Dealing with an Abnormal Pap Test: Latinas’ Views

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Abstract

Background: There is a disproportionate burden of cervical cancer among Latinas in the United States, compared to non-Latina white (NLW) women. At least some of this discrepancy may be attributed to both low screening rates and poor adherence to recommended diagnostic follow-up after an abnormal Pap test. The purpose of this study was to assess knowledge, attitudes, barriers and facilitators of follow-up care, after an abnormal Pap test result in rural Latinas.

Methods: We conducted 26 semi-structured interviews among Latinas aged 21 and older who received an abnormal Pap test result in rural Eastern Washington. Interviews were conducted in Spanish or English. Atlas.ti was used for coding and analysis.

Results: Fear of diagnosis, stigmatization and secrecy around an abnormal Pap test result were described as the primary barriers to follow-up, as well as cost, transportation, insufficient information and poor communication with health care providers. Among facilitators of follow-up care, personal motivation and family- and provider-support were mentioned as key factors.

Discussion: There are important cultural factors derived from Latinas’ knowledge and misconceptions that may affect follow-up care in this population. Health care providers should focus on adapting both culturally-competent and culturally-relevant communication strategies to deliver health information to Latinas in rural areas. Our results may help inform interventions designed to increase cervical cancer screening and adherence to follow-up care among Latinas residing in a rural areas.

Keywords

Cervical cancer screening; Pap test; Latinas; Beliefs; Barriers; Facilitators

Introduction

Latinas in the United States (US) have the highest rates of cervical cancer incidence compared to all other US racial/ethnic groups [1], experiencing nearly 70% higher incidence and 50% higher mortality from cervical cancer than non-Latina white (NLW) women (World Health Organization) [2]. Lack of access, low rates of screening and poor adherence to follow-up care after an abnormal Pap test are major factors that contribute to the high mortality rates among Latinas [3,4]. Other research suggests insurance status, cost, transportation, acculturation and sociodemographic factors including education, income and marital status also may be associated with lack of adherence to Pap test screening [5-8]. Personal and cultural barriers, such as fear and embarrassment also have been mentioned [9,10], with research on factors associated with decreased rates of follow-up for abnormal Pap results highlighting the importance of anxiety and coping styles, as well as fatalistic health beliefs and misconceptions about an abnormal Pap test result [11-14].

Little is known, however, about factors associated with follow-up after an abnormal Pap test result among rural, migrant Latinas [15-17]. We sought to assess knowledge, attitudes, and cultural barriers and facilitators with Pap testing and follow-up care after an abnormal Pap test result among a population of predominately immigrant Latinas living in a rural setting. This qualitative study was conducted as part of a randomized controlled trial to increase cervical cancer screening and follow-up care among Latinas residing in the Yakima Valley, Washington.

Methods

Study setting

Semi-structured interviews were conducted in the Yakima Valley from February 2011 to May 2011. The population in the Valley is approximately 67% Hispanic [18], with a large proportion of the population conducting seasonal agricultural work.

Study design

We conducted 26 semi-structured interviews among Latinas aged 21 years old and older who had ever received an abnormal Pap test result. Participants were recruited by local bilingual (Spanish and English) research staff at community events and from flyers posted in the Valley. Seven women were referred from the local Breast, Cervical and Colon Health Program (Washington State Department of Health) [19], a federally-funded program to provide screening and follow-up services to low income women.

The questionnaire was developed from the extant literature [9], and informed by ongoing, iterative analysis. Questions included those regarding experiences with Pap testing, reactions to abnormal Pap test results and barriers and facilitators to follow-up care after receipt of abnormal Pap results. Interviews were conducted in the participants’ preferred language (Spanish or English) by trained bilingual-bicultural research staff. All interviews were audio-recorded and transcribed verbatim, in the participant’s preferred language. The Institutional Review Board at the Fred Hutchinson Cancer Research Center (File # 7290) approved this study.

Analysis

Interviews were analyzed using Content Analysis [20], where we condensed our transcripts into discreet meaningful units of analysis (codes). The first and second authors then independently coded the data, meeting weekly to review the coding and establish agreement about code meaning, text fragments to be used for each code and generation of new codes. Following an iterative process, a codebook was created to guide our coding process in which codes were grouped into higher levels of abstraction to create categories and relevant themes. Matrices were developed with main relevant themes.
The content of each theme was reanalyzed in order to abstract the full richness of context. Discrepancies about codes were discussed until consensus was reached. This process enabled us to assess the relation of concepts and themes that arose from the data [21-23]. Four main themes and consequent sub-themes are described in this study: 1) knowledge about Pap tests and cervical cancer prevention; 2) personal experiences with abnormal Pap test results; 3) perceived barriers to follow-up care; and 4) perceived facilitators to follow-up care. Transcripts were coded using ATLAS.ti (6.0).

