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## LOW KNOWLEDGE OF CERVICAL CANCER AND CERVICAL PAP SMEARS AMONG WOMEN IN PERU, AND THEIR IDEAS OF HOW THIS COULD BE IMPROVED

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## Abstract

Estimates of the percentage of women who have had Pap smears in Peru vary between 7% and 43%. This study explores what women know about cervical cancer and Pap smears, as well as their barriers to obtaining Pap smears. Focus group discussions (FGD) were conducted with a total of 177 women in four Peruvian cities. Discussions reveal that most women did not know what causes cervical cancer. Most women did not know the purpose of Pap smears, although knowledge about Pap smears was higher than knowledge about cervical cancer. Fear, embarrassment, and lack of knowledge were the main barriers identified for not getting Pap smears. Programs and policies aiming to increase Pap smear coverage must start by educating women on cervical cancer and its prevention in order to improve women's perceptions about the screening test and increase Pap smear seeking behaviors in the long term.

## INTRODUCTION

Cervical cancer is the most common type of cancer, as well as one of the primary causes of cancer-related deaths, among Peruvian women [1-3]. The incidence rate for cervical cancer in Peru is one of the highest of the Americas, estimated at 34.5 per 100,000; the mortality rate is estimated at 16.3 per 100,000 [2, 4-8]. Though Pap smear cervical screening has successfully lowered cervical cancer incidence and mortality in developed countries, and the Peruvian Ministry of Health declared the reduction of cervical cancer incidence as one of its national priorities a decade ago, Pap smear screening coverage among women is still fairly low in Peru, as is the case in other Latin American countries [9-12]. Estimates of Pap smear coverage in Peru range from 7% to 42.9% [6, 9, 11, 13-15].

Low Pap smear coverage may be due to factors ranging from those associated with the healthcare delivery system to women themselves, who may not know of the importance of Pap smears or may avoid getting them. Various studies have found a lack of education,

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especially surrounding preventative care and reproductive and sexual health, to be a principal barrier to Pap smears [16-18]. Cultural barriers have also been found to influence women's Pap smear-seeking behaviors: women view allopathic healthcare as a last resort to be used when home-based or traditional interventions fail; women feel embarrassment at their modesty being compromised with a pelvic exam; and women fear the possibility of having cancer [4, 16, 17, 19]. In addition, factors related to social capital, such as the emotional and/or financial support women receive from their partners, family, or friends, may influence this preventative behavior [16, 18, 20].

Studies have also documented factors that motivate women to seek cervical cancer screening. Perceived benefits of getting screened include "feeling peace of mind" upon learning that their Pap smears were negative, feeling empowered and in control of their health and bodies, and being able to get treatment for vaginal discharges and other gynecological conditions at the time of the screening [4, 16]. Also, in Peru, screened women reported knowing an average of 11 women who had been screened, whereas women who did not get screened reported knowing only six women who had been screened [20].

Regarding interventions to increase Pap smear-seeking behaviors, a Cochrane systematic review was conducted in 1999 on "Interventions targeted at women to encourage the uptake of cervical screening" using randomized controlled trials (RCTs) or quasi-RCTs [21]. Cochrane reviews are "systematic reviews of primary research on human health care and health policy... that are internationally recognized for their high standards" and which are designed to guide evidence-based health practice [22]. The review found that of the 35 studies that qualified for the review, there was some evidence supporting the use of invitation letters for women as a method to increase cervical cancer screening, but there was limited evidence for the success of other types of interventions [21]. However, these intervention trials were all conducted in developed countries, and may not have the same effect in developing settings. Relevant interventions that have taken place in developing country settings in recent years have shown that school and church-based programs, as well as women's and other community groups that already exist on the ground, might be effective networks through which to reach women [2, 16, 20]. It is also clear that provider's recommendations can be important: a recent study in Jamaica found that women who had received a recommendation to get a Pap smear in their last provider visit were eight times more likely to have ever had a Pap smear and twice as likely to have had a Pap smear in the last year, compared to women who did not receive this recommendation from their providers [23].

This study seeks to explore women's knowledge concerning cervical cancer and Pap smears, identify their perceived barriers to obtaining Pap smears, and describe possible intervention ideas, all as identified by Peruvian women in twenty-two focus groups conducted in four Peruvian cities.

