BARRIERS AND FACILITATORS OF CERVICAL CANCER SCREENING AMONG HISPANIC WOMEN

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Hispanic women are less likely than non-Hispanic white women to utilize Pap test screening. Additionally, Hispanic women have higher rates of cervical cancer than non-Hispanic white women. To better understand the barriers and facilitators for Pap test screening, we conducted 13 focus groups with 84 Hispanic women aged 18–61 years. The moderator guide was developed using the Health Belief Model. These focus groups were part of a larger study aimed at developing intervention materials for women on the US-Mexico border. Most of the women knew about cervical cancer and the Pap test. Perceived benefits of screening were finding cancer early, and feeling good about taking care of one's health. Personal barriers to having the test included embarrassment, fear, and pain. System barriers included physician gender and insensitivity to patient needs. Although the male partner was mentioned as a possible barrier in every group, most women expressed that this was not an issue for them personally. Facilitating factors fell into three categories: information/education, low cost or free tests, and supportive physicians and friends. Results of the focus group study were used in the subsequent development of a survey instrument and an intervention in a larger study. (*Ethn Dis*. 2007;17:129–134)

Key Words: Hispanic, Cervical Cancer Screening, Barriers to Screening

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INTRODUCTION

Hispanic women have a rate of invasive cervical cancer twice as high as that of non-Hispanic white women.[1] Nationally, the incidence of cervical cancer has been reported as 15.8 cases per 100,000 in Hispanic women, and 8.7 per 100,000 in non-Hispanic white women, with mortality rates of 3.5 per 100,000 and 2.5 per 100,000, respectively.[2] Mortality from cervical cancer among Hispanics may be higher in communities along the Texas–Mexico border. According to the latest report of the Texas Department of State Health Services Cancer Epidemiology and Surveillance Branch (1998–2002), the rate of cervical cancer in El Paso County was 15.4/100,000 and the mortality rate was 4.2/100,000.[3]

Invasive cervical cancer can be prevented through routine screening using the Papanicolau test (Pap test) to identify and treat cervical dysplasia, a precancerous condition.[4] Hispanic women have a lower rate of participation in cervical cancer screening programs than other women. Nationwide in 2002, 90% of Hispanic women over age 18 reported having a Pap test within the last three years, while 96.2% of non-Hispanic white women and 96% of non-Hispanic black women reported having had the test.[5] In Texas during that same year, the rates for non-Hispanic white women, non-Hispanic black women and Hispanic women were 96.1%, 95.3% and 90.4% respectively.[5] In a recent study done in El Paso, Texas, only 69% of Hispanic women age 18–25 reported ever having had a Pap test.[6]

Suggested reasons for the low rate of cervical cancer screening among Hispanic women include embarrassment, fear and hopelessness concerning the possibility of a cancer diagnosis, lack of knowledge about cervical cancer and screening,[7,8,9] and lack of health insurance.[10,11,12]

El Paso, Texas presents a unique opportunity to better understand the beliefs of Hispanic women about cervical cancer screening. Situated directly on the US-Mexico border, El Paso is ~78% Hispanic, and most are of Mexican origin. Directly across the border, Ciudad Juarez, Chihuahua, is one of the largest cities in Mexico, with approximately 2 million residents. Residents often have family on both sides of the border and move fairly freely back and forth, with ~234,000 legal border crossings per day. It is not uncommon for residents of both sides of the border to cross for medical care.[13,14] Many women on both sides of the border use Mexican pharmacies to obtain both oral and injectable contraceptives without a prescription and at low cost.[15] Because women in the United States commonly receive cervical cancer screening where they obtain birth control, the use of over-the-counter contraceptives may influence the rate of screening on the US-Mexico border.

This paper describes results of focus groups used to explore the attitudes and beliefs of Hispanic women in El Paso about cervical cancer and screening. These focus groups were part of a larger study aimed at developing culturally appropriate, theoretically sound intervention materials. Focus group data were used to guide the development of a theoretically based survey instrument, and results of both the focus groups and the survey were used to inform intervention development.

