

Cervical Cancer Knowledge and Facilitators and Barriers to Screening Among Women in Two Rural Communities in Guatemala: A Qualitative Study

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Abstract

Background Approximately 80% of deaths due to cervical cancer occur in the developing world. In Guatemala, limited access to effective screening and treatment has resulted in an alarmingly high cervical cancer incidence and mortality rates. Despite access to free-of-cost screening women continue to face significant barriers in obtaining screening for cervical cancer.

Methods In-depth interviews (N=21) were conducted among women in two rural communities in Guatemala. Qualitative IDIs followed semi-structured guide to explore knowledge related to cervical cancer and barriers and facilitators to cervical cancer screening.

Results Cervical cancer knowledge was variable across sites and across women. Women reported barriers to screening including ancillary costs, control by male partners, poor provider communication and systems-level resource constraints. Facilitators to screening included a desire to know one's own health status, conversations with other women including community health workers and extra-governmental health fairs.

Conclusions Findings speak to the many challenges women face in obtaining screening for cervical cancer in their communities as well as existing facilitators. Future interventions must focus on improving cervical cancer-related knowledge as well as mitigating barriers and leveraging facilitators to promote screening.

Background

Cervical cancer is a highly preventable disease. Despite this, there were an estimated 604,127 new cases and 341,831 deaths due to cervical cancer globally in 2020, making it the fourth most common cancer among women.[1] Cervical cancer incidence and mortality disproportionately burden women in low- and middle-income countries (LMICs), reflecting a lack of access to effective screening, vaccination and treatments that enable both preventive and curative care. In 2020, the incidence rate of cervical cancer in LMICs was 18.8 per 100,000 women versus 11.3 in high income countries (HICs) and the mortality rate in LMICs was more than twice that of HICs (12.4 per 100,000 women versus 5.2 per 100,000 women).[1]

Guatemala is one such nation where limited access to effective screening and treatment has resulted in an alarmingly high cervical cancer incidence of 20.3 per 100,000 and a mortality rate of 11.9 per 100,000 women in 2018.[2] Surprisingly, given the high burden of cervical cancer in the country, cervical cancer screenings are provided free-of-cost through the Guatemala Ministry of Health (MOH) [3], both through local women's health clinics and contracts with non-government organizations (NGOs).[4] In the early 2000s, NGOs in Guatemala introduced visual inspection with acetic acid (VIA) and cryotherapy as an alternative to cytology-based screening (i.e. Pap smears).[4] VIA was formally integrated into the national cervical cancer screening program in 2008 and now accounts for the majority of cervical cancer screenings in the country.[4] In 2015, the MOH launched a pilot implementation trial for human

papillomavirus (HPV) testing in urban settings to evaluate its feasibility as an alternative to traditional screening methods.[5]

Despite these services, approximately 64% of women in Guatemala report lifetime cervical cancer screening, with lower rates among indigenous and rural women.[6] This disconnect suggests the need for a more nuanced exploration of the barriers women in Guatemala face in obtaining cervical cancer screening. Extant literature in other LMICs settings suggests that limited cervical cancer knowledge [7], fear of the procedure [7] and possible positive test results [8], embarrassment [7, 9] and competing costs [8, 9] present significant barriers to cervical cancer screening. In Guatemala in particular, cost and distance, permission required to attend, not wanting to attend screening alone, and language discordance with providers were found to be associated with never being screened.[6] In addition to these barriers, even if women are able to access screening, its effectiveness in reducing cervical cancer incidence and mortality further depends upon access to follow-up care and treatment, which are also often lacking.[10]

In August 2020, the World Health Assembly adopted the Global Strategy for cervical cancer elimination to reduce the age-adjusted incidence rate of cervical cancer to less than 4 per 100,000 women-year in all countries by the end of the century through the promotion of HPV vaccines, screening, and treatment.[11] In light of this global effort, a better understanding of the reasons why free-of-cost screening in Guatemala has not resulted in improved cervical cancer outcomes is warranted. To our knowledge, the present study is the first to utilize in-depth, qualitative interviews to elucidate barriers and facilitators to cervical cancer screening among women in two rural communities in Guatemala.