## METHODS

#### Setting

Peru has a total population of almost 29.2 million; an estimated two-thirds of the population lives on the coast, and almost one-third reside in the capital city of Lima [24]. The four cities selected represent each of the three main geographic regions of Peru, as well as the capital city: Lima (Peru's coastal capital), Iquitos (rainforest), Huancayo (highlands), and Chincha (coast).

## Sampling

Purposive sampling, a non-probabilistic sampling method, was used to select members for the focus groups [25]. Key informants in the communities, often a health worker, assisted the research assistants in recruiting women for the 22 focus group discussions (FGD). With the exception of Lima, in each city two FGD in urban areas and two FGD in semi-urban areas were conducted between May and August 2007. Ten FGD were conducted with women of varying socioeconomic status (SES) in urban and peri-urban areas in Lima, the more heterogeneous capital city (four with women of high SES, four for with women of middle SES, and two with women of low SES). We conducted four focus groups among women of middle and high SES because the FGD turned out to be small due to recruitment difficulties within these groups. Though the setting of the FGD varied by location (i.e., public health centers, community buildings, hotel conference room), all were held in private rooms that allowed participants to speak freely.

A total of 177 women participated in the 22 FGD. As is the common practice in studies with non-probabilistic sampling such as this one, saturation, defined as the process of interviewing until no new information is obtained from subsequent interviews, was used as the threshold for sample size [25, 26]. In all locations, half of the focus groups were among women 18 to 25 years of age (n = 89) and the other half were with women aged 26 to 40 years (n = 88). Also, in each city (excluding Lima) half the focus groups were conducted in urban locations (n = 54) and the other half in semi-urban areas (n = 58). In Lima, the more heterogeneous capital city, all focus groups were urban, but participants varied by social class: high (n = 20), middle (n = 18), and low (n = 27).

#### Study Design

The focus group guide was developed based on the study objectives and related topics of interest by the principal investigator (VPS)—a Peruvian social scientist—and the lead research assistant (AB). This guide was field tested for content, flow, and language in a Lima peri-urban area, and modified accordingly. All FGD were facilitated by two research assistants using the focus group guide to guide the discussion. Before starting the discussions, the research assistants described the study in detail, and women were asked for written consent to participate, as well as to be audio-recorded. Focus groups specifically allowed women to build upon what others were saying, providing an in-depth, qualitative exploration of both the structural and cultural barriers to Pap smears as identified by actual and potential patients. During the final part of the focus groups, participants shared initial ideas about interventions to promote Pap smear-seeking behaviors. Then, the research assistants provided a 5-10 minute health education presentation on cervical cancer and Pap smears. Once the presentation and associated questions were complete, women were again asked for more ideas regarding promotion of Pap smear seeking behaviors among women in their communities.

#### **Data Management and Analysis**

All focus group discussions were transcribed. Codes were developed based on the main issues explored in this study: knowledge of cervical cancer and Pap smears, barriers to getting Pap smears, factors that would motivate women to seek Pap smears, and ideas for possible interventions. The research team established initial codes and added additional codes as information emerged from the transcripts. Then the analysis was stratified to determine if there were any observable trends by region, age group, urban versus semi-urban areas, and in Lima by SES. Atlas.ti, a qualitative data analysis software, was used to code and analyze the data [27].

#### **Ethical Conduct of Research**

Approval from the Institutional Review Boards of Tulane University School of Public Health and Tropical Medicine and the Peruvian non-governmental organization PRISMA were obtained prior to initiating this study.

## RESULTS

### **Cervical Cancer Knowledge**

Knowledge of cervical cancer was very vague among women in all regions, age groups, and socio-economic status. For the most part, when women were asked what they knew about cervical cancer, the majority was silent. A few women hesitantly volunteered a response, yet the responses usually indicated a lack of knowledge about what cervical cancer was. For example, a young woman from a semi-urban site in the rainforest explained, "We know that this cancer exists, but we don't know how it starts, if it's contagious . . . we just don't know." In fact, in a few of the focus groups with younger women, participants often used the terms uterine, ovarian, and cervical cancer interchangeably.

Regarding the causes of cervical cancer, again most women did not volunteer an answer and often, after some silence, our question was responded to with an answer formulated as a question to us. In the few cases where answers were given, Human Papilloma Virus (HPV) was the most common—and correct—response. In eight urban focus group discussions (FGD), half of these with women of middle SES in Lima, at least one woman correctly associated HPV with cervical cancer. However, women did not have a clear understanding of the relationship between HPV and cervical cancer.