METHODS

Focus groups were used to explore beliefs about cervical cancer and screening and to better understand cultural barriers to screening, as well as barriers related to access and availability of Pap tests. The focus groups allowed us to hear the women talk about cervical cancer screening in their own words, which were later incorporated into the survey instrument for the larger study. Results reported here are from the focus group interviews. Survey results will be reported in a future paper.

Study Sample

Hispanic women aged ≥18 years who lived in selected areas of El Paso were eligible to be included. This area has a population of ~75,000 and is largely Hispanic (97%).[16] Women were recruited by lay health workers (*promotoras*) employed by local community-based organizations. Because we were interested in hearing what women of different ages had to say about cervical cancer screening, we recruited respondents from three age groups: young women (ages 18–25; *n*=18), middle aged women (ages 26–39; *n*=44) and older women (ages ≥40; *n*=22). We believed these groups might have different issues given the differences in life stage and that women would speak more freely among others of the same age group. We determined that three focus groups for each age range would give us good information, but that we would conduct more groups if necessary to reach saturation. We completed 13 focus groups.

Focus Groups

Focus groups were held in community settings, including clinics, community-based organizations, and community centers. Women were asked to read and sign an informed consent before discussion began. They also completed a six-item demographic survey. The demographic survey included age, educational attainment, insurance coverage, and their usual source of medical care as well as history of Pap screening and mammography. If the woman was not literate, the investigator read the consent and survey to her. The moderator explained the purpose of the group, that the group would be recorded, and that all information would be kept confidential.

The theoretical framework for the focus group guide was the Health Belief Model (HBM). Questions were developed to elicit beliefs about the causes of and risks for cervical cancer, the seriousness of cervical cancer, and the benefits of being screened, as well as the barriers to and facilitators for having a Pap test. The moderators were experienced in focus group methods and were fluent in Spanish and English. All group discussions were held in Spanish, although in one of the groups both Spanish and English were used. Women were given a $10 cash incentive for participation.

Data Management and Analysis

The focus group tapes were transcribed, but not translated from Spanish to English since all researchers were native or fluent Spanish speakers. The transcripts were reviewed separately by two investigators, and several themes emerged based on the constructs of the HBM and the resulting questions in the moderator guide (knowledge, personal barriers, system barriers, and facilitators). After discussion to clarify the themes and enssure agreement, the investigators re-read the transcripts and each statement was coded for theme by using color coding in Microsoft Word. Results were in agreement 93% of the time. The two coders reviewed differences and came to agreement on coding.

Statements were arranged into topics based on the agreed-upon theme. These grouped statements were then evaluated for common ideas around each theme across all focus groups.

Human Subjects

This study was approved by the Committee for the Protection of Human subjects at the University of Texas Health Sciences Center at Houston.

RESULTS

Description of Sample

Thirteen focus groups were conducted with 84 women; four with women aged 18–25, four with women aged 26–39 and five with women aged 40–61. None of the women participated in more than one group. Table 1 summarizes the demographic information.

Perception of Cervical Cancer Risk and Pap Test Screening Benefits

Perceptions about cervical cancer risk and benefits of being screened fell into three broad categories: knowledge of cervical cancer, risk factors, and screening guidelines; value of screening; and procedural knowledge about the Pap test.

Although a few women in the focus groups had never heard of cervical cancer or confused it with ovarian cancer, most knew cervical cancer can be prevented or detected early with Pap tests. They knew that regular exams detect cancer before it is at an advanced stage and that cancer may not always have symptoms:

> The Pap can detect cervical cancer. To detect in time because if one waits until one has unbearable pain well… and above all regular examinations. This is what is going to detect it. In order to find it in an early stage and not at an advanced stage when it can no longer be treated.

Beginning sexual activity at an early age and having multiple partners were mentioned as risk factors for cervical cancer. One woman mentioned being able to prevent cervical cancer by "…not being promiscuous. Not having

Table 1. Results of the Demographic Survey

	Number (Percent)
Educational Attainment	
Some elementary school	24 (28.9)
Junior High/Middle school	11 (13.3)
Some high school	31 (37.3)
High school graduate	11 (13.3)
Some college	6 (7.2)
Age	
18–25	18 (21.4)
26–39	44 (52.4)
40 and over	22 (26.2)
Any health insurance?	
Yes	22 (26.2)
No	62 (73.8)
Ever had Pap?	
Yes	68 (81.0)
No	16 (19.0)
Ever had Mammogram? (age 40 and over)	
Yes	16 (72.7)
No	6 (27.3)
Have usual source of care?	
Yes	71 (84.3)
No	13 (15.7)

sexual relations here and there." Also mentioned were having a family history of cervical cancer and having many children. The most commonly mentioned misinformation about cervical cancer was that vaginal infections cause cervical cancer; several women also mentioned lack of proper hygiene as a cause. The use of intrauterine devices (IUDs), douche solutions, and colored bathroom tissue were also mentioned as possible causes.

