researchers Embarrassment Worry about outcomes Health-seeking behaviour only prompted by symptoms	
	Discomfort with inserting items into vagina Concern with hygiene and/or vaginal discharge Fear of pain or injury Novelty of test	Fatalism Inability to cope with results Stigma of having cancer
Cues to Action	Local Leaders / Community Health workers Peer-to-Peer education and recruitment Increasing knowledge Screening necessary without symptoms Fear of contracting cancer	
Self-efficacy	Spousal permission not required	

Embarrassment

There were many overlapping themes with barriers to screening and the associated embarrassment. Through our focus groups and key stakeholder discussions, there were two meaningful definitions of embarrassment. The first definition was 'community embarrassment' ('kiswaaza" in Luganda). It was described as the discomfort that one may feel depending on how they are perceived by others. The second can be described as 'personal embarrassment' ('kikuswaaza' in Luganda) or shyness/discomfort related to their own genitalia (Table 3).

Table 3.

Factors associated with embarrassment

Community Embarrassment
Confusion of HPV for HIV
Place of recruitment
Location of self-collection
Privacy
Relationship with health worker
Gender of the physician performing screening
Handling of the swab
Personal Embarrassment
Age of participant
Novelty of the test
lack of knowledge

An important theme was the diminishment of embarrassment over time. In the group of women with previous involvement in the ASPIRE project, they described having embarrassment initially, but after multiple education meetings and actually performing self-collection, they didn't feel embarrassed about screening. In fact, they noted that they would overcome their embarrassment if they knew they needed to for another reason. This was clearly described by this participant,

> *"After knowing that you are HPV positive, then the fear goes away because you want to know what is going on, so you are free to go to the doctor to have the pelvic examination to see what is going on … you need to know what next. See the doctor at that stage, no embarrassment."*

The data demonstrates that embarrassment is not a static emotion. It is often quoted as an important barrier to screening, yet its not acknowledged as potentially the most modifiable barrier, compared to other factors such as age, socioeconomic status, and religion. This woman describes the modifiability of embarrassment,

> *"Embarrassment is not an issue concerning cervical cancer, Because HIV is very shameful compared to cancer. Nowadays people don't feel ashamed because of HIV because they are used to it. So even with cancer, people will get used to it and there will be no more embarrassment, it's not an issue. Through more training and seminars, people will get to know more, they will come to self-collection and everything will be okay."*

Perceived Benefits and Cues to Action

The women in both focus groups universally acknowledged that embarrassment would not be a major deterrent to screening if women had appropriate knowledge and education about the need for screening and if they had a private place to perform the self-collection. All women endorsed peer-to-peer education and engaging local leaders as some of the best strategies to recruit women and in fact, many women had already told their friends about the project and were eager to participate in the next phase of the ASPIRE project.

> *"Through these people who have self-collected and through more training, they also help those who have never attended the training, who have never self-collected, to make them be confident that self-collection is not painful. You do it yourself, it's not the doctor doing it. I think that through them, more people will come to do the self-collection."*

Overall participants did not see large barriers to expanding the project, capacity building and resources, notwithstanding. The women were very positive that further recruitment and screening would not be a barrier. The history of the ASPIRE project since 2008 and the ongoing education initiatives have already 'sensitized' women to the topic. Some women articulated their knowledge of the importance of screening and the ability to diagnose and treat the disease early. They had a variety of suggestions such as media messages, seminars and workshops, counselling sessions, incentives, as a means to improve uptake for screening.

Discussion

In the setting of a largely preventable condition and the availability of a vaccine, it is a great tragedy that cases of cervical cancer continue to rise and that more research is not being done on the science of implementation. Significant research is focused on screening senstivity, specificity, vaccine targets and efficacy, but the most important of these factors is whether people will engage in screening and vaccination. This study is uniquely focused on implementation and engagement of the local women in a low-recource community in Uganda in a novel screening program that has the potential to make cervical cancer screening widely available in the community where people live and work.

The medical literature provides a limited discussion of the psychosocial aspects of screening and these factors play a vital role in screening uptake and ongoing engagement with the patient. One study by Mutyaba and colleagues demonstrates that screening among medical professionals, who are charged with carrying out screening, is low (40). If even medical workers, who are meant to be the most informed are reluctant to partake in screening, then much work needs to be done to change the paradigm.

Health Belief Model

The Health Belief Model provides an important framework upon which to understand cervical cancer screening uptake and treatment. We found that women did not percieve themselves to be at great risk of cervical cancer, but that they perceived the diagnosis to be quite severe and fatal. They did not see the benefit of screening if results would only cause worry and a definitive treatment was not available. For those who had the knowledge that the disease could be caught early and treated, that was a significant cue to action to initiate screening. These findings are consistent with other studies exploring cervical cancer screening behaviour (8,20,21,29,41).

Embarrassment

The women of Kisenyi defined embarrassment in two forms, community embarrassment and personal embarrassment, which are consistent with the literature. The first is closely related to a definition by the psychology literature which describes embarrassment as the uncomfortable, self-concious, feeling a person has following the transgression of a social norm or rule (42). This is in-relation to a real, or perceived, other person. Personal embarrassment is closely related to, shame, which differs in that is is defined by a person's uncomfortable feeling with one's self (42).

The majority of the research regarding embarrassment and health screening is in the colorectal screening literature. In this setting, Consedine and colleagues sought to further characterize embarrassment by focusing on the specific aspects of the colorectal screening encounter that engendered embarrassment. They were able to discern a distinct phenomenon called medical embarrassment which is specific to the medical encounter and is not indicative of trait embarrassment (43). Medical embarrassment was further subdivided by Consedine into bodily embarrassment and judgment concern. In his research, these two factors were shown to have significant impact in screening behaviour (25,43). Women in our study were concerned with handling of swab and the potential associated smell of the sample, which is closely related to bodily embarrassment. The women in our study also focused on judgement concern in their discomfort around perceptions of being tested for HIV, concerns for privacy, and the importance of location of self-collection and study recruitment.

Another key finding from our study is the dynamic nature of embarrassment, and other psychosocial barriers, and the profound role that acknowledging and addressing psychosocial barriers can have in uptake of cervical cancer screening and treatment. Participants in our study noted that through the ASPIRE education seminars, their knowledge of early detection and treatment increased and their fear and embarrassment of screening dimished. After learning about the positive benefits of screening, they opted to screen, despite initial psychosocial barriers. White and colleagues conducted 6 focus groups and 10 in-depth of women attending VIA screening in a primary health care centre in Zambia. Women described similar worries and fears regarding the fatality of cervical cancer and the associated reluctance of screening (41). In this study, women were exposed to the education program in a local clinic in Zambia and their attitudes about screening changed as a result. This lends credence to our data and supports the importance of addressing psychosocial concerns. In fact, addressing psychosocial barriers may show greater benefit in a shorter amount of time, then attempts to address other known berriers such as socio-economic status, education level, access to services, or cost of services.

Overcoming psychosocial barriers

The participants of our study reiterated the power of local leaders and peer-to-peer education several times. In a culture that often relies on community authorities, such as *Sengas* (paternal aunties) for health information, rather than physicians, the role of these community members is vital (8). Women often discussed the role of their peers in encouraging them to come for screening and the important role that peers have in ‘changing the social norm’ regarding screening. What once seemed foreign and intimidating, may become familiar and approachable following the advice of a peer. This has been demonstrated among female and male sex workers in Africa in the setting of HIV/AIDS screening and treatment and has the great potential for cervical cancer screening and treatment (44).

Women also described the importance of changing the social norms around screening through media compaigns, drama groups, and overall increased awareness, similar to what has been done in the setting of HIV/AIDS. In the early stages of HIV/AIDS screening and treatment programs, the stigma and fatalism associated with an HIV/AIDS diagnosis was similar to what many women are currently reporting for cervical cancer. As antiretrovirals became more widely available, education improved, and the social norm changed around the topic, more women were willing to test. It is hoped that the same can be achieved with cervical cancer screening.