Young women from all four study locations incorrectly mentioned infections and improper hygiene as the second most common cause of cervical cancer after HPV. In a few focus groups with women of all ages, genetics, miscarriages, and abortions were also proposed as potential causes. A young woman from the urban rainforest region cited both infections and abortions as a possible cause of cervical cancer (using the word uterine cancer to respond to a question about cervical cancer):

In a workshop we had, they explained that women are subject to uterine cancer, but only women who have had more than two or three abortions, or who had a vaginal infection that wasn't treated well or completely cured.

In two FGD, both with women of middle SES from Lima, participants associated sexual promiscuity with cervical cancer. One woman linked various conditions mentioned above with cervical cancer, in addition to the hygiene of one's sexual partner and sexual promiscuity:

I have read that it [cervical cancer] can have various causes: it can be genetic ...; it can happen when you have sex and you are a promiscuous person; or you can acquire it because of hygiene, washing, with the person you had sex with. It accumulates on one part of the penis. It's like a piece of skin and lots of, well, harmful substances can accumulate, dirt and those types of things. That is why it is recommended to get a Pap smear, to check, so that the woman can know her health status with respect to that specific organ.

Other causes that were incorrectly linked to cervical cancer were use of the intrauterine birth control device (IUD) and of hormones, two well-known modern methods of contraception among Peruvian women (~90% of women have heard of IUD and ~95% have heard of a hormonal; whereas ~15% of women have used IUDs at some point in their lives, and >70%

If a woman is using a Copper T [IUD device] and causes it to move during sex, it can damage the cervix and cause cancer.

Despite the lack of knowledge surrounding cervical cancer, more than a third of the FGD included at least one participant who reported knowing someone who has or had cervical cancer. These participants were from both age groups, but only in urban areas. A young woman of low SES in Lima explained what happened to her neighbor:

My neighbor suffered from that. When she had cancer she was skinny. She used to be fat, but then she became skinny, skinny . . . there was no cure for her. When the cancer is malignant I think they take out your uterus.

In four of the FGD, and more among younger women than older women, at least one person in the group correctly explained that cervical cancer could be cured if detected in time. As a young woman of low SES from Lima explained:

I know that if you detect the cancer during its initial period, it is curable, right? And if you detect it during the next stage, it may be curable, but it could also come back again.

#### Pap Smear Knowledge

Knowledge about cervical Pap smears was slightly higher than knowledge about cervical cancer. However, even though women in more focus groups were familiar with the term "Pap smear" than with the term "cervical cancer," most women still did not know the purpose of Pap smears. The most commonly reported purpose of Pap smears across the different FGD was to screen for all types of vaginal infections or diseases—this was brought up by someone in 13 of the FGD; young women from urban areas cited this belief the most. For example, a woman of low SES from Lima explains:

Well, from what I understand, a Pap smear . . . is to determine the state of your reproductive organs, if they are ok, if there is any variation . . . to see if there is any type of disease, sexually transmitted infection, or infection at all.

Other perceived purposes of the exam ranged from screening for ovarian or uterine cancers (in nine FGD) to preventing diseases or inflammation (in four FGD) to preventing cancer (in three FGD). One young woman from the urban rainforest explained:

My teacher explained that a Pap smear is a type of cleaning. That is how she explained it to us, as a vaginal cleaning, an internal washing that a woman can do, so that she can then do the exam, when they diagnose a fungus, uterine cancer, any type of bacteria that could be there.

In the semi-urban highlands, another young woman had similar associations between vaginal infections, lack of hygiene, and Pap smears, despite the fact that she had in fact had a Pap smear before:

It is important for us to get that test [Pap smear] because we can get any type of infection, not just infections from sexual relations, but also from lack of hygiene and all of that. I have gotten that test and it went really well.

In five FGD at least one participant specified that Pap smears screen for pre-cancerous cells, though in those discussions, women did not specify that the smear exclusively screened for pre-cancerous cells in the cervix. The groups that brought up detection of pre-cancerous cells happened to all be composed of older women from urban areas in all four study locations. And in three FGD, someone in the group mentioned that Pap smears screen for

cervical cancer. A woman of middle SES in Lima, for example, explained the purpose of the Pap smear:

[The purpose of a Pap smear] is to see if you have cancerous cells on the cervix. They take a sample and analyze it to see if there is any indication that could generate a cancer, but the idea is to prevent it, because I believe that cancer is very aggressive when you get it, or rather, it advances very rapidly and is not something that can be easily cured. So you have to prevent it in order to cure it. If you don't prevent it you won't be able to cure it later.