Methods

Study Setting

Santiago, Atitlán

Santiago, Atitlán is a majority Maya-Tz'utujil community on the southern shore of Lake Atitlán. Santiago's roughly 45,000 inhabitants live in 20 *cantones* or neighborhoods, located in the town's center and spreading out to more rural, surrounding neighborhoods. Nearly all of Santiago's inhabitants speak Tz'utujil as their first language and Spanish as a second language. A small proportion speak only Tz'utujil. [12]

Livingston, Izabal

Livingston, Izabal is situated on the Caribbean coast of Guatemala and is accessible only by boat. Livingston is an ethnically diverse community with a large Garifuna (Afro-Caribbean) population as well as Maya-Q'eqchi and *Ladino* (mixed race) populations. Most inhabitants speak Spanish and either Garifuna or Q'eqchi.[13]

Study Population

Participants were recruited from a larger pool of women who had been randomly sampled to participate in the HPV Multi-Ethnic Study (HPV MES), which involved completing a quantitative survey on prior screening behavior and acceptability of Human Papillomavirus (HPV) self-collection sampling to screen for cervical cancer as well as the opportunity to participate in self-collection HPV-based screening.[13] Details and main results of this study are described elsewhere.[13, 14] Following completion of the quantitative survey, women consented to be contacted for an in-depth, semi-structured interview. Interview participants in both communities were sampled purposively by neighborhood.

Community Partners

The study team worked with collaboratively with community partners at both study sites. In Santiago, the team worked with local health clinic, Rxiiin T'Namet, which provides family and reproductive health services to residents including workshops and community outreach. In Livingston, research was supported by a local HIV-focused health clinic, Iseri Ibagari. The clinic provides HIV testing, referrals for treatment, and health education workshops focused on reproductive health. Both community partners helped to publicize the study to the larger community and provided private spaces for in-depth, semi-structured interviews.

All study procedures were approved by the Institutional Review Boards at the University of Michigan (HUM00096559) and the Instituto de Nutrición de Centro America y Panamá (INCAP) (MI-CIE-16-009), located in Guatemala City.

Data Collection

Interviews were conducted privately in the women's homes or spaces provided by community partners. Interviews were conducted in Spanish by the lead qualitative investigator and began with the administration of informed consent in the participant's preferred language. An interpreter provided real-time translation for participants in Santiago Atitlán who completed the interview in Tzu'tujil. Interviews followed a semi-structured interview guide to better understand the facilitators and barriers to cervical cancer screening faced by participants (Table 1) and were conducted until common themes suggested data saturation. Interview were recorded and transcribed verbatim by native Spanish speakers. Those conducted in Tzu'tujil were translated and transcribed into Spanish by a native Tzu'tujil speaker.

Table 1
Sample items from the semi-structured interview guide

Can you tell me a little bit about cervical cancer?
Where did you get this information from?
Before today, had you ever spoken with a doctor about cervical cancer screening?
Can you tell me a little more about that conversation?
Have you ever been screened for cervical cancer?
In general, how was your experience?

Analysis

Utilizing an adapted framework analysis approach [15], the transcribed data were analyzed by three Spanish-speaking study team members who independently reviewed five transcripts for emergent themes that related to the original research questions. Codes were created to characterize emergent themes and revised in an iterative process to ensure coverage and reliability between coders. The resulting final codebook included 56 codes, their definitions, and examples of each code from interviews. The remaining 16 transcripts each were coded by the three Spanish-speaking study team members; coding inconsistencies were reconciled by the lead qualitative investigator and organized using NVivo 9 (QSI International). Data were then organized by theme using an analytic matrix, which was reviewed by the lead investigator and a fourth Spanish-speaking study team member. Illustrative quotes were selected relating to salient themes and subthemes and translated into English. Translations were reviewed by two native-Spanish speaking members of the research team for consistency with their original significance.

Results

Twenty-one women (Santiago Atitlán, n = 10; Livingston, n = 11) were interviewed. Participant demographics, stratified by community, are provided in Table 2. Women in Livingston had higher average household incomes, educational attainment, and literacy. Marriage rates in both communities were comparable. About 80% of women in both communities reported having ever been screened for cervical cancer.