Strengths and Limitations

This study is the first of its kind to specifically address embarrassment, in depth, as a psychosocial barrier to gynecologic screening. The assessment was uniquely timed following a pilot study on HPV DNA self-collection in a community-setting, so women could comment on cervical cancer screening in general and HPV DNA testing in particular. The opinions elicited in this study were also unique in incorporating those who had been exposed to previous educational screening for cervical cancer and those who had not, to provide a diversity of perspectives.

This study was limited in its exploration of the multiple ethnic groups within the target community. We were able to access Luganda and Swahili speakers, but a significant Somali population exists in the community that were difficult to recruit due to language barriers. Furthermore, views of the most embarrassed women may not have been elicited given the focus group format. It may be that those women most embarrassed to discuss screening would be deterred by such a methodology. Unfortunately, an in-depth interview format, also may not reach these women.

Conclusions and Policy Implications

This study demonstrates the important role of psychosocial barriers in cervical cancer screening and the factors that facilitate the modification of these barriers. The women in this study reported many of the same psychosocial barriers to screening (fear, anxiety, embarrassment, shame) as in other studies, yet they also noted that these diminished greatly with increasing knowledge and education. Participants overwhelmingly supported the role of peer-to-peer education in mitigating psychosocial barriers and facilitating screening uptake.

The results in their final form will be presented back to the local community for knowledge dissemination and the data will also play a critical role in the development and design of a larger study exploring the clinical outcomes associated with community-based HPV self-collection versus Visual Inspection with Acetic Acid. In general, this data supports the integration of psychosocial outcomes at the onset of any screening program. In doing so, participants may experience less embarrassment and be more willing to engage in further screening and treatment activities.

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Contributorship Statement

Flora Teng - primary author, present at all focus groups, completed transcription, thematic analysis of data and wrote majority of manuscript.
Sheona Mitchell - secondary author, contributed to study design, analysis and structure of discussion, present at focus groups, edited manuscript.
Musa Sekikubo - co-author, contributed to study design and secondary thematic analysis, edited manscript.
Christine Biryabarema - co-author, contributed to study design and guided focus group design.
Josaphat Byamugisha - co-author, contributed to study design and format of analysis, edited manuscript.
Malcolm Steinberg - co-author, advised extensively in initial study design.
Deborah Money - co-author, advised in initial study design and edited manuscript.
Gina Ogilvie - lead author, advised in initial study design, thematic analysis and contributed to final editing of the manuscript.

Data Management and Sharing: All authors had full access to the data of the study and accept full responsibility for the integrity of the data and the accuracy of the analysis. Thematic analysis and interview transcripts will be available from the corresponding author upon request.

Competing Interests:
None of the authors have a conflict of interest.

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Title

Understanding the role of embarrassment in gynecologic screening: A qualitative study from the ASPIRE cervical cancer screening project in Uganda

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Abstract

Objective: To define embarrassment and develop an understanding of the role of embarrassment in relation to cervical cancer screening and self-collected HPV DNA testing in Uganda.

Design: Cross-sectional, qualitative study using semi-structured one-to-one interviews and focus groups.

Participants: Six key-informant health workers and 16 local women, purposively sampled. Key informant inclusion criteria: Ugandan members of the project team. Focus group inclusion criteria: Woman age 30-69 years, Luganda or Swahili speaking, living or working in the target Ugandan community. Exclusion criteria: unwillingness to sign informed consent.

Setting: Primary and tertiary low-resource setting in Kampala, Uganda

Results: In Luganda, embarrassment relating to cervical cancer is described in two forms. ‘Community embarrassment’ describes discomfort based upon how a person may be perceived by others. ‘Personal embarrassment’ relates to shyness or discomfort with her own genitalia. Community embarrassment was described in themes relating to place of study recruitment, amount of privacy in dwellings, personal relationship with health workers, handling of the vaginal swab, and misunderstanding of HPV self-collection as HIV testing. Themes of personal embarrassment related to lack knowledge, age, and novelty of the self-collection swab. Overall, embarrassment was a barrier to screening at the outset and diminished over time through education and knowledge. Fatalism regarding cervical cancer diagnosis, worry about results, and stigma associated with a cervical cancer diagnosis were other psychosocial barriers described. Overcoming psychosocial barriers to screening can include peer-to-peer education, drama, and media campaigns.

Conclusions: Embarrassment and other psychosocial barriers may play a large role at the onset of a screening program, but over time as education and knowledge increase, and the social norms around screening evolve, its role diminishes. The role of peer-to-peer education and community authorities on health care cannot be overlooked and can have a major impact in overcoming psychosocial and social barriers to screening.

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Strengths and limitations of this study

Strengths
○ This study is unique in the qualitative evaluation of the specific role of embarrassment in cervical cancer screening in Uganda. ○ The study also provides a novel comparison between a group of women who have had previous education on cervical cancer screening compared with those who have not.
Limitations
○ The research team was limited in its ability to explore the perspective of all ethnic groups in the target community. ○ The focus group format may have been prohibitive for the most embarrassed women to participate.

Introduction

Approximately 233,700 women die in the developing world every year from cervical cancer which is largely preventable through screening and treatable in the early stages (1). In Uganda, 80% of cervical cancer is diagnosed at stage III or IV (2) largely due to a lack of screening infrastructure. With HPV emerging as a more sensitive screening test for cervical cancer, there are opportunities for Low and Middle Income countries (LMIC) to employ this technology to prevent cervical cancer morbidity and mortality (3). Screening programs in the developed world have made strides in increasing screening uptake (4) and recent advances such as high-risk Human Papillomavirus (hrHPV) DNA testing have improved screening among the most difficult-to-reach women (5–7). The HPV vaccine is currently being offered for primary prevention in young women but the benefits will not be realized for many years to come.

Screening remains the best option for prevention and yet in LMIC, and Uganda specifically, cytologic (Papanicolau smear) screening programs are cost-prohibitive, resource-intensive, and not widely available (8). These barriers to screening, in addition to barriers of misinformation, access, psychosocial burden, and lack of reliable treatment options make screening uptake highly challenging. If the new technologies of hrHPV DNA testing or HPV vaccination are to have any impact, a better understanding, and renewed focus on understanding a woman's motivation for screening is essential.

A significant cervical cancer screening barrier cited by women in both the developing and developed world is embarrassment (9–15). Embarrassment in gynaecologic screening is a well-known, but ill-defined phenomenon. From screening for sexually transmitted infections to cervical cancer, many women cite embarrassment as reason for not participating in screening (4,6,7,9–12,14–24) yet little is known about the specfic components of screening that are most embarrassing and the wider impact this has on screening uptake and adherence. Some studies discuss lack of privacy, discomfort with sexuality, fear of judgement, and religious rationale as contributors to embarrassment (7,9,16,25). Embarrassment is commonly viewed as a static psychosocial barrier with little discussion on how it can evolve and dissipate. With such strong psychosocial barriers to screening, it follows that compliance with future testing or initiating screening at all, may be threatened.

Context and Setting

The ASPIRE (Advances in Screening and Prevention in Reproductive Cancers - http://www.aspireafrica.ca/) project was created to fill the gap in early detection and treatment of cervical cancer in Uganda. To date, this collaboration has conducted a baseline survey to explore the acceptability of self-collected HPV DNA testing and attitudes towards cervical cancer screening (26,27). As well as, a feasibility study enrolling 200 women and taking them from HPV swab self-collection to colposcopy and treatment (28).

The key results from the initial phase of the ASPIRE assessment of 300 women in a low-resource community in Uganda showed that embarrassment was cited as significant barrier to self-collection (26). Of those unwilling to collect a swab, 36% reported they would be embarrassed to collect a swab at home. In contrast, of those willing to collect a swab, 2% reported that they would be embarrassed to do so. Embarrassment to collect the swab at home was a significant negative predictor for participation (AOR 0.09 95% CI: 0.03-0.29) (26).

The objectives of this study are to define embarrassment in Uganda and develop an understanding of the role of embarrassment in relation to cervical cancer screening and self-collected HPV DNA testing. In addition, the aim is to determine viable solutions to overcoming barriers to embarrassament specifically and to cervical cancer screening overall. This study was designed to better understand embarrassment as a barrier to screening with the hope of informing the development of a prospective study investigating community-based HPV self-collection.