General knowledge of Pap smear procedures was higher than the knowledge about its purpose. In about two-thirds of the FGD, women explained that Pap smears should be performed annually, and in approximately half of the FGD, women stated that one should begin to get Pap smears upon initiating sexual activity or between 17-20 years of age. In two FGD, women associated starting to get Pap smears with childbirth. One young woman from the urban rainforest explained:

They started talking about that [Pap smears] when I was 16. I didn't know what it was, but since my mom had mentioned it, I asked her "What is that?" She told me, "It's a test that women get when they begin to have sexual relations, or when they have children rather"... I don't know if I am right.

However, the lack of clarity about Pap smears, their purpose, and logistics associated with this screening test was evident among most women in the groups. For example, one woman from a low SES area of Lima mentioned that she had had a Pap smear many years ago that came out negative, and thought that meant she never had to do one again.

#### **Barriers to Getting Pap Smears**

Embarrassment and fear were by far the most common barriers to getting Pap smears that women mentioned; these emotions were described in 17 of the 22 FGD. Women described embarrassment about the process of undressing, or simply being undressed, in front of a provider, as well as being seen naked or having their genitals exposed to a provider. Embarrassment was more commonly described among the younger women. A young woman of middle SES from Lima explained:

To me it seems like a taboo. . . . The idea that I have to go to a doctor so he can examine me and touch me, that's a problem because it is embarrassing, but of course that is just ignorance, right? Because a good doctor isn't going to grab you or do anything wrong. On the contrary, he is doing you a favor, he's doing you a service, but either way, having to undress in front of him is really difficult. You don't know where to look, you start blushing, and so everyone would rather just avoid it and so they tell themselves, "Well, what can I do, nothing bad is going to happen to me. I don't feel any pain, I don't have any symptoms, no, no, no," and the time passes, and then all of a sudden you are 40 years old and you have to do a bunch of medical exams all at once!

Some women, in about one-fourth of the FGD and mostly from semi-urban areas, specifically cited discomfort with a male provider as their source of embarrassment. A few women also attributed this modesty about being seen or touched by a male provider to conservative Peruvian culture. A young woman of middle SES from Lima explained:

The truth is that I would feel uncomfortable; this was the issue at first, that a doctor was touching me. And that is an issue, a prejudice of mine, right? Because one has to understand that the doctor is a professional and that he is just doing his job, as a professional. He has no other motive, but I still feel very uncomfortable that a man is seeing me. Some girls don't feel this way, and good for them, but I do feel

uncomfortable. I prefer that a woman see me. That's the other issue, right? I think it also has to do with the mentality of Peruvian women. I at least come from a rather conservative family, and my parents are from much more conservative families, generation to generation. I think that has a lot of influence in terms of the cultural and educational issues, because this continent definitely has a much more conservative people than, for example, United States or Europe, where people are, well let's say . . . the way of life and the education is different, more accepting, but here, not yet, because of the culture.

When the issue of provider gender was brought up in the discussion, women tended to report a preference for a female provider, but there were a few women who felt that the provider's gender was not an issue or that seeing a male provider had its advantages. For example, this young woman from the Lima low SES sub-group explains:

I have no problem if the doctor is male or female, no, because there have been cases where I have been seen by female doctors and they, because they are women, they treat you just the same, and they don't care if you are in pain. A male doctor is more of a gentleman, so he treats you much better.

The fear and embarrassment surrounding the process of getting a Pap smear were often driven by misinformation or horror stories about others' painful experiences, stories which were rampant in all groups. As a woman from the semi-urban coast explained:

Sometimes [we do not get Pap smears] because of misinformation, because we don't go to a Health Center where a nurse/midwife will tell us how it really is. No, we go along with what our friends say. This has also happened to me. They have told me "oh, it hurts. Oh it's really bad. They remove a piece inside." And I have been traumatized my whole life by this [laughter], and I still have never done it because of this fear.