Table 2
Demographic characteristics by study component and study site

	Survey participants			Interview participants		
	Total (N = 956)	Santiago (N = 500)	Livingston (N = 456)	Total (N = 21)	Santiago (N = 10)	Livingston (N = 11)
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Age, mean (SD)	33.92 (9.45)	34.78 (8.44)	32.97 (10.38)	35.33 (9.17)	36.50 (8.95)	34.27 (9.68)
Ethnicity, n (%)						
Tz'tujil	483 (50.42)	483 (96.60)	0 (0)	10 (47.62)	10 (100)	0 (0)
Ladino	122 (12.76)	9 (1.80)	113 (24.78)	4 (19.05)	0 (0)	4 (36.36)
Garifuna	145 (15.27)	0 (0%)	145 (31.80)	6 (28.57)	0 (0%)	6 (54.55)
Q'eqchi'	191 (19.98)	0 (0%)	191 (41.89)	1 (5.76)	0 (0%)	1 (9.10)
Other	15 (1.57)	8 (1.60)	7 (1.54)	0 (0)	0 (0%)	0 (0)
Literate, n (%)	653 (68.31)	255 (51.00)	398 (87.28)	15 (71.43)	5 (50%)	10 (90.91)
Education, n (%)						
Less than primary	500 (52.30)	347 (69.40)	153 (33.55)	8 (38.09)	2 (18.18)	6 (60)
Primary/Secondary	255 (26.67)	100 (20.00)	155 (33.99)	7 (33.33)	5 (45.45)	2 (20)
More than secondary	193 (20.19)	50 (10.00)	143 (31.36)	6 (28.57)	4 (36.36)	2 (20)
Unknown	8 (0.84)	3 (0.60)	3 (1.10)	0 (0)	0 (0)	0 (0)
Married/United	683 (71.44)	431 (86.20)	252 (55.26)	12 (57.14)	6 (60)	6 (54.55)
Ever Screened (Pap/VIA), n (%)	602 (62.97)	337 (67.40)	265 (58.11)	17 (80.95)	8 (80)	9 (81.81)
Screened in Past Year, n (%)	235 (24.58)	101 (20.20)	134 (29.39)	8 (38.10)	2 (20)	6 (54.55)

Cervical Cancer and Screening Knowledge and Beliefs

Cervical cancer knowledge discussed in qualitative interviews was variable across sites and across women. Overall, women in Livingston shared greater cervical cancer knowledge than women in Santiago, though several women at both sites reported no cervical cancer-related knowledge. This knowledge difference is supported by previously published quantitative findings among the larger HPV MES sample, which found higher knowledge of HPV and perceived severity of cervical cancer in Livingston.[13] In Livingston, the majority of interview participants had heard of cervical cancer and several women reported knowledge related to cervical cancer development and symptomology, including that it is often asymptomatic, resulting in later-stage diagnoses and poor prognoses for women who are not regularly screened.

I had heard of cancer of the neck of the womb [cervix], that if someone is not periodically getting their Pap smear...you can't detect it because it's silent...it has no symptoms and then it's there, so you didn't realize, and it's already advanced significantly. (Livingston, Garifuna, Age 46–50, Screened)

In comparison, no knowledge of cervical cancer as well as misinformation related to cervical cancer was more commonly reported in Santiago. For example, several women shared beliefs about the causes of cervical cancer that were not related to sex or to HPV, including that it is caused by sadness or worry, bad food, or lack of vitamins. While sharing her desire to learn more about cervical cancer one women asked:

[...] I want to know more about where this illness comes from. Let's say my daughter, some days she's fine but other days her stomach hurts. That's why I ask, how does this illness start [...] could it be that you get sick a lot...or you have a certain diet. I don't know. That's just what I have heard. (Santiago, Tzutujil, Age 46–50, Screened)

Poor hygiene or a lack of personal care was also commonly cited as a cause of cervical cancer.

There are cases in which they say that all of a sudden the cancer appears in the neck of the womb [cervix] when you don't take care of yourself or don't have good hygiene... (Santiago, Tzutujil, Age 40–45, Screened)

Women at both sites, including those self-reporting lower levels of knowledge spoke of the connection between cervical cancer and sex, though few mentioned HPV. Many discussed this relationship in terms of male partners engaging in extra-relational sex with other women or with sex workers as well as women themselves having multiple sex partners. In turn, women discussed the need to "cuidarse" or take care of oneself within the context of sexual relationships. When asked what it mean to take care of oneself in relation to cervical cancer, one Santiago participant explained through an interpreter:

She has heard that to take care of herself, she shouldn't sleep with other men. Because she heard that when men have sexual relations with a lot of women...it's possible that you get infected with this illness. (Santiago, Tzutujil, Age 30–35, Never-screened)

Knowledge related to cervical cancer screening also differed greatly across participants. In both Santiago Atitlán and Livingston, several women reported no knowledge of cervical cancer screening but familiarity

with Pap smears specifically, suggesting women may obtain screening without understanding its purpose. When asked if she had heard of a test to detect cervical cancer, one participant in Santiago responded:

I don't know of one. I don't know simply because we subject ourselves to any of that. (Santiago, Tzutujil, Age 30–35, Never-screened)

However, when asked if she had heard specifically of Pap smears, she responded:

Yeah, I have heard, well they told me that it's a small apparatus that is introduced to a women's internal part where they examine her.

Women posited that lack of knowledge related to cervical cancer and screening in their communities was tied to limited sexual education informed by cultural taboos around sex and reproductive health.

There are teachers that see this as taboo and so they don't want to speak openly about sexuality, few speak about it or see it as something normal, like a normal part of life [...] so maybe of the 100%, 45% have the freedom to speak this way, openly, about sexuality, both others, they are limited. (Livingston, Garifuna, Age 26–30, Screened)

Despite these taboos, informal and formal conversations (e.g., community trainings or *charlas*) between women were an important source of knowledge. Speaking about her friend who encouraged her to get screened, one Livingston women explained:

Because she is also open, because there are people who are embarrassed to talk about these things, like they are very private sometimes, but with her I don't have any problem talking with her. (Livingston, Garifuna, Age 46–50, Screened)

Barriers to Cervical Cancer Screening

Women across both communities expressed similar barriers to obtaining cervical cancer screening. Barriers generally fell into one of three, often intersecting, categories: individual, interpersonal and system-level. At the individual level, cost was the most cited barrier. Though all women in Guatemala are entitled to free cervical cancer screening through publicly run women's health clinics, in practice ancillary costs including transportation, food, and loss of income pose significant barriers to screening.

There's a shortage of money... You go to a [women's clinic] and you pay for a taxi, you pay for a pick-up truck and sometimes people just can't do it and then, because of this they say, "better not, I have to save up to go there, better not, and if I go and they don't see me, better to not go". (Santiago, Tzutujil, Age 26–30, Screened)

Women also perceived the cost of future tests and treatment that may result from a diagnosis as a barrier to seeking screening. When asked why she had never been screened, one participant in Livingston explained:

Maybe because it requires money and also if one suffers from an illness that's what happens because people have many illnesses and sometimes they tell you, you have to buy this medicine now and you do not have money, I cannot buy it. (Santiago, Tzutujil, Age 36–40, Screened)

Women understood this both abstractly and from personal experience. Among those who had previously received screening, two women shared their own stories of being unable to afford treatment after a positive screening. One participant from Livingston recalled being unable to afford a biopsy after doctors found a lesion on her cervix during a routine Pap smear:

Well, in fact I got a video colposcopy because according to the results, I have [...] an ulcer on my cervix. I got a video colposcopy [...] and the doctor explained everything to me, that I have to do another test to make sure it doesn't become cancerous, you have to detect it early, so it doesn't become cancer. But with my economic situation...for me I can't afford more tests. (Livingston, Ladino, Age 26–30, Screened)

At the interpersonal level, several women also cited male partners as a potential barrier to obtaining screening among women, citing a culture of “machismo” in which women are seen as subordinate to men.[16] This barrier was twofold: men who exert economic control over their female partners may refuse to provide the money for screening or male partners may withhold permission, explicitly or tacitly, for their female partners to obtain a screening.

Because they are men who say no, because of machismo...and the women also say “my partner doesn't want me to,” so no. Women are scared that they [the men] will hit them or leave them. (Santiago, Tzutujil, Age 30–35, Screened)

For other women, this control was more subtle. After experiencing extreme abdominal pain, one women’s mother insisted she obtain a Pap smear:

I didn't want to go, but my mom came and told me, “let's go because this...is going to kill you”. So I went with [my family] to get the exam, but it was already late and my husband was about to come back from the mountain and I got very worried because we didn't have money, and he didn't know anything and no one told him anything. I went that one time in a hurry and that was the only time I have done [a Pap smear]. (Santiago, Tzutujil, Age 40–45, Screened)

Women described how knowledge acquisition related to cervical cancer was also informed by gender norms.