Methods

We conducted key stakeholder interviews with the Ugandan ASPIRE research team which included members of the Department of Obstetrics and Gynecology at the local tertiary hospital, nurses from the local health unit, and community health workers in the target community. This method was used to obtain an initial framework to understand embarrassment in Uganda. We subsequently conducted three community focus groups to further develop these ideas, the first two groups included 8 women in each and the third group involved all participants that attended the first two focus groups. The community focus group discussion guide was developed using peer-reviewed research articles on key barriers and facilitators to cervical cancer screening (9,20,29–32) and discussion points generated within the ASPIRE key stakeholder interviews (Box 1). This methodology was used to incorporate local knowledge and cultural practice with current peer-reviewed knowledge. All participants signed informed consent and their confidentiality was ensured. This study received ethical approval from the local university in Uganda and the partner University in Canada.

Box 1. Focus Group Discussion Guide

Items included in the focus group topic guide
(1) Definition of embarrassment with regard to cervical cancer (2) Implications of embarrassment on cervical cancer screening and treatment (including HPV self-collection) (3) Overcoming embarrassment (4) Other barriers to cervical cancer screening (5) Perception of cervical cancer

(6) Evaluation and future directions for the ASPIRE project
Items included in stakeholder consultation
(1-6) of the focus group topic guide (7) Focus group methodology (8) Focus group data analysis

A subset of key stakeholders participated in the focus groups to facilitate discussion. Local women were invited to participate through a purposive sampling lead by the ASPIRE community health workers (33). We recruited women between the ages of 30-69 who live or work within the target community in Uganda. Using the rich knowledge of the ASPIRE community health workers, we sought information rich participants who would be willing to share their views. We recruited a total of 16 women to attend the focus groups. The first focus group was comprised of 8 previous participants in the ASPIRE project. The second focus group was comprised of 8 women naïve to the ASPIRE project. The third focus group was conducted with all 16 women to review results, disseminate the findings, and seek clarification on any underdeveloped ideas. This recruitment strategy was specifically chosen to capture diverse perspectives from an experienced group and a naïve group. We hypothesized that the ASPIRE-experienced group would describe less embarrassment than the ASPIRE-naïve group. The community health workers involved in the project acted as focus group facilitators and the ASPIRE project coordinator (DB) assisted in translation and cultural interpretation of the results. Transcription and thematic analysis was undertaken following each focus group, with the goal of generating new ideas for discussion in subsequent groups. The topics were flexible and driven by the focus-group participants, in keeping with the foundation of qualitative research (34).

Data collection and Analysis

All stakeholder interviews and focus group discussions were audiotaped and transcribed by the primary researcher (FT) and Luganda translator (DB). Workshops were undertaken in Luganda and English. The English portion of the audiotape was transcribed. The Luganda translator reviewed the audiotape and written transcript to verify appropriate translation and content. During the second review, the translator also assisted as cultural liaison to ensure that the data correctly reflected the Ugandan cultural context. A thematic analysis was undertaken after the each focus group and the code structure was was refined with each analysis. The stakeholder interviews were analyzed and reported in the Results and were also used to inform content of the discussion guide used for subsequent focus groups.

A final thematic analysis was undertaken at the conclusion of the three workshops by FT and the data was presented to the participants at a final meeting to ensure that the content was correct and reflective of the intentions of the group (35). The coding structure was developed using grounded theory and content analysis (36). A second independent thematic analysis was undertaken by MS to enhance inter-rater reliability (37) and to ensure that all themes were internally convergent and externally divergent, meaning that categories were structured so that they were internally consistent, but distinct from one another. (38) Following the development of the code structure, a framework analysis was undertaken using the Health Belief Model (39). This framework has been utilized in understanding screening behaviours, preventative actions, illness behaviour and has been well-validated in these settings (20,21,39).

Results

Demographics

Of the 16 women that we surveyed, the average age was 44 years old with a range between 30 and 57. The majority of women were married (50%) and had attended primary school with or without some secondary education (75%). Eighty-eight percent worked outside the home and lived in the target district in Kampala within 30 minutes from the health centre (Table 1).

Table 1.

Demographic characteristics of focus group participants (n=16)

Characteristic		*Number of Participants*
Age groups		
	26-30	2
	31-35	4
	36-40	1
	41-45	1
	46-50	0
	51-55	5
	56-60	3
Marital Status		
	Single	7
	Married	8
	Widowed	1
Education of the participant		
	No schooling or some primary schooling	1
	Primary with or without some secondary schooling	12
	Secondary	1
	Postsecondary	2
Work outside of home		
	No	2
	Yes	14
Live in		

Kisenyi		
	No	2
	Yes	14
Housing		
	Rent	10
	Own	6
Religion		
	7th Day Adventist	1
	Anglican/protestant	4
	Catholic	5
	Muslim	6
Time to walk to nearest health center, min		
	< 30	14
	30 - 60	2

Perceived Susceptibility

Women perceived themselves to be at low risk for HPV infection, but the HIV screening model influenced perceptions for HPV screening. They could understand the need for HPV screening from their knowledge of the HIV paradigm. For some women, there was a belief that testing was only necessary for sexually active women. Similarly for cervical cancer, women perceived themselves to be at low risk and there was a lack of knowledge regarding the relationship between HPV and cervical cancer. In addition, most people do not seek care unless there are symptoms. One woman highlighted,

> *"For Africans its hard to go to the hospital if you are not sick. You have to actually be sick in bed before you will go for treatment." (Focus Group 1 – Previous ASPIRE Participant)*

Perceived Severity

Women acknowledged a sense of fatalism regarding cancer and felt that 'knowing their status' would be a situation too difficult to cope with. In addition, they didn't want to worry about the outcome. They felt that worrying would make the disease worse. One woman described,

> *"They don't want to know their [cervical cancer screening] status because if they know their status, they don't see any solution. They will just die, there is no treatment, there is nothing to be fixed. It is like a death sentence." (Key Stakeholder Interview)*

Surprisingly, some described that they would rather have HIV because there is a perception that there is an effective treatment, compared to a cancer diagnosis that has no cure.

> *"Nowadays, people say that if someone to gets cancer, at least let her get HIV, than getting cancer, because for HIV there is treatment, but for cancer, there is no treatment." (Focus Group 2 – ASPIRE Naïve Participant)*

There were also some women who felt that the testing and/or biopsy would actually cause cancer. Some women perceived that before they got a biopsy/test they were healthy and after the test, they were sick, so it must have been the test that made them sick. Women were concerned about the overbearing cost of cancer treatment in LMIC. Alternatively, those women who had an awareness of HPV perceived that HPV could be treated and this diagnosis was less severe.

Perceived Benefits and Cues to Action

The women in both focus groups universally acknowledged that embarrassment would not be a major deterrent to screening if women had appropriate knowledge and education about the need for screening and if they had a private place to perform the self-collection. All women endorsed peer-to-peer education and engaging local leaders as some of the best strategies to recruit women and in fact, many women had already told their friends about the project and were eager to participate in the next phase of the ASPIRE project.

> *"Through these people who have self-collected and through more training, they also help those who have never attended the training, who have never self-collected, to make them be confident that self-collection is not painful. You do it yourself, it's not the doctor doing it. I think that through them, more people will come to do the self-collection." (Focus Group 1 – ASPIRE Participant)*

Overall participants did not see large barriers to expanding the project, capacity building and resources, notwithstanding. The women were very positive that further recruitment and screening would not be a barrier. The history of the ASPIRE project since 2008 and the ongoing education initiatives have already 'sensitized' women to the topic. Some women articulated their knowledge of the importance of screening and the ability to diagnose and treat the disease early. They had a variety of suggestions such as media messages, seminars and workshops, counselling sessions, incentives, as a means to improve uptake for screening.