Various women of all ages talked about a fear that the provider would "cut out" something, as in the quote above, or that their uterus would be "pulled down," and mostly that this process was very painful. A young woman from the urban highlands shared a similar sentiment about rumors concerning the procedure:

They have explained to me that they use a type of spoon, something like that, and just imagining it scares me . . . or a stick, no, just thinking about it. . . . What I mean is that women get scared, I don't know what to say. Perhaps because people exaggerate, you get scared and then don't want to do anything, even something so simple. I don't know, really it's about the lack of information.

Despite concerns about pain and discomfort, none of the women who had gotten a Pap smear mentioned that it was painful. Some described it as uncomfortable, but most described it as painless.

Fear of the results of the Pap smear and the possibility of having cancer was also brought up, though it was not brought up very often nor discussed as intensely as the fear associated with the process of getting the Pap smear. This fear of having cancer or of having something "slightly serious" was brought up in three FGD (younger and older groups), but was not something that led to intense discussions.

Following fear and embarrassment, the next most common barrier to getting Pap smears as voiced in about half of the FGD was a general lack of knowledge concerning its purpose. Many women, mostly young women from urban areas, explained that while they had heard the name of the procedure, they were not sure what it was for or how important it was. Since

Well, I have never been well informed about what a Pap smear is, and I don't know when a woman should get one, nor in what circumstances.

Another woman of middle SES from Lima blamed the level of sexual education in schools:

I think that more than anything it is the lack of a culture of health, because in high schools, they generally teach you sex education and they tell you about condoms and that's it. They don't tell you anything else. They don't tell you about tests. They just don't tell you those things... I think it's that they don't teach us in high schools, on top of everything else.

A few women mentioned that even though their doctors had recommended they get a Pap smear, they refused the procedure out of fear or ignorance about the test. However, based on this comment from a young woman from low SES Lima, the opposite occurs as well:

I wanted to get one [a Pap smear] before I had my child, because I wasn't able to have children and I asked why.... People told me to get a Pap smear because it might clean me out, but when I went to a doctor he told me "No, no, you can't get one because you don't have kids" and so I didn't get one.

Cost and lack of time was brought up by at least one woman in about one-third of the focus groups; these reasons were cited more frequently in urban areas. In some groups, the mention of cost initiated a conversation among women about the actual cost of the exam. Among women who talked about the lack of time, many cited their responsibilities to their families and careers. Several women explained that because they were mothers, they did not have time to get a Pap smear. For example, a woman from the urban rainforest explained:

I have a 4-year-old daughter, so first I was pregnant, then 2 months after [giving birth] I got my period. "Next month I'll go," but then the month passed. "Next month I'll go," then I realized my daughter was already a year old. That is how time passes. . . . I don't have a steady partner. I don't have a partner at all at the moment. . . . I think that it's my fault, I should have gone already.

However, other participants mentioned that women who do not have kids are harder to reach because as childless adults, they are less responsible for others. Thus, they do not visit the health center as often because they do not have pre-natal and post-natal check-ups or pediatric visits. Other women admitted that they simply do not prioritize Pap smears. For example, a young woman of middle SES from Lima explained:

The truth is, first I didn't get one because of that [fear]. I was afraid that they would cut something inside me. . . . I was misinformed, but later on when I found out that no, they don't cut anything, I said "ok, I am going to do it," especially since I have cancer insurance, so I should take advantage of the discount and everything. But I ended up not having any time, and well, I don't make time to go.

Other participants attributed the low incidence of Pap smears to the fact that women seek advice for any abnormal discharges or symptoms first from pharmacists, or prefer to treat themselves with natural medicines and other remedies at home:

You can tell your mother about it, or the pharmacist, because at the pharmacy you can just go and tell them what you have and they give you something, without being doctors. They can resolve it easily because they see you don't have time and just want to solve the problem there. No one worries about prevention.

Finally, in three of the FGD, at least one woman mentioned that because she "feels healthy" she does not feel she needs to seek a Pap smear. And in two of the FGD, women cited a lack of trust in healthcare providers as their reasons for not getting Pap smears.