Results

Study population characteristics are presented in Table 1. Participants were mainly Spanish-speaking (53.8%), of Mexican descent (76.9%), with a mean age of 41 years (range: 22-69 years) and had been in the US for over 10 years (61.5%).

We identified four main themes and appropriate sub-themes regarding women’s experiences with abnormal Pap test results (Table 2).

Personal experiences with pap test and cervical cancer prevention knowledge

Participants referred to their Pap test experiences by describing feelings of nervousness, uncertainty, fear/being scared, embarrassment, and being uncomfortable. Women expressed having such feelings due to a lack of knowledge about what the Pap test entails, including what occurs during the procedure/process. For instance, several participants mentioned these feelings in regard to the Pap test necessitating the examination of a woman’s most intimate parts and the body positioning when being examined. Nevertheless, some participants focused on the benefits of getting checked and knowing they are healthy, despite the negative aspects of the Pap test.

“It’s a little uncomfortable. It’s a little painful. (...). Like, I’m a little embarrassed, but at the time you do not have to think about it. So, I’ve put it in my mind that they [the doctors] are just doing their job, and it is good for you, it is your health, and that’s that.”

Participants associated Pap testing with prevention, though there were misconceptions about the use of Pap tests. For example, participants felt that Pap tests could be used to detect most diseases of the uterus and cervix, such as cancer, venereal diseases, infections, viruses, and Human Papillomavirus (HPV).

“When they do a Papanicolaou, they can detect many diseases. I would say it is to detect various diseases, such as cancer, cysts, venereal diseases or any other disease”

Some participants discussed the importance of Pap tests for detecting cancer in early stages, when treatment options are more optimistic and the disease is less advanced.

Personal experiences with abnormal Pap test results

Most women reported receiving the news of an abnormal Pap test result over the telephone and/or by mail. Several participants returned for care following their abnormal Pap test results, only after experiencing repeated unspecific symptoms. For most women, receiving the abnormal Pap test result was a traumatic experience. Participants reported feeling anxious and depressed, had fear of death and worry about a cancer diagnosis, thinking about their children and future, worrying about the potential cost of treatment and the financial burden for their families.

“Just the thought of having something wrong. I have two children. My children were little at the time and I thought ‘No, my kids... I am going to die and they are going to be left all by themselves. That was most stressful. I was afraid”

Some participants blamed themselves for not keeping adequate hygiene or having had too many sexual partners in their youth. Women also reported being blamed by their partners, while others blamed their partners’ sexual activity for their abnormal Pap result.

“What did I do wrong? Because one always tries to take care of
one’s body, and when you start a relationship with someone, well, you use condoms, but since I had been with that person for years, not just a few months or so, you trust them more. (...) And I said, “No, it wasn’t my fault, it was the other person’s fault. Because this is something you get, so he must have been with someone else.”

Perceived barriers to follow up

Table 3 presents the perceived barriers to follow up after an abnormal Pap test result and corresponding quotes.

**Fear:** Participants mentioned fear of the unknown in regard to the nervousness, anxiety and stress that resulted from having to wait for test results. Having to deal with such anxiety made some participants contemplate not going back for their results.

“Not knowing if it [HPV and colorectal cancer] will continue from there. Not knowing what other answers I will get after the next exam. Most of all just not knowing anything”.

**Secrecy:** Most women only shared their test result with one or two close family members, such as their mothers, sisters, daughters or husbands, while a few didn’t share their result with anyone at all. The reasons cited for not wanting to share test results included being embarrassed about HPV being a sexually transmitted disease and its implications, not wanting to be judged or have to deal with stigmatization from their families and friends, not having anyone close with which to share, not wanting to worry their family with a possible cancer diagnosis, and not wanting to burden their families with transportation and potential treatment costs (Table 3).

**Lack of information:** Women discussed not knowing what to expect, in regard to the entire disease experience, as an important barrier to follow-up. For instance, participants reported not understanding the meaning of an abnormal Pap test, not knowing about cervical cancer, not knowing about HPV, and lack of knowledge about other general concepts of the human body or sex. Additionally, several participants reported having trouble understanding the information presented to them and, in some instances, trouble obtaining information from their health care providers.