Barriers to cervical cancer screening

Barriers to cervical cancer screening and HPV self-collection could easily be divided into barriers inherent to screening in general, barriers related to the use of the HPV swab, and overarching barriers related to the outcomes of the test (Table 2). Our focus group participants felt that cervical cancer screening in general was predicated upon trust in the researchers, adequate knowledge and an awareness of their risk of cervical cancer. One woman felt that a major barrier to screening was the worry that screening would incite, she described,

> *"What if I get my sample. What results will I get? That fear of getting the results, … Am I positive? Am I negative? Really people fear to hear what [results] they will get, so they end up saying, I'd rather not test. I'd rather not collect, so that I may not know any results about what is happening to me." (Focus Group 1 – ASPIRE Participant)*

The women had valuable insight into the barriers associated with HPV self-collection. Many women admitted to the initial novelty of the swab and discomfort with inserting items into the vagina as barriers. Women were also concerned of the swab causing infection or injury. For one group, there was significant discussion regarding hygiene and the cleanliness of vaginal discharge. Closely related to this was the associated embarrassment of having to give a swab of vaginal secretions (with a potential smell) to a health worker.

Gender perspective

Interestingly, barriers that were not endorsed included spousal permission and cultural beliefs, practices, and norms. When questioned, women were universally in support of screening whether they had spousal permission or not. One woman alluded to the mistrust and lack of communication within marriages as a source of HPV risk and as a result felt strongly about the importance of screening.

> *"You have to take care of your life. You can't say that my husband refused me to go for testing. It is not his life, its mine. You have to protect your life." (Focus Group 2 – ASPIRE Naïve Participant)*

> *"These men, they always go for treatment. Like an example for HIV. they test and they are positive. They start the treatment without telling their wives, so he keeps on going for treatment, when the wife doesn't know anything. So everyone is concerned about his or her life." (Focus Group 2 – ASPIRE Naïve Participant)*

Women in Kisenyi also described cultural practices that normalized the insertion of items into the vagina. Not all women endorsed this activity, but some women reported inserting herbs to widen the birth canal during the later stages of pregnancy, which provided some women a comfort with their genitalia.

> *"I don't think it has to do with shyness, because women they actually douche, they use herbs for all sorts of things. Even when they are pregnant, they use herbs, it is in most of cultures here, particularly in central Uganda, you use herbs to enlarge your birth canal to make sure you don't get an episiotomy." (Key Stakeholder Interview)*

Table 2. Health Belief Model Framework Analysis

Health Belief Model Parameter	ASPIRE Respondents	
	HPV Self-Collection	Cervical Cancer
Perceived Susceptibility	Perceived risk is low Testing will cause the disease Screening is only necessary for sexually active women	
	HIV education model increases risk awareness	Limited knowledge of link between HPV and cervical cancer
Perceived Severity	HPV can be treated	Cervical cancer is a death sentence Cervical cancer treatment is expensive No cure for cancer Would rather get HIV than cervical cancer
Perceived Benefits	Early detection Treatment availibility Protecting yourself	Some treatment may be beneficial
Perceived Barriers	Lack of time Lack of knowledge Mistrust of Researchers Embarrassment Worry about outcomes Health-seeking behaviour only prompted by symptoms	
	Discomfort with inserting items into vagina Concern with hygiene and/or vaginal discharge Fear of pain or injury Novelty of test	Fatalism Inability to cope with results Stigma of having cancer
Cues to Action	Local Leaders / Community Health workers Peer-to-Peer education and recruitment Increasing knowledge Screening necessary without symptoms Fear of contracting cancer	
Self-efficacy	Gender Perspective - Spousal permission not required	

Embarrassment

There were many overlapping themes with barriers to screening and the associated embarrassment. Through our focus groups and key stakeholder discussions, there were two meaningful definitions of embarrassment. The first definition was 'community embarrassment' ('kiswaaza" in Luganda). It was described as the discomfort that one may feel depending on how they are perceived by others. The second can be described as 'personal embarrassment' ('kikuswaaza' in Luganda) or shyness/discomfort related to their own genitalia (Table 3).

Table 3.
Factors associated with embarrassment

Community Embarrassment
Confusion of HPV for HIV Place of recruitment Location of self-collection Privacy Relationship with health worker Gender of the physician performing screening Handling of the swab
Personal Embarrassment
Age of participant Novelty of the test lack of knowledge

An important theme was the diminishment of embarrassment over time. In the group of women with previous involvement in the ASPIRE project, they described having embarrassment initially, but after multiple education meetings and actually performing self-collection, they didn't feel embarrassed about screening. In fact, they noted that they would overcome their embarrassment if they knew they needed to for another reason. This was clearly described by this participant,

> *"After knowing that you are HPV positive, then the fear goes away because you want to know what is going on, so you are free to go to the doctor to have the pelvic examination to see what is going on … you need to know what next. See the doctor at that stage, no embarrassment." (Focus Group 3 – Participant)*

The data demonstrates that embarrassment is not a static emotion. It is often quoted as an important barrier to screening, yet its not acknowledged as potentially the most modifiable barrier, compared to other factors such as age, socioeconomic status, and religion. This woman describes the modifiability of embarrassment,

> *"Embarrassment is not an issue concerning cervical cancer, Because HIV is very shameful compared to cancer. Nowadays people don't feel ashamed because of HIV because they are used to it. So even with cancer, people will get used to it and there will be no more embarrassment, it's not an issue. Through more training and seminars, people will get to know more, they will come to self-collection and everything will be okay." (Focus Group 3 – Participant)*

Discussion

In the setting of a largely preventable condition and the availability of a vaccine, it is a great tragedy that cases of cervical cancer continue to rise and that more research is not being done on the science of implementation. Significant research is focused on screening senstivity, specificity, vaccine targets and efficacy, but the most important of these factors is whether people will engage in screening and vaccination. This study is uniquely focused on implementation and engagement of the local women in a low-recource community in Uganda in a novel screening program that has the potential to make cervical cancer screening widely available in the community where people live and work.

The medical literature provides a limited discussion of the psychosocial aspects of screening and these factors play a vital role in screening uptake and ongoing engagement with the patient. One study by Mutyaba and colleagues demonstrates that screening among medical professionals, who are charged with carrying out screening, is low (40). If even medical workers, who are meant to be the most informed are reluctant to partake in screening, then much work needs to be done to change the paradigm.

Health Belief Model

The Health Belief Model provides an important framework upon which to understand cervical cancer screening uptake and treatment. Our study fits into the overall context of the Health Belief Model with a specific focus on embarrassment. We found that women did not percieve themselves to be at great risk of cervical cancer, but that they perceived the diagnosis to be quite severe and fatal. They did not see the benefit of screening if results would only cause worry and a definitive treatment was not available. For those who had the knowledge that the disease could be caught early and treated, that was a significant cue to action to initiate screening. These findings are consistent with other studies exploring cervical cancer screening behaviour (8,20,21,29,41).

Embarrassment

Although several themes emerged, many of these have been described previously but by focusing on an analysis of embarrassment specifically we found that the women of Kisenyi defined embarrassment in two forms, community embarrassment and personal embarrassment,. The first is closely related to a definition by the psychology literature which describes embarrassment as the uncomfortable, self-conscious, feeling a person has following the transgression of a social norm or rule (42). This is in-relation to a real, or perceived, other person. Personal embarrassment is closely related to shame, which differs in that it is defined by a person's uncomfortable feeling with one's self (42).

The majority of the research regarding embarrassment and health screening is in the colorectal screening literature. In this setting, Consedine and colleagues sought to further characterize embarrassment by focusing on the specific aspects of the colorectal screening encounter that engendered embarrassment. They were able to discern a distinct phenomenon called medical embarrassment which is specific to the medical encounter and is not indicative of trait embarrassment (43). Medical embarrassment was further subdivided by Consedine into bodily embarrassment and judgment concern. In his research, these two factors were shown to have significant impact in screening behaviour (25,43). Women in our study were concerned with handling of swab and the potential associated smell of the sample, which is closely related to bodily embarrassment. The women in our study also focused on concern of being judged in their discomfort around perceptions of being tested for HIV, concerns for privacy, and the importance of location of self-collection and study recruitment.