#### Types of Interventions

Women had various ideas about types of interventions to encourage women to get Pap smears. Many women felt that an educational program would be an ideal intervention; this was suggested in about half of the FGD. They asserted that this education should not only present basic information about cervical cancer and Pap smears, but also emphasize that cervical cancer can be treated if caught in time, hence the importance of this test. As a young woman from the urban coast recommended:

Continue with these talks that you are giving [referring to this focus group discussion and our presentation at the end about cervical cancer and Pap smears]. Explain a little more detail to the people. The majority of women have heard of Pap smears, but we don't know what it is, or what women have to do, so I would say, continue with these talks.

Some women felt that to make the educational programs more appealing to women, these programs should provide women's testimonies of their experiences with cervical cancer and Pap smears, directly addressing the fears and doubts that women have regarding getting screened for cervical cancer. For example, an older woman in the urban coast recommended using video testimony of women:

Through videos perhaps . . . have cases of women who have had problems, in this case problems with their cervix, no? And how you can avoid those problems. And you could also have flyers, or conversations from woman to woman, as we are having right now, conversing in a group, to discuss what are the concerns . . . primarily so that they can get over their fear, primarily for that.

Providing educational workshops at schools was brought up in numerous groups. As one woman of middle SES from Lima explains:

... these issues of sexual and reproductive health should begin in high school, because if you teach the girl from a young age, letting her know that it is necessary, that it is part of her life, then when she grows up she will do it [get a Pap smear], right?

In addition to educational workshops or programs, in almost half of the FGD, women also suggested free screening campaigns, including raffles or free medicines for the first 100 women that get their Pap so that the screening is awarded, not stigmatized. One young woman from the semi-urban coast suggested both a workshop and a free Pap smear all at once:

If people come to your door and say "Come get your Pap smear," they won't do it, because they don't know what it is . . . but if you have a talk first where you explain what it is, how you treat [cervical cancer], what you can prevent, I think everyone would come to do it. And if it's free, even better.

Other suggestions included one-on-one interactions with peer educators, and educational information through different media, specifically television and radio programs. Women of high SES in Lima also felt that annual reminders from health insurance companies and health centers would be useful. In very few groups, at least one woman suggested health fairs, training programs for teachers, and using theater to educate women on Pap smears. Finally, one woman of middle SES from Lima felt men should also be targeted in these educational campaigns:

Men don't know that they are the carriers of this virus and they are not going to know for a very long time if we don't do something, right?

#### Intervention Leaders

When asked who would be the most influential person to lead these educational sessions, women had mixed opinions. Medical providers were the most popular choice and were suggested in about one-fourth of the FGD. However, they were closely followed by the suggestion of health promoters, which was closely followed by the discussion of having community members provide such educational interventions. A young woman from the urban highlands explains her choice for peers:

Usually, communication occurs between friends. They tell you about a problem, so you know about problems girls can have, so you respond with what you think it could be or what they should do. That would be how to do it, to say "get a Pap smear," and you could just inform your friends that way, explaining the disease and what they can do. It has to be someone that knows, but also someone you already trust, because if I don't already trust the person [who provides the information], I won't do it.

Other less common suggestions for intervention leaders included local and national celebrities, women's groups' members, foreign specialists, traditional healer, and psychologists.

When the topic of gender was discussed, women tended to favor female facilitators, stating that women would feel more comfortable hearing from other women. A young woman from the semi-urban coast explained:

When one goes to a specialist, or in this case a female specialist, one feels more trust. When it is a man, you feel too ashamed to talk, but when it is with a woman it's different. She has her own experience, she also has a partner, maybe she is married, so you can talk about the issues more.

But there was no consensus on the issue of gender. For example, a woman of low SES from Lima felt that male promoters would be taken more seriously:

For the talk, it can be a man, because women will trust him more.

#### Intervention Locale

Similarly, focus group participants had many ideas about where these interventions could be based as to attract the maximum number of people. Many women insisted that interventions should be held at as many different locations as possible in order to reach women from different professions, ages, SES, and residential locations. However, educational settings were most mentioned: universities, technical institutes, and high schools were discussed in one-fourth of the FGD. Work centers were mentioned in a few FGD, as were public settings that include health centers, municipal buildings, plazas and markets. As stated by an older woman in a middle SES group in Lima:

I think that an informative talk should be promoted through a health campaign in the workplace, in work centers, because often there just isn't time for people to become informed, they are not dependent on these issues, so, if you go to where the person already is, I think it would be easier, right?