Most women agreed that Pap screening should begin with the onset of sexual activity; women disagreed, however on the required frequency of the exam. Most women said the exam should be done annually and some recommended exams every six months. Some women reported receiving Pap tests only as part of prenatal or postpartum care; exams were not done regularly after childbearing was complete. Women did not agree about the age when screening should begin; answers ranged from 18 to 40. In general the women were able to describe the exam.

The women recognized the importance of screening to themselves and to their families. One woman said: "It's to prevent cancer, even more important if one has children." The benefit of screening mentioned most frequently was that cervical cancer, if found in time, is curable. Other benefits included knowing that everything is okay, knowing that one is taking preventive measures, and taking care of one's health and one's family. Several of the focus groups mentioned the proverb: *Mejor prevenir que lamentar* (usually translated to mean "better to be safe than sorry").

Responses varied when women were asked if having a Pap test took away virginity. Some believed that the introduction of the speculum would impair a woman's virginity, while others were doubtful. Many believed that the association of the speculum with loss of virginity was more common in the past and also more common in the interior and rural areas of Mexico.

Perceived Barriers to Screening

Perceived barriers to screening included both individual barriers and system barriers. The most commonly mentioned individual barrier was embarrassment, followed by the perception that the test is painful and fear of results of the test.

Embarrassment was spontaneously mentioned in every group. At times this embarrassment was influenced by the gender of the examiner. For example:

> Well, at least in my case, I am very easily embarrassed. I never ask a (male) doctor anything. However if it is a female physician I will ask questions…doubts that I have. Why are you doing that, what is that for…but with a (male) doctor, I don't even want to look in his face. One turns to the side and doesn't ask questions.

Other women said that they would be embarrassed no matter what the physician's gender. Many felt that embarrassment would be a strong barrier for older women. One said:

> There are persons of a certain age…-for example my mother. As far as I know my mother has never had one (Pap test)… because in the past, just going to buy sanitary napkins would make her embarrassed.

Very few were not embarrassed by the exam. One woman told us that to increase the number of women getting screened, we would need to "change the test" to a blood test or another less embarrassing procedure.

Pain or anxieties about pain were a common response to the question about what might keep women from screening. Several women, however, said that the pain was bearable and that it would not keep them from screening. Several women described the pain as a "pulling" sensation, and a few complained of bleeding after the Pap test. One woman stated:

> Because it is a pain that is bearable. Because you can stand it. Yes, it hurts, to me it has hurt, but I can stand it. It's not like they are pulling out a piece of live flesh, it isn't like that. But it hurts when they are working (down) there, yes it hurts!

Fear was also mentioned in every group. When asked what they were afraid of, the women most often mentioned pain, finding out something might be wrong, and less often, being reported to immigration if a woman did not have legal status. One woman described her annual conversation with her supportive husband about why she does not want to go for screening:

> It's that I am afraid (to go), and he says, 'but you have to go in case you have it (cancer). They can do something about it'....It's that I am afraid, I say, and you aren't the one who will receive the bad news, are you? And he says 'but what if you don't have it? And I say, but what if I do...?

Another woman reported:

> I was going...I've only had three because...my mom and two sisters have cancer and now I am afraid and I say, no, it is better not to know...and so I don't go. It's been two years since I've had one, this year will be three.

Regarding the threat of being reported to immigration authorities, at least two of the groups went into some detail, and all groups touched on it. Women who are awaiting legal status (which can take several years) believe they cannot use federal services and risk deportation if they do. Some women avoid all services for fear of accidentally using one that is federally funded. One group pointed out that "everyone who doesn't have papers is afraid to go to the clinics." One woman said:

> In reality, they are afraid that a neighbor will talk to immigration or something, and they are careful because (of that). Or maybe they had a fight with this person and they say, "Well now they will turn me in to immigration". So they just stay quiet.