Another key finding from our study is the dynamic nature of embarrassment, and other psychosocial barriers, and the profound role that acknowledging and addressing psychosocial barriers can have in uptake of cervical cancer screening and treatment. Participants in our study noted that through the ASPIRE education seminars, their knowledge of early detection and treatment increased and their fear and embarrassment of screening dimished. After learning about the positive benefits of screening, they opted to screen, despite initial psychosocial barriers. White and colleagues conducted 6 focus groups and 10 in-depth of women attending VIA screening in a primary health care centre in Zambia. Women described similar worries and fears regarding the fatality of cervical cancer and the associated reluctance of screening (41). In this study, women were exposed to the education program in a local clinic in Zambia and their attitudes about screening changed as a result. This lends credence to our data and supports the importance of addressing psychosocial concerns. In fact, addressing psychosocial barriers may show greater benefit in a shorter amount of time than attempts to address other known barriers such as socio-economic status, education level, access to services, or cost of services.

Overcoming psychosocial barriers

The participants of our study reiterated the power of local leaders and peer-to-peer education several times. In a culture that often relies on community authorities, such as *Sengas* (paternal aunties) for health information, rather than physicians, the role of these community members is vital (8). Women often discussed the role of their peers in encouraging them to come for screening and the important role that peers have in 'changing the social norm' regarding screening. What once seemed foreign and intimidating, may become familiar and approachable following the advice of a peer. This has been demonstrated among female and male sex workers in Africa in the setting of HIV/AIDS screening and treatment and has the great potential for cervical cancer screening and treatment (44).

Women also described the importance of changing the social norms around screening through media compaigns, drama groups, and overall increased awareness, similar to what has been done in the setting of HIV/AIDS. In the early stages of HIV/AIDS screening and treatment programs, the stigma and fatalism associated with an HIV/AIDS diagnosis was similar to what many women are currently reporting for cervical cancer. As antiretrovirals became more widely available, education improved, and the social norm changed around the topic, more women were willing to test. It is hoped that the same can be achieved with cervical cancer screening.

Strengths and Limitations

This study is the first of its kind to specifically address embarrassment, in depth, as a psychosocial barrier to gynecologic screening. The assessment was uniquely timed following a pilot study on HPV DNA self-collection in a community-setting, so women could comment on cervical cancer screening in general and HPV DNA testing in particular. The opinions elicited in this study were also unique in incorporating those who had been exposed to previous educational screening for cervical cancer and those who had not, to provide a diversity of perspectives.

This study was limited in its exploration of the multiple ethnic groups within the target community. We were able to access Luganda and Swahili speakers, but a significant Somali population exists in the community that were difficult to recruit due to language barriers. Furthermore, views of the most embarrassed women may not have been elicited given the focus group format. It may be that those women most embarrassed to discuss screening would be deterred by such a methodology. Unfortunately, an in-depth interview format, also may not reach these women.

Conclusions and Policy Implications

This study demonstrates the important role of psychosocial barriers in cervical cancer screening and the factors that facilitate the modification of these barriers. The women in this study reported many of the same psychosocial barriers to screening (fear, anxiety, embarrassment, shame) as in other studies, yet they also noted that these diminished greatly with increasing knowledge and education. Participants overwhelmingly supported the role of peer-to-peer education in mitigating psychosocial barriers and facilitating screening uptake.

The results in their final form will be presented back to the local community for knowledge dissemination and the data will also play a critical role in the development and design of a larger study exploring the clinical outcomes associated with community-based HPV self-collection versus Visual Inspection with Acetic Acid. In general, this data supports the integration of psychosocial outcomes at the onset of any screening program. In doing so, participants may experience less embarrassment and be more willing to engage in further screening and treatment activities.

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Contributorship Statement

Flora Teng - primary author, present at all focus groups, completed transcription, thematic analysis of data and wrote majority of manuscript.
Sheona Mitchell - secondary author, contributed to study design, analysis and structure of discussion, present at focus groups, edited manuscript and completed revisions.
Musa Sekikubo - co-author, contributed to study design and secondary thematic analysis, edited manuscript.
Christine Biryabarema - co-author, contributed to study design and guided focus group design.
Josaphat Byamugisha - co-author, contributed to study design and format of analysis, edited manuscript.
Malcolm Steinberg - co-author, advised extensively in initial study design.
Deborah Money - co-author, advised in initial study design and edited manuscript.
Gina Ogilvie - lead author, advised in initial study design, thematic analysis and contributed to final editing of the manuscript.

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Competing Interests:
None of the authors have a conflict of interest.

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12 March, 2014

Dr. Trish Groves

Deputy Editor BMJ

London, UK

Re: Revision of manuscript ID bmjopen-2014-004783

Dear Dr Groves,

Thank you for accepting the manuscript Understanding the role of embarrassment in gynecologic screening: A qualitative study from the ASPIRE cervical cancer screening project in Uganda for publication with minor revisions. The reviewers comments were very thoughtful and have been addressed in the attached documentation.

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Sincerely,

Flora Fang-Hwa Teng, MD MPH

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Title

Understanding the role of embarrassment in gynecologic screening: A qualitative study from the ASPIRE cervical cancer screening project in Uganda

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Data Management and Sharing: All authors had full access to the data of the study and accept full responsibility for the integrity of the data and the accuracy of the analysis. Thematic analysis and interview transcripts will be available from the corresponding author upon request.

Key Words: Embarrassment, qualitative research, cervical cancer screening, HPV self-collection, community-based participatory research

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Abstract

Objective: To define embarrassment and develop an understanding of the role of embarrassment in relation to cervical cancer screening and self-collected HPV DNA testing in Uganda.

Design: Cross-sectional, qualitative study using semi-structured one-to-one interviews and focus groups.

Participants: Six key-informant health workers and 16 local women, purposively sampled. Key informant inclusion criteria: Ugandan members of the project team. Focus group inclusion criteria: Woman age 30-69~~5~~ years, Luganda or Swahili speaking, living or working in the target Ugandan community. Exclusion criteria: unwillingness to sign informed consent.

Setting: Primary and tertiary low-resource setting in Kampala, Uganda

Results: In Luganda, embarrassment relating to cervical cancer is described in two forms. 'Community embarrassment' describes discomfort based upon how a person may be perceived by others. 'Personal embarrassment' relates to shyness or discomfort with her own genitalia. Community embarrassment was described in themes relating to place of study recruitment, amount of privacy in dwellings, personal relationship with health workers, handling of the vaginal swab, and misunderstanding of HPV self-collection as HIV testing. Themes of personal embarrassment related to lack knowledge, age, and novelty of the self-collection swab. Overall, embarrassment was a barrier to screening at the outset and diminished over time through education and knowledge. Fatalism regarding cervical cancer diagnosis, worry about results, and stigma associated with a cervical cancer diagnosis were other psychosocial barriers described. Overcoming psychosocial barriers to screening can include peer-to-peer education, drama, and media campaigns.

Conclusions: Embarrassment and other psychosocial barriers may play a large role at the onset of a screening program, but over time as education and knowledge increase, and the social norms around screening evolve, its role diminishes. The role of peer-to-peer education and community authorities on health care cannot be overlooked and can have a major impact in overcoming psychosocial and social barriers to screening.

Abstract word count: 298 (Max 300 words)

Strengths and limitations of this study

Strengths

- This study is unique in the qualitative evaluation of the specific role of embarrassment in cervical cancer screening in Uganda.
- The study also provides a novel comparison between a group of women who have had previous education on cervical cancer screening compared with those who have not.

Limitations

- The research team was limited in its ability to explore the perspective of all ethnic groups in the target community.
- The focus group format may have been prohibitive for the most embarrassed women to participate.

Introduction

Approximately 233,700 women die in the developing world every~~per~~ year from cervical cancer which is largely preventable through screening and treatable in the early stages (1). In Uganda, 80% of cervical cancer is diagnosed at stage III or IV (2) largely due to a lack of screening infrastructure. With HPV emerging as a more sensitive screening test for cervical cancer, there are opportunities for Low and Middle Income countries (LMIC) to employ this technology to prevent cervical cancer morbidity and mortality (3). Screening programs in the developed world have made strides in increasing screening uptake (4) and recent advances such as high-risk Human Papillomavirus (hrHPV) DNA testing have improved screening among the most difficult-to-reach women (5–7). The HPV vaccine is currently being offered for primary prevention in young women but the benefits will not be realized for many years to come.