Discussions about potential intervention locales focused on places where there is a captive audience of women of different ages, who are sometimes simply waiting for an appointment or event. Young women from a lower SES community in Lima mentioned hairdressers, since many go to hairdressers on weekends to get their hair cut or styled for evenings out.

When older women of low SES from Lima were asked about hairdressers, they responded that they cut their own hair to save money and suggested their neighborhood meetings instead. Specifically, all households in the low SES area where we conducted our focus groups are expected to attend a monthly neighborhood meeting, and in many cases they are fined for not attending. Older women of low SES in Lima also suggested the market and door-to-door strategies to reach women their age. One woman from the urban highlands suggested public health centers since people are often waiting long periods of time for their appointments.

#### Intervention Advertising

Women in the focus groups also suggested a variety of creative ways to advertise about a possible program or intervention. Most of these ideas came from the focus groups among women of middle and high SES from Lima, although one young woman from the urban highlands did suggest a commercial in order to get the information out. Using the media—television, radio, newspapers, or text messages—was the most common suggestion in the FGD. In one FGD among higher SES older women, a few women jumped on the idea of having famous women become spokeswomen for the cause: having campaigns where famous women who have had cervical cancer tell their own story as a way to educate others in a personal way.

Fliers or postings in strategic locations were also brought up in a few groups. A young woman of middle SES from Lima recalled an innovative campaign for breast cancer she had seen in the local department store:

In the fitting rooms in [name of department store] there were little flyers that explained how to check yourself [for breast cancer].... When you entered the fitting room it told you how you had to lift your arm and check yourself. And one time, I was trying on clothes and that's what I did [laughter].... But you know, it seems like an excellent idea that I never would have thought of.

In two separate FGD, women talked about using music to attract people from the community to an event or campaign: in one case, the community is gathered by the sound of a trumpet; in the other case, a woman recalled an HIV campaign which used music to bring people together in the rural community. In general, urban women were more vocal than semi-urban women about all of their ideas concerning an intervention.

## DISCUSSION

Most women who participated in the FGD did not know much about cervical cancer and Pap smears, regardless of socio-economic status (in Lima) and rural/urban groups (in the different cities). Though many women knew that they should get Pap smears, and even how often, most were unsure about why they should get this screening test. This finding resembles a U.S.-based study indicating that although 85% of women had received a Pap smear, only 27% of participants were familiar with HPV [29]. Another significant finding is that few knew cervical cancer was treatable; it makes sense that some women would not bother to get tested for an untreatable disease.

It was not entirely surprising that the few women who did know about cervical cancer correctly associated it with HPV. Some of the HPV vaccine trials were held in Peru, and the arrival of the HPV vaccine in Peru was covered extensively in 2006 [30]. The HPV vaccine continues to be discussed and promoted through different forms of media, including radio, flyers at health facilities and other forms of promotion. The range of information varies: there have been interviews on the radio that have covered information regarding cervical cancer, whereas some promotion has simply focused on the HPV vaccine availability.

Our finding that misinformation and rumors from other women may prevent women from seeking Pap smears initially seems to contradict others' assertions that knowing other women who have had Pap smears make women more likely to get tested themselves [4, 16, 20]. However, not a single woman in any of the focus groups who had gotten a Pap smear prior to the focus group described the experience as painful or uncomfortable. Thus, it seems more likely that women who have not had Pap smears themselves are the ones that are spreading daunting rumors that are more based on their fears than on anyone's actual experience with the procedure, but more research is needed to determine this.

Because cost was brought up in about a third of the groups, and "fear of the results" was also discussed, though less frequently, it is also important to note here that until recently, the only specialized cancer hospital in Peru was located in Lima. Costs of treatment for cancer, including transport to and living expenses associated with treatment for those outside of Lima, are beyond what most women could afford. Though Pap smear exams are available at a very low cost in public sector health facilities (when we asked participants, the most common response among those who know was approximately S/.4, equivalent to US\$1.30), treatment for detected cancers is not free.

We did not find patterns of knowledge or attitudes that were exclusive to a single region: issues that came up in one region were often voiced in other regions as well. The only differences observed by regions had to do with intervention ideas: most ideas involving publicity and advertising campaigns were brought up in Lima, which may also be the region where more forms of communication and advertisement are available. However, one focus group in Iquitos had an idea to use music to attract people to a campaign; the participant had seen music used this way by the Global Fund for AIDS. In other words, regional background and experience may have influenced the types of intervention ideas, but future research with a larger sample would be necessary to ascertain this observation.