Other barriers mentioned included procrastination, fear of losing virginity, previous bad experiences, lack of time and lack of information about the need for screening and where to go.

System barriers were mentioned by all of the groups. They discussed the cost of exams, although they acknowledge the existence of low-cost testing. Still, they believed that meeting requirements for low-cost testing is difficult, because most clinics require proof of income and other documents which would discourage women who do not have legal status in the United States. Groups also mentioned that because the low-cost clinics are so full, women have to wait a long time to be seen.

Providers were also discussed. Complaints were voiced in every group that doctors don't spend enough time, the exam is painful, and some doctors don't stop when a woman says it hurts. Concern about medical students or residents being present during the exam was also voiced in one group. One woman said:

> You know what makes me embarrassed? It is when the doctor comes in to do the exam with a couple more. Why do they need to see? One is enough, this is what embarrasses me.

When other women suggested these were probably students, she replied "One is enough." Another common barrier was having male instead of female providers. Most women across all groups expressed feeling more comfortable with female providers, although a few said they preferred male providers. One idea was that the first exam might be easier with a female:

> I think that the first time one goes it is preferable to have a woman doctor. Why? Because of trust. Because we are the same. Of course, she is a professional, true, not a patient, but it gives one more confidence when having this type of exam. Because of culture more than anything.

Another added:

> Yes, one has more confidence in a woman doctor. Including asking things like, "listen, I am feeling this or that". A woman knows what it is to menstruate, and one just has more faith in her.

A final barrier raised by every group was the woman's perception of her partner's feelings about screening. Many women felt that men did not want their partners to go for screening. Although many thought this only occurred in the past, or among older women or women living in small towns in Mexico, others believed that it continues to be an issue today. The consensus was that some men feel jealous and don't want another man looking at his partner "down there." In most groups, however, participants said that they would not be deterred by a spouse or boyfriend.

> Because they don't have the intimacy of a husband and wife, an exam by the doctor is very different but there are some men who don't want them to go. But me, for my part for example, if my husband said "I don't want you to go", no, I am not going to ask permission, you go to work and somehow I will go and I will have my exam! Because I want to.

Another woman added:

> You just go, and you take a bath and, there. And when he comes home, you are watching the television, and you have taken a bath because making tortillas made you sweat. When he comes home you are fresh and pretty for him, and he doesn't know (you went).

Facilitators

Facilitators fell into three categories: information/education, low cost or free tests, and supportive physicians and friends. Women in all the groups told us that education about the need for the exam and how it is done would be an important facilitator. The need for better education about the test, when it should be done, and what it is for, right in the local community, was stressed in every group.

> Offer more information, because there is still a lot of ignorance, and I don't know…make more publicity. In their neighborhood, someone could say 'look, we're going to have a little (educational) talk. We're not going to do anything to you; we're not going to charge you.
>
> Or they could even go to individual's homes…so as to make it more private, more confidential…right in the *colonias*. Then there is more confidence.

Another facilitator was low cost or free services. Many women mentioned getting Pap tests in Ciudad Juarez, directly across the border from El Paso.

> (in Juarez it is free) in all the clinics. Only the private doctors charge. But the clinics, like IMSS, and all the health centers, it is free. Lots of people go there for (medical) services, because they offer things free to those who don't have money.
>
> There are places (in El Paso) that will accommodate your needs. That is to say the cost. For example, in La Fe they have a program where it is only $5 to consult with a doctor. So cost is no longer an excuse. There are places that accommodate to one's possibilities. If one doesn't go and doesn't take (the test) it is because they don't want to.

Groups mentioned the attitude of the physician and support from other women as facilitators of screening.

> I think that we need to rouse each other up. If we can't do this for each other, we need to think. First, someone that tells us that it will hurt, that they will be embarrassed, this and that…we should think about our families. Think about ourselves, because we are the ones affected.

DISCUSSION

The purpose of this study was to use focus groups to explore attitudes and beliefs about cervical cancer and Pap test screening among Hispanic women of Mexican origin and to better understand women's perceptions about cervical cancer risk and the benefits of screening, as well as barriers to having a Pap test.