Screening remains the best option for prevention and yet in LMIC, and Uganda specifically, cytologic (Papanicolau smear) screening programs are cost-prohibitive, resource-intensive, and not widely available (8). These barriers to screening, in addition to barriers of misinformation, access, psychosocial burden, and lack of reliable treatment options make screening uptake highly challenging. If the new technologies of hrHPV DNA testing or HPV vaccination are to have any impact, a better understanding, and renewed focus on understanding a woman's motivation for screening is essential.

A significant cervical cancer screening barrier cited by women in both the developing and developed world is embarrassment (9–15). Embarrassment in gynaecologic screening is a well-known, but ill-defined phenomenon. From screening for sexually transmitted infections to cervical cancer, many women cite embarrassment as reason for not participating in screening (4,6,7,9–12,14–24) yet little is known about the specfic components of screening that are most embarrassing and the wider impact this has on screening uptake and adherence. Some studies discuss lack of privacy, discomfort with sexuality, fear of judgement, and religious rationale as contributors to embarrassment (7,9,16,25). Embarrassment is commonly viewed as a static psychosocial barrier with little discussion on how it can evolve and dissipate. With such strong psychosocial barriers to screening, it follows that compliance with future testing or initiating screening at all, may be threatened.

Context and Setting

The ASPIRE (Advances in Screening and Prevention in Reproductive Cancers - http://www.aspireafrica.ca/) project was created to fill the gap in early detection and treatment of cervical cancer in Uganda. To date, this collaboration has conducted a baseline survey to explore the acceptability of self-collected HPV DNA testing and attitudes towards cervical cancer screening (26,27). As well as, a feasibility study enrolling 200 women and taking them from HPV swab self-collection to colposcopy and treatment (28).

The key results from the initial phase of the ASPIRE assessment of 300 women in a low-resource community in Uganda showed that embarrassment was cited as significant barrier to self-collection (26). Of those unwilling to collect a swab, 36% reported they would be embarrassed to collect a swab at home. In contrast, of those willing to collect a swab, 2% reported that they would be embarrassed to do so. Embarrassment to collect the swab at home was a significant negative predictor for participation (AOR 0.09 95% CI: 0.03-0.29) (26).

The objectives of this study are to define embarrassment in Uganda and develop an understanding of the role of embarrassment in relation to cervical cancer screening and self-collected HPV DNA testing. In addition, the aim is to determine viable solutions to overcoming barriers to embarrassament specifically and to cervical cancer screening overall. This study was designed to better understand embarrassment as a barrier to screening with the hope of informing the development of a prospective study investigating community-based HPV self-collection.

Methods

We conducted key stakeholder interviews with the Ugandan ASPIRE research team which included members of the Department of Obstetrics and Gynecology at the local tertiary hospital, n~~N~~urses from the local health unit, and community health workers in the target community. This method was used to obtain an initial framework to understand embarrassment in Uganda. We subsequently conducted three community focus groups to further develop these ideas, the first two groups included 8 women in each and the third group involved all participants that attended the first two focus groups. The community focus group discussion guide was developed using peer-reviewed research articles on key barriers and facilitators to cervical cancer screening (9,20,29–32) and discussion points generated within the ASPIRE key stakeholder interviews (Box 1). This methodology was used to incorporate local knowledge and cultural practice with current peer-reviewed knowledge. All participants signed informed consent and their confidentiality was ensured. This study received ethical approval from the local university in Uganda and the partner University in Canada.

Box 1. Focus Group Discussion Guide

Items included in the focus group topic guide
(1) Definition of embarrassment with regard to cervical cancer
(2) Implications of embarrassment on cervical cancer screening and treatment (including HPV self-collection)
(3) Overcoming embarrassment

(4) Other barriers to cervical cancer screening (5) Perception of cervical cancer (6) Evaluation and future directions for the ASPIRE project
Items included in stakeholder consultation
(1-6) of the focus group topic guide (7) Focus group methodology (8) Focus group data analysis

A subset of key stakeholders participated in the focus groups to facilitate discussion. Local women were invited to participate through a purposive sampling lead by the ASPIRE community health workers (33). We recruited women between the ages of 30-69 who live or work within the target community in Uganda. Using the rich knowledge of the ASPIRE community health workers, we sought information rich participants who would be willing to share their views. We recruited a total of 16 women to attend the~~3~~ focus groups. The first focus group was comprised of 8 previous participants in the ASPIRE project. The second focus group was comprised of 8 women naïve to the ASPIRE project. The third focus group was conducted with all 16 women to review results, disseminate the findings, and seek clarification on any underdeveloped ideas. This recruitment strategy was specifically chosen to capture diverse perspectives from an experienced group and a naïve group. We hypothesized that the ASPIRE-experienced group would describe less embarrassment than the ASPIRE-n~~N~~aï~~i~~ve group. The community health workers involved in the project acted as focus group facilitators and the ASPIRE project coordinator (DB) assisted in translation and cultural interpretation of the results. Transcription and thematic analysis was undertaken following each focus group, with the goal of generating new ideas for discussion in subsequent groups. The topics were flexible and driven by the focus-group participants, in keeping with the foundation of qualitative research (34).

Data collection and Analysis

All stakeholder interviews and focus group discussions were audiotaped and transcribed by the primary researcher (FT) and Luganda translator (DB). Workshops were undertaken in Luganda and English. The English portion of the audiotape was transcribed. The Luganda translator reviewed the audiotape and written transcript to verify appropriate translation and content. During the second review, the translator also assisted as cultural liaison to ensure that the data correctly reflected the Ugandan cultural context. A thematic analysis was undertaken after the each focus group and the code structure was was refined with each analysis. The stakeholder interviews were analyzed and reported in the Results and were also used to inform content of the discussion guide used for subsequent focus groups.

A final thematic analysis was undertaken at the conclusion of the three workshops by FT and the data was presented to the participants at a final meeting to ensure that the content was correct and reflective of the intentions of the group (35). The coding structure was developed using grounded theory and content analysis (36). A second independent thematic analysis was undertaken by MS to enhance inter-rater reliability (37) and to ensure that all themes were internally convergent and externally divergent, meaning that categories were structured so that they were internally consistent, but distinct from one another. (38) Following the development of the code structure, a framework analysis was undertaken using the Health Belief Model (39). This framework has been utilized in understanding screening behaviours, preventative actions, illness behaviour and has been well-validated in these settings (20,21,39).

Results

Demographics

Of the 16 women that we surveyed, the average age was 44 years old with a range between 30 and 57. The majority of women were married (50%) and had attended primary school with or without some secondary education (75%). Eighty-eight percent worked outside~~ and~~ the home and~~,~~ lived in the target district in Kampala~~,~~ within 30 minutes from the health centre (Table 1).

Table 1.

Demographic ~~characteristics of~~characteristics of focus group participants (n=16)*

Characteristic		*Number of ~~Participants~~ Participants ~~(%)~~*
Age groups		
	26-30	2 ~~(13)~~
	31-35	4 ~~(25)~~
	36-40	1 ~~(6)~~
	41-45	1 ~~(6)~~
	46-50	0 ~~(0)~~
	51-55	5 ~~(31)~~
	56-60	3 ~~(19)~~
Marital Status		
	Single	7 ~~(44)~~
	Married	8 ~~(50)~~
	Widowed	1 ~~(6)~~
Education of the participant		
	No schooling or some primary schooling	1 ~~(6)~~
	Primary with or without some secondary schooling	12 ~~(75)~~
	Secondary	1 ~~(6)~~

	Postsecondary	2 ~~(13)~~
Work outside of home		
	No	2 ~~(13)~~
	Yes	14 ~~(88)~~
Live in Kisenyi		
	No	2 ~~(13)~~
	Yes	14 ~~(88)~~
Housing		
	Rent	10 ~~(63)~~
	Own	6 ~~(38)~~
Religion		
	7th Day Adventist	1 ~~(6)~~
	Anglican/protestant	4 ~~(25)~~
	Catholic	5 ~~(31)~~
	Muslim	6 ~~(38)~~
Time to walk to nearest health center, min		
	< 30	14 ~~(88)~~
	30 - 60	2 ~~(13)~~
~~* values for some variables do not sum to 100% due to rounding~~		