#### Study Limitations

This study of 22 focus groups was not exhaustive in terms of participants' ages, geographical regions, or ethnic backgrounds, and it is not meant to be representative of women in the regions sampled. However, we reached saturation with regards to answers to our main research questions, suggesting that at least among women in the selected cities, we may have not obtained much additional information with more FGD. Due to limited time and resources, we limited the study to urban and semi-urban areas and did not include rural areas. However, compared to more urban areas, there are less health facilities that offer Pap smears in rural areas, and education levels are lower. Hence, we would expect that knowledge about this topic would be even more limited in rural areas compared to urban ones. Though it is likely that there were some women in each group who were slightly inhibited, at least initially, and thus we may have underestimated their knowledge on several items, the type of conversation and interactions we observed actually led us to believe that there were some topics that women simply did not know much about. Finally, the data presented is based on focus groups, which tend to solicit group norms. We aimed to overcome this limitation by encouraging women to express their personal opinions, even if they may have been different from the majority ideas being proposed, but it is likely that some may have still felt inhibited about expressing their own ideas if different from the rest.

#### **Programmatic and Policy Implications**

It is clear that mass information and education regarding cervical cancer prevention is needed for women of all ages, SES, and geographical regions of Peru. Considering that knowledge concerning Pap smear procedures was stronger than knowledge about the purpose of Pap smears, the ability to treat cervical cancer and the truth about possible

barriers, the latter topics need to be better integrated into a framework of disease prevention. Participants provided diverse suggestions about interventions, including the inclusion of the topic in the high school curriculum. However, as one woman from Lima mentioned, she did not pay attention to her teacher's presentation on Pap smears because she was not sexually active at that time and thus did not feel it concerned her. Ten years later, this woman admitted that she still had not learned about the issue. Thus, issues of age-appropriateness regarding content and the perception of risk and susceptibility need to be balanced with the intention of instilling a culture of prevention from an early age.

Some women confessed that although they had heard of Pap smears and knew they should get them upon becoming sexually active, their fear and embarrassment associated with getting the exam prevented them from doing so. This may not be unfounded: using data from clinic observations in the same four study locations revealed disruptions during medical exams were very common, affecting patient privacy and confidentiality; if women are embarrassed about others (including the provider) seeing them or hearing them during their visit, this is not unlikely [31]. These issues should be addressed by ensuring provider training on how to respect women's privacy and minimize embarrassment for them. Provider training at medical, nursing, and midwifery schools should focus on these barriers and how to address them.

Health facilities and providers have a captive audience with Peruvian patients, who often sit in waiting rooms for hours at a time. The study on clinic visits described above found that health education and counseling regarding cervical cancer prevention during medical visits is minimal, even when women are overdue for Pap smears [31]. Health education messages could be provided in print or video form in waiting rooms to target women waiting whether to see a provider for their own reproductive health, or even waiting for other clinic services.

#### **Research Implications**

We have described knowledge about the causes of cervical cancer and the purpose of Pap smears, as well as the barriers associated with this procedure. This introductory knowledge can serve as the foundation for future research, such as surveys applied to a larger and representative sample, which would allow us to obtain a more precise picture of what individual women in Peru really know, and how this knowledge varies by age, region, and socioeconomic status. This study has also described ideas for educational programs on Pap smears and cervical cancer. Once interventions to improve knowledge and increase Pap smear-seeking behaviors among women are implemented, it will be key to evaluate these interventions to determine their impact.

## CONCLUSION

This study highlights Peruvian women's widespread lack of information, as well as misinformation, regarding cervical cancer and Pap smears. Even when women are aware of Pap smears and the procedures related to them, fear and embarrassment, lack of time, and preference for home treatment prevent women from getting tested. There is a clear need and desire for health education associated to cervical cancer prevention and screening in this population. In fact, most focus groups ended with the women thanking the research team for bringing them together to talk about this issue, and asking them to return and hold this type of meeting more often. These requests demonstrate the interest Peruvian women have in learning more about their health. Participating women provided very clear suggestions regarding possible mechanisms through which health education messages could be provided, and whom they would trust for information on this topic. The next step is to design and

evaluate interventions for promoting Pap smear-seeking behaviors among women in Peru and to pursue further research that can enhance the impact of these interventions.

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