I also think it's machismo. The majority of women live with machista men, they demand order, food, everything in the house. So I think this also influences the lack of knowledge. (Livingston, Garifuna, Age 26–30, Screened)

Fear was also a barrier commonly expressed by women in both communities. At the individual level, fear of pain or discomfort during the screening itself was common among the women screening-naïve women.

[I have not been screened] well, out of fear, why lie to you. I have this fear, I can't explain it exactly...but every time that I have to do the Pap smear, they notify me, but I always end up refusing. The fear about the Pap smear; how do I explain it, what I am scared of is the instrument. (Livingston, Garifuna, Age 26–30, Never-screened)

[...] they say that it hurts, that they insert I don't know what, a tube that, yes but when I went when I saw, I realized that no...that it wasn't like that. (Livingston, Garifuna, Age 26–30, Screened)

Women in both communities expressed fear of embarrassment or *vergüenza* of being seen by a doctor or other healthcare worker. Notably, this fear often presented a barrier to seeking screening even when free-of-cost screening was available. Often this fear centered on the need for a healthcare provider to view intimate body parts to conduct the screening.

I'm embarrassed. I don't know why, my daughters have told me, "Listen this is where they are providing Pap smears for free, why don't you go mama. You are sick. It's deadly. You have said yourself you have never taken care of these things...maybe you have a bad stomach". But I say I have decided to die this way...I don't want [doctors] to see me I say. [...] So it happens that I have never done [a Pap smear]. (Livingston, Ladina, Age 50–55, Screened)

Women in Santiago expressed similar concerns:

Before in Santiago Atitlán, women almost never saw the doctor because of embarrassment of being seen [nude]. Because the women only want to be seen by their husbands and no one else. Because it would be an ugly thing for them to be seen by someone else so they, more than anything, feared [the embarrassment]. (Santiago, Tzutujil, Age 26–30, Screened)

Fear of disclosure of personal information was another barrier. In both communities, women cited personal experience or experiences among their friends and family in which their medical confidentiality was violated. This fear stemmed, in part, from the fact that healthcare workers were often well known in the community or even related to their patients.

Well, uh, when people know each other, it's uncomfortable because, imagine that they're looking at you, there are people who do not have professional ethics and they are talking about your vagina and all of these things, but when there are people that don't know you, that's not an issue, there is security. (Livingston, Garifuna, Age 26–30, Screened)

To avoid potential violations of their privacy, women at both sites traveled to other towns to obtain screenings.

Well, because I think that at times here at the health center you lose a little bit of ethics, then because we all know each other, already there isn't much confidence in this sense...if one knows the things going on with a patient, it doesn't need to come out...it needs to be something confidential...because this has to do

with someone's willingness to do [a screening]. Because if one sees that there is no formality, then what for. Better I don't do it or I find somewhere else to do it. (Livingston, Ladina, Age 20–25, Screened)

Further, general concerns about treatment by providers presented a barrier to screening for many women. In Santiago Atitlán in particular, indigenous-identifying participants described experiences of discrimination when obtaining screening at the local health center.

[...] after a while laying down my vagina started to hurt. I had a Pap smear not long before and it did not hurt much but that day it hurt a lot. The speculum wouldn't go in, it doesn't reach the uterus maybe... They thought that I didn't understand Spanish, so she was explaining to the other nurse, "the speculum won't go in what are we going to do"... (Santiago, Tzutujil, 30–35, Screened)

When asked how this experience made her feel she responded:

[It made me feel] bad, I asked the nurse why she didn't put the speculum in. "No it went in. It reached the uterus," she told me. But I heard what they were saying because I was laying there with my legs open. But I was angry with myself. If I had done it in another place, it would have been better to pay...it's free, but as they say, what's free comes at a cost.

System-level resource constraints were commonly cited by women in both Santiago Atitlán and Livingston. Despite access to government subsidized screenings at public health clinics, women cited shortages of tests and long wait times.