Perceived Susceptibility

Women perceived themselves to be at low risk for HPV infection, but the HIV screening model influenced perceptions for HPV screening. They could understand the need for HPV screening from their knowledge of the HIV paradigm. For some women, there was a belief that testing was only necessary for sexually active women. Similarly for cervical cancer, women perceived themselves to be at low risk and there was a lack of knowledge regarding the relationship between HPV and cervical cancer. In addition, most people do not seek care unless there are symptoms. One woman highlighted,

> *"For Africans its hard to go to the hospital if you are not sick. You have to actually be sick in bed before you will go for treatment." (Focus Group 1 – Previous ASPIRE Participant)*

Perceived Severity

Women acknowledged a sense of fatalism regarding cancer and felt that 'knowing their status' would be a situation too difficult to cope with. In addition, they didn't want to worry about the outcome. They felt that worrying would make the disease worse. One woman described,

> *"They don't want to know their [cervical cancer screening] status because if they know their status, they don't see any solution. They*

> *will just die, there is no treatment, there is nothing to be fixed. It is like a death sentence."* (Key Stakeholder Interview)

Surprisingly, some described that they would rather have HIV because there is a perception that there is an effective treatment, compared to a cancer diagnosis that has no cure.

> *"Nowadays, people say that if someone to gets cancer, at least let her get HIV, than getting cancer, because for HIV there is treatment,~~.~~ but for cancer, there is no treatment."* (Focus Group 2 – ASPIRE Naïve Participant)

There were also some women who felt that the testing and/or biopsy would actually cause cancer. Some women perceived that before they got a biopsy/test they were healthy and after the test, they were sick, so it must have been the test that made them sick. Women were ~~also~~ concerned about the overbearing cost of cancer treatment in LMIC. Alternatively, those women who had an awareness of HPV perceived that HPV could be treated and this diagnosis was less severe.

Perceived Benefits and Cues to Action

The women in both focus groups universally acknowledged that embarrassment would not be a major deterrent to screening if women had appropriate knowledge and education about the need for screening and if they had a private place to perform the self-collection. All women endorsed peer-to-peer education and engaging local leaders as some of the best strategies to recruit women and in fact, many women had already told their friends about the project and were eager to participate in the next phase of the ASPIRE project.

> *"Through these people who have self-collected and through more training, they also help those who have never attended the training, who have never self-collected, to make them be confident that self-collection is not painful. You do it yourself, it's not the doctor doing it. I think that through them, more people will come to do the self-collection." (Focus Group 1 – ASPIRE Participant)*

Overall participants did not see large barriers to expanding the project, capacity building and resources, notwithstanding. The women were very positive that further recruitment and screening would not be a barrier. The history of the ASPIRE project since 2008 and the ongoing education initiatives have already 'sensitized' women to the topic. Some women articulated their knowledge of the importance of screening and the ability to diagnose and treat the disease early. They had a variety of suggestions such as media messages, seminars and workshops, counselling sessions, incentives, as a means to improve uptake for screening.

Barriers to cervical cancer screening

Barriers to cervical cancer screening and HPV self-collection could easily be divided into barriers inherent to screening in general, barriers related to the use of the HPV swab, and overarching barriers related to the outcomes of the test (Table 2). Our focus group participants felt that cervical cancer screening in general was predicated upon trust in the researchers, adequate knowledge and an awareness of their risk of cervical cancer. One woman felt that a major barrier to screening was the worry that screening would incite, she described,

> *"What if I get my sample. What results will I get? That fear of getting the results, … Am I positive? Am I negative? Really people fear to hear what [results] they will get, so they end up saying, I'd rather not test. I'd rather not collect, so that I may not know any results about what is happening to me."* *(Focus Group 1 – ASPIRE Participant)*

The women had valuable insight into the barriers associated with HPV self-collection. Many women admitted to the initial novelty of the swab and discomfort with inserting items into the vagina as barriers. Women were also concerned of the swab causing infection or injury. For one group, there was significant discussion regarding hygiene and the cleanliness of vaginal discharge. Closely related to this was the associated embarrassment of having to give a swab of vaginal secretions (with a potential smell) to a health worker.

Gender perspective

Interestingly, barriers that were not endorsed included spousal permission and cultural beliefs, practices, and norms. When questioned, women were universally in support of screening whether they had spousal permission or not. One woman alluded to the mistrust and lack of communication within marriages as a source of HPV risk and as a result felt strongly about the importance of screening.

> *"You have to take care of your life. You can't say that my husband refused me to go for testing. It is not his life, its mine. You have to protect your life."* *(Focus Group 2 – ASPIRE Naïve Participant)*

> *"These men, they always go for treatment. Like an example for HIV. they test and they are positive. They start the treatment without telling their wives, so he keeps on going for treatment, when the wife doesn't know anything. So everyone is concerned about his or her life."* *(Focus Group 2 – ASPIRE Naïve Participant)*

Women in Kisenyi also described cultural practices that normalized the insertion of items into the vagina. Not all women endorsed this activity, but some women reported inserting herbs to widen the birth canal during the later stages of pregnancy, which provided some women a comfort with their genitalia.

> *"I don't think it has to do with shyness, because women they actually douche, they use herbs for all sorts of things. Even when they are*

pregnant, they use herbs, it is in most of cultures here, particularly in central Uganda, you use herbs to enlarge your birth canal to make sure you don't get an episiotomy." *(Key Stakeholder Interview)*

Table 2. Health Belief Model Framework Analysis

Health Belief Model Parameter	ASPIRE Respondents	
	HPV Self-Collection	Cervical Cancer
Perceived Susceptibility	Perceived risk is low Testing will cause the disease Screening is only necessary for sexually active women	
	HIV education model increases risk awareness	Limited knowledge of link between HPV and cervical cancer
Perceived Severity	HPV can be treated	Cervical cancer is a death sentence Cervical cancer treatment is expensive No cure for cancer Would rather get HIV than cervical cancer
Perceived Benefits	Early detection Treatment availibility Protecting yourself	Some treatment may be beneficial
Perceived Barriers	Lack of time Lack of knowledge Mistrust of Researchers Embarrassment Worry about outcomes Health-seeking behaviour only prompted by symptoms	
	Discomfort with inserting items into vagina Concern with hygiene and/or vaginal discharge Fear of pain or injury Novelty of test	Fatalism Inability to cope with results Stigma of having cancer
Cues to Action	Local Leaders / Community Health workers Peer-to-Peer education and recruitment Increasing knowledge Screening necessary without symptoms Fear of contracting cancer	
Self-efficacy	Gender Perspective - Spousal permission not required	

Embarrassment

There were many overlapping themes with barriers to screening and the associated embarrassment. Through our focus groups and key stakeholder discussions, there were two meaningful definitions of embarrassment. The first definition was 'community embarrassment' ('kiswaaza" in Luganda). It was described as the discomfort that one may feel depending on how they are perceived by others. The second can be described as 'personal embarrassment' ('kikuswaaza' in Luganda) or shyness/discomfort related to their own genitalia (Table 3).

Table 3.