All groups expressed a combination of accurate and inaccurate knowledge of cervical cancer and screening, and all expressed a desire to have more information. In general, the women knew about cervical cancer and the benefits of regular screening, although they were not clear when to initiate screening or how often a woman should be screened. Since the time these groups were held, the guidelines for cervical cancer screening have changed, and this change has likely caused more confusion. Future interventions aimed at increasing screening should clearly explain new screening guidelines.

The women had some misconceptions about the causes of cervical cancer, and none specifically mentioned human papillomavirus or even a virus as the cause. They did cite multiple sexual partners as a risk factor, but did not seem to connect cervical cancer to sexually transmitted disease. In a previous study with young Hispanic women [17] we asked women about their level of agreement with the statement "Others will think I am sexually active if I have a Pap test." Those who agreed with this statement were significantly less likely to have been screened. Given a reluctance among unmarried Hispanic women to disclose sexual activity, it is difficult to know how to impart the information that cervical cancer is, for the most part, a sexually transmitted disease.[18,19,20,21] Certainly this should not be the message in large media or community-based campaigns, as it might lead to a decrease in screening among sexually active women who do not wish to disclose this activity.

Barriers to screening included embarrassment, pain and fear. These same barriers have been uncovered in several studies with minority women.[10,22–24] These internal barriers are not easy to overcome, being individual perceptions and emotions, and it is likely that an intervention with a multi-pronged approach, including interpersonal communication between patient and provider is necessary. According to our findings, addressing the system would make more sense than trying to change the way women feel about cervical cancer screening. System changes might include changing how Pap tests are delivered, changing physician training, and making Pap tests more accessible and available. If caregivers were better trained to put women at ease, to guard women's privacy, and to do a vaginal exam without causing undue pain, then these very real barriers would be easier to overcome. Interventions aimed at women themselves might encourage having a friend go to the exam with them, or teach women to better communicate their fears and embarrassment to caregivers.

The fear of being deported because of immigration status is real in most US-Mexico border communities and in other communities with many immigrants. Interventions must include information about programs based on eligibility criteria other than documentation and what women need to know about qualifying for low-cost screening. Although Pap tests are available at no cost in Mexico, women waiting for documentation will not risk crossing the border. Consequently, it is important to ensure that US-Mexico border communities provide low cost services that can be accessed by these women.

System barriers such as cost, how women are treated at clinics, and the gender of providers should be addressed. Although cost was mentioned in all groups, it did not seem as important as other issues. Our previous study found that women without health insurance were less likely to have had a Pap test.[17] Ensuring that more women are covered by health insurance is a priority for decreasing the rates of cervical cancer.

Although most of the women in our groups did not have issues with their significant others forbidding the exam, they all knew of women who did. Interventions should also be developed for men so that they can better understand what the Pap test is, and the importance of finding early changes in order to prevent or treat cancer.

According to these women, educational interventions that take place in the community, led by trained community health workers, would be acceptable and useful for increasing the use of cervical cancer screening.

CONCLUSIONS

Our findings were used by the project team to develop appropriate HBM-based questions for the survey used to collect data in the larger study. In addition, we used these data in the development of educational materials. These materials included a video and flip chart to be used by lay health workers, using the words women used to describe cervical cancer and screening, and the specific situations that they discussed.

Low rates of cervical cancer screening continue to affect the Hispanic community. Development of new interventions should focus on barriers and facilitators specific to women in each community. In addition, providers should receive more training to improve patient-provider interactions and to decrease women's embarrassment and fear of the exam.

To decrease the burden of cervical cancer in El Paso, Texas, a multiple-pronged approach should include information on cervical cancer and the Pap test, on locations where Pap tests are provided, and on criteria for eligibility. Additionally, programs should include information for male significant others and training for providers to make them aware of patient concerns and to improve provider skills.

Cervical cancer is preventable through screening and treatable if found early. No woman should die of cervical cancer. Theory-based interventions developed for specific populations, in combination with changes in the delivery system, will help to prevent these unnecessary deaths.

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Manuscript draft: Byrd, Chavez, Wilson
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