Suppose there at the [public women's health clinic] one goes early, at six in the morning...and you leave at eleven or twelve in the afternoon. It's a long time for someone, and you have to be cooking and doing things in the house. (Santiago, Tzutujil, 30–35, Never-screened)

Due to these shortages, women often sought screenings through traveling health campaigns or jornadas; however, these options also presented challenges. When describing the process for obtaining a free screening at health campaign in Livingston, one participant explained:

You could say, the woman who gets there first, gets the test. Because when they come, when they give screenings, they only bring tools for a certain number of people...if they only bring enough for 50 people, only 50 people will be seen...you have to wait until the next time come back...it's stressful because...sometimes you don't sleep because you're thinking about waking up the next day early to go running [to get screened]. (Livingston, Garifuna, Age 25–30, Screened)

Barriers to obtaining a free or low-cost screening in turn, create a tiered system in which those women who could afford to pay out of pocket for a screening at a private clinic, were more likely to seek care. Speaking about healthcare more broadly, one woman in Santiago Atitlán explained:

I don't go because I don't have much money. In the [private hospital], it's not the same as going to the [public women's health clinic]. At the [public women's health clinic] they don't charge, but there aren't

specialists. There are times when for this reason people don't go to the doctor to see what illness they have, until they are even more sick. (Santiago, Tzutujil, Age 25–30, Screened)

Facilitators to Cervical Cancer Screening

Despite significant barriers to screening, a large proportion of our sample reported being screened at least once in her lifetime and women described several facilitators to screening. In both communities, the desire to know one's health status motivated women to obtain screening.

Well, I thought, if I don't do it, I'll get worse. I have heard that there are many young women who do [the screening] quickly to stay clean, and that's why I thought to do [the screening] before something bad happens to me (Santiago, Tzutujil, Age 45–50, Screened)

Among some women who had obtained previous Pap smears, screening was often precipitated by symptoms or other health concerns.

What happened was I had a miscarriage, or they had to do a curettage because all of a sudden my bleeding was really, really heavy so they sent me to do a curettage but they told me first they were going to do a Pap smear. (Livingston, Ladina, Age 25–30, Screened)

The first time I did [the Pap smear] was because my stomach hurt really bad, so I said, "I don't know what I have" because it hurt a lot and I had a lot of discharge. It hurt constantly so I went, that's why I went to see what I had. (Santiago, Tzutujil, 25–30, Screened)

Women also described interpersonal and system level facilitators that promoted cervical cancer screening. Though not consistent across participants, some women expressed that provider-communicated screening guidelines helped them to obtain screenings. When asked how she knew to obtain her first screening, one Livingston resident replied:

Well, in general how I told you, through information, through the [local health clinic] because sometimes one goes there...they explained to me what it was about, why it was good to do it and because of that, I had no problem [getting screened]. (Livingston, Garifuna, 45–50, Screened)

At the system level, health fairs, or “jornadas”, outside of the public health system also facilitated screening. Women often traveled to nearby towns hosting health campaigns for a variety of health services. Of note, several women described health campaigns as irregular, lacking follow-up and often tied to some other event.

If they bring [materials] for only 50 people, they are only going to attend to 50 people. So if someone comes after those 50, they cannot get their Pap smear. They have to wait until the next time they have the health fair and they can go. They also don't do follow-up. (Livingston, Garifuna, 25–30, Screened)

In one extreme example, a participant from Santiago Atitlán obtained her first and only Pap smear during the aftermath of Hurricane Stan in 2005, which resulted in mudslides that killed over 1,000 residents.

I got my Pap smear after the accident caused by Hurricane Stan. That day, they set up shelters for people and they came from the health center to do a health fair and I took advantages to get my Pap smear. (Santiago, Tzutujil, 30–35, Screened)

Discussion

Cervical cancer is a major public health concern for women in LMICs, where barriers to screening often prevent early diagnosis and treatment.[6, 17, 18] The present study sought to examine the cervical cancer knowledge and barriers and facilitators to screening among a sample of women in two rural communities in Guatemala. Barriers and facilitators at the individual, interpersonal, and system levels were identified by women in both communities.