Factors associated with embarrassment

Community Embarrassment
Confusion of HPV for HIV Place of recruitment Location of self-collection Privacy Relationship with health worker Gender of the physician performing screening Handling of the swab
Personal Embarrassment
Age of participant Novelty of the test lack of knowledge

An important theme was the diminishment of embarrassment over time. In the group of women with previous involvement in the ASPIRE project, they described having embarrassment initially, but after multiple education meetings and actually performing self-collection, they didn't feel embarrassed about screening. In fact, they noted that they would overcome their embarrassment if they knew they needed to for another reason. This was clearly described by this participant,

> *"After knowing that you are HPV positive, then the fear goes away because you want to know what is going on, so you are free to go to the doctor to have the pelvic examination to see what is going on … you need to know what next. See the doctor at that stage, no embarrassment."* *(Focus Group 3 – Participant)*

The data demonstrates that embarrassment is not a static emotion. It is often quoted as an important barrier to screening, yet its not acknowledged as potentially the most modifiable barrier, compared to other factors such as age, socioeconomic status, and religion. This woman describes the modifiability of embarrassment,

> *“Embarrassment is not an issue concerning cervical cancer, Because HIV is very shameful compared to cancer. Nowadays people don't feel ashamed because of HIV because they are used to it. So even with cancer, people will get used to it and there will be no more embarrassment, it’s not an issue. Through more training and seminars, people will get to know more, they will come to self-collection and everything will be okay.” (Focus Group 3 – Participant)*

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~~*Perceived Benefits and Cues to Action*~~

~~The women in both focus groups universally acknowledged that embarrassment would not be a major deterrent to screening if women had appropriate knowledge and education about the need for screening and if they had a private place to perform the self-collection. All women endorsed peer-to-peer education and engaging local leaders as some of the best strategies to recruit women and in fact, many women had already told their friends about the project and were eager to participate in the next phase of the ASPIRE project.~~

> ~~*“Through these people who have self-collected and through more training, they also help those who have never attended the training, who have never self-collected, to make them be confident that self-collection is not painful. You do it yourself, it’s not the doctor doing it. I think that through them, more people will come to do the self-collection.”*~~

~~Overall participants did not see large barriers to expanding the project, capacity building and resources, notwithstanding. The women were very positive that further recruitment and screening would not be a barrier. The history of the ASPIRE project since 2008 and the ongoing education initiatives have already ‘sensitized’ women to the topic. Some women articulated their knowledge of the importance of screening and the ability to diagnose and treat the disease early. They had a variety of suggestions such as media messages, seminars and workshops, counselling sessions, incentives, as a means to improve uptake for screening.~~

Discussion

In the setting of a largely preventable condition and the availability of a vaccine, it is a great tragedy that cases of cervical cancer continue to rise and that more research is not being done on the science of implementation. Significant research is focused on screening senstivity, specificity, vaccine targets and efficacy, but the most important of these factors is whether people will engage in screening and vaccination. This study is uniquely focused on implementation and engagement of the local women in a low-recource community in Uganda in a novel screening program that has the potential to make cervical cancer screening widely available in the community where people live and work.

The medical literature provides a limited discussion of the psychosocial aspects of screening and these factors play a vital role in screening uptake and ongoing engagement with the patient. One study by Mutyaba and colleagues demonstrates that screening among medical professionals, who are charged with carrying out screening, is low (40). If even medical workers, who are meant to be the most informed are reluctant to partake in screening, then much work needs to be done to change the paradigm.

Health Belief Model

The Health Belief Model provides an important framework upon which to understand cervical cancer screening uptake and treatment. Our study fits into the overall context of the Health Belief Model with a specific focus on embarrassment. We found that women did not percieve themselves to be at great risk of cervical cancer, but that they perceived the diagnosis to be quite severe and fatal. They did not see the benefit of screening if results would only cause worry and a definitive treatment was not available. For those who had the knowledge that the disease could be caught early and treated, that was a significant cue to action to initiate screening. These findings are consistent with other studies exploring cervical cancer screening behaviour (8,20,21,29,41).

Embarrassment

Although several themes emerged, many of these have been described previously but by focusing on an analysis of embarrassment specifically we found that t~~T~~he women of Kisenyi defined embarrassment in two forms, community embarrassment and personal embarrassment,~~ which are consistent with the literature~~. The first is closely related to a definition by the psychology literature which describes embarrassment as the uncomfortable, self-conscious, feeling a person has following the transgression of a social norm or rule (42). This is in-relation to a real, or perceived, other person. Personal embarrassment is closely related to~~,~~ shame, which differs in that it~~s~~ is defined by a person's uncomfortable feeling with one's self (42).

The majority of the research regarding embarrassment and health screening is in the colorectal screening literature. In this setting, Consedine and colleagues sought to further characterize embarrassment by focusing on the specific aspects of the colorectal screening encounter that engendered embarrassment. They were able to discern a distinct phenomenon called medical embarrassment which is specific to the medical encounter and is not indicative of trait embarrassment (43). Medical embarrassment was further subdivided by Consedine into bodily embarrassment and judgment concern. In his research, these two factors were shown to have significant impact in screening behaviour (25,43). Women in our study were concerned with handling of swab and the potential associated smell of the sample, which is closely related to bodily embarrassment. The women in our study also focused on ~~judgement ~~concern of being judged in their discomfort around perceptions of being tested for HIV, concerns for privacy, and the importance of location of self-collection and study recruitment.

Another key finding from our study is the dynamic nature of embarrassment, and other psychosocial barriers, and the profound role that acknowledging and addressing psychosocial barriers can have in uptake of cervical cancer screening and treatment. Participants in our study noted that through the ASPIRE education seminars, their knowledge of early detection and treatment increased and their fear and embarrassment of screening dimished. After learning about the positive benefits of screening, they opted to screen, despite initial psychosocial barriers. White and colleagues conducted 6 focus groups and 10 in-depth of women attending VIA screening in a primary health care centre in Zambia. Women described similar worries and fears regarding the fatality of cervical cancer and the associated reluctance of screening (41). In this study, women were exposed to the education program in a local clinic in Zambia and their attitudes about screening changed as a result. This lends credence to our data and supports the importance of addressing psychosocial concerns. In fact, addressing psychosocial barriers may show greater benefit in a shorter amount of time~~,~~ tha~~e~~n attempts to address other known ba~~e~~rriers such as socio-economic status, education level, access to services, or cost of services.

Overcoming psychosocial barriers
The participants of our study reiterated the power of local leaders and peer-to-peer education several times. In a culture that often relies on community authorities, such as *Sengas* (paternal aunties) for health information, rather than physicians, the role of these community members is vital (8). Women often discussed the role of their peers in encouraging them to come for screening and the important role that peers have in 'changing the social norm' regarding screening. What once seemed foreign and intimidating, may become familiar and approachable following the advice of a peer. This has been demonstrated among female and male sex workers in Africa in the setting of HIV/AIDS screening and treatment and has the great potential for cervical cancer screening and treatment (44).

Women also described the importance of changing the social norms around screening through media compaigns, drama groups, and overall increased awareness, similar to what has been done in the setting of HIV/AIDS. In the early stages of HIV/AIDS screening and treatment programs, the stigma and fatalism associated with an HIV/AIDS diagnosis was similar to what many women are currently reporting for cervical cancer. As antiretrovirals became more widely available, education improved, and the social norm changed around the topic, more women were willing to test. It is hoped that the same can be achieved with cervical cancer screening.

Strengths and Limitations

This study is the first of its kind to specifically address embarrassment, in depth, as a psychosocial barrier to gynecologic screening. The assessment was uniquely timed following a pilot study on HPV DNA self-collection in a community-setting, so women could comment on cervical cancer screening in general and HPV DNA testing in particular. The opinions elicited in this study were also unique in incorporating those who had been exposed to previous educational screening for cervical cancer and those who had not, to provide a diversity of perspectives.

This study was limited in its exploration of the multiple ethnic groups within the target community. We were able to access Luganda and Swahili speakers, but a significant Somali population exists in the community that were difficult to recruit due to language barriers. Furthermore, views of the most embarrassed women may not have been elicited given the focus group format. It may be that those women most embarrassed to discuss screening would be deterred by such a methodology. Unfortunately, an in-depth interview format, also may not reach these women.

Conclusions and Policy Implications

This study demonstrates the important role of psychosocial barriers in cervical cancer screening and the factors that facilitate the modification of these barriers. The women in this study reported many of the same psychosocial barriers to screening (fear, anxiety, embarrassment, shame) as in other studies, yet they also noted that these diminished greatly with increasing knowledge and education. Participants overwhelmingly supported the role of peer-to-peer education in mitigating psychosocial barriers and facilitating screening uptake.

The results in their final form will be presented back to the local community for knowledge dissemination and the data will also play a critical role in the development and design of a larger study exploring the clinical outcomes associated with community-based HPV self-collection versus Visual Inspection with Acetic Acid. In general, this data supports the integration of psychosocial outcomes at the onset of any screening program. In doing so, participants may experience less embarrassment and be more willing to engage in further screening and treatment activities.

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None of the authors have a conflict of interest.

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