Limited knowledge related to cervical cancer was common but differed across women and site. These findings are in line with previous quantitative and qualitative research in Guatemala [19] and other LMIC contexts.[20–22] Notably, while some women reported no knowledge of cervical cancer screening in general, they were aware of and, in some instances, had obtained screening. This discordance suggests that women may be screened by healthcare providers during other health care visits without adequate explanation of the purpose of the procedure or its risks. This is congruent with other provider-related interpersonal barriers to screening reported by women in our sample, including poor communication, experiences of discrimination and distrust of healthcare providers as well as earlier research which found patient/provider language discordance to be a barrier to screening.[6] In contrast, community health workers and workshops were identified by women as facilitators to screening. Community health workers (CHWs) have been found to be effective in increasing cervical cancer knowledge among women in other LMIC settings [23] and task shifting from physicians to CHWs has been found to be an effective strategy for the management of non-communicable diseases, including screening.[24] Our results suggest that interventions to improve screening may include promoting the integration of CHWs in clinical settings to facilitate patient-provider communication and ensure women understand screening recommendations and the risks and benefits of cervical cancer screening.

Resource limitations were a major barrier to screening for most women. Despite the availability of free-of-cost screening to low-income women in Guatemala through government-funded women's health clinics, few women reported being able to access these services due to the associated costs of travel or food, barriers that have been identified in other LMIC settings.[8, 9, 25, 26] Cost of future procedures associated with a positive screening was also a concern and several women described personal experiences in which they were unable to afford follow-up care associated with a positive screening. Gender norms related to economic control also presented a barrier to women whose male partners were unwilling to provide needed funds to obtain screening. Interventions to limit ancillary and future costs, including minimizing the need for and/or subsidizing the cost of travel, must be considered when developing future screening programs to promote utilization of free or low-cost screening and to reduce help minimize potential interference by partners.

At the system level, shortages of materials, long wait times and irregularities in service also hindered women's ability to access government subsidized services. Through formal agreements with the Guatemalan government, non-governmental organizations provide a significant proportion of healthcare services throughout Guatemala, including approximately 15% of cervical cancer screenings.[4] Though health fairs implemented by non-government organizations helped supplement governmental programs, irregular scheduling, shortages of tests and similar cost-related barriers were described also plagued these programs. As such, the implementation of less resource-intensive screening methods [5] by governmental programs and NGOs is an important step to addressing these barriers.

Despite significant barriers to screening, most participants reported at least one previous cervical cancer screen and women identified several important facilitators to screening, including internal motivation to maintain one's health, health fairs and formal or informal conversations with other women. Programs to improve cervical cancer screening should leverage women's own desire for good health and the power of interpersonal relationships in fostering health promotive behaviors, while reducing financial and logistical barriers to screening. For example, at-home self-screening for HPV has been proposed as one method to improve cervical cancer outcomes in LMICs, as this type of screening can assuage barriers such as cost (test can be performed in home) and embarrassment (test can be performed by woman).[14]

Limitations

The findings of this study should be understood in the context of its limitations. Women who chose not to enroll in the larger HPV MES cohort and those who did enroll but chose not to participant in the qualitative interview may be systematically different from those agree to participate. Social desirability bias may have impacted women's responses during interviews. The sensitive nature of the interview was described to participants during recruitment and steps taken to ensure participant privacy were explained in detail at the start of each interview and throughout conversations.

Conclusions

The World Health Organization has identified the "robust understanding of the social, cultural, societal and structural barriers to the uptake of services" as a strategic action necessary to achieve the elimination of cervical cancer.[27] This study is the first to our knowledge to qualitatively examine cervical cancer knowledge and barriers and facilitators to screening among women in two rural communities in Guatemala. Our findings speak to the many challenges women face in obtaining screening for cervical cancer in their communities but also to existing facilitators that may be leveraged for future interventions. Future research must focus on mitigating barriers through education and alternative screening methods.

Declarations

Ethics approval and consent to participate:

All study protocols and procedures were approved by the Institutional Review Boards at the University of Michigan (HUM00096559) and the Instituto de Nutrición de Centro America y Panamá (INCAP) (MI-CIE-16-009), located in Guatemala City. All methods were carried out in accordance with relevant guidelines and regulations. All participants completed the informed consent process prior to the start of each interview.

Consent for publication:

Participants were notified of future publication of results during informed consent process.

Availability of data and material:

The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request.

Competing interest:

The authors have no conflicts of interest to disclose

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Authors contributions:

Study design and conceptualization: Bevilacqua, Meza

Protocol development (measures, safety protocol): Bevilacqua, Gottschlich, Murchland

Analysis: Bevilacqua, Alvarez, Gottschlich

Writing: Bevilacqua

Editing and interpretation of data: Bevilacqua, Gottschlich, Meza, Alvarez, Rivera-Andrade Murchland

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