Participants also mentioned feeling self-conscious about directly asking for information from their providers. Some women reported feeling embarrassed to ask for information on delicate matters such as the female reproductive system, while others blamed themselves for not having understood the physician’s explanations. Only one participant mentioned having trouble understanding the language, explaining that there were no Spanish-speaking translators available at the time.

**Cost and transportation:** Cost was a commonly cited barrier

<table>
<thead>
<tr>
<th>III. Perceived Barriers to Follow-up</th>
<th>Explanations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear/Anxiety</td>
<td>“Not knowing if it will continue from there. Not knowing what other answers I will get after the next exam. Most of all just not knowing anything”</td>
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<td>Secrecy</td>
<td>“It’s like you “fall into depression”, because sometimes you are scared to tell people what is going on. And you just keep it to yourself.”</td>
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<td>“I did not feel I could trust my friends enough to share it because my fear was that they would say something negative, I was afraid already (to hear negative advice)”</td>
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<td>Lack of Information</td>
<td>“A lot of anxiety, a lot of stress, a lot of crying. And, again, it leads back to if I would have had information, if I would have known what to expect, I think I wouldn’t have been so worked up.”</td>
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<td>“It is taboo, I mean, you don’t talk about your woman’s parts with anybody or ask information, you just try to handle it the best you can”</td>
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<td>Cost/Transportation</td>
<td>“Ah, well, I do want to go to the doctor but I don’t because of lack of transportation, because no one can take me, and I have no money to go to the doctor and I have no insurance and I have nothing and that is why I don’t get my check-ups.”</td>
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<td>“It’s either you go have your Pap smear or pay the rent. If you can’t pay your rent then your family will be on the streets. Then the Pap smear is not going to help you with that.”</td>
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<td>“It is too embarrassing to go to the doctor and not having the money to pay. They will say ‘this lady comes to the doctor and has no money to pay’. Yes, it is embarrassing”</td>
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<tr>
<th>IV. Perceived Facilitators to Follow-up</th>
<th>Explanations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Motivation</td>
<td>“It’s a way to care of yourself and the way to care for others is taking care of yourself.”</td>
</tr>
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<td>Friends/Family Support</td>
<td>“(From) My sisters, everything, courage is what they provided. Yes, they took care of me. “Here’s your food” and this and that... And they never asked how much it would cost. More than that: You’ll get the operation and... we will all pay.”</td>
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<td>Relationship with health care provider</td>
<td>“Most doctors I have had have been women doctors. I like it because I feel more comfortable. Because thinking that the both of us are women, makes me feel a little freer to express anything at that time.”</td>
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<td>Appropriate delivery of information</td>
<td>“After they explained what the process was going to be like and everything then I was able to relax. Now I am in the hands of my doctor and of God and just move ahead.”</td>
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<td>Payment Options</td>
<td>“The doctor, the gynecologist was adamant in her response. She said that it was not alarming (the result) and I shouldn’t be frightened. (...) She helped me feel safe because in case something could happen, well, I know they are detecting it early”.</td>
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<td>“I think if I had a clinic where it was free, or a program that could help if you paid a part, even if it was just a portion, if one can pay a portion, you pay what you can pay and what you can’t, then the program would cover. I think it would help many women to follow-up, I know it would help me a lot.”</td>
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<td>“Many women do not know (about funding programs), and for me, I do wish there were more centers that would inform us about these things and other ways to help us”</td>
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friendship, although participants also told other close relatives such as caregivers, family members or friends. They stated that their families and friends offered both emotional and instrumental support, such as cheering them on, offering transportation and helping pay for part of the costs of follow-up care.

Relationship with health care provider: All of our participants said they trusted their providers and followed their instructions to follow-up, if they were kind and expressed empathy towards them. Many women said they would need to develop a relationship with the provider, while others said they felt supported by “their doctor.”

“If I was going to a regular doctor, if that doctor already knew me well, and he inspired confidence and he did some sort of counseling, then yes, I would continue to go (to her follow-up appointments)”

Several participants reported feeling more comfortable with a female provider, because female providers could relate to them and understood them better. Furthermore, participants stated that with a female provider they wouldn’t have to feel embarrassed about getting the Pap test and exposing their bodies as they would with a male provider.

Appropriate delivery of information: Having information delivered by their provider in a clear manner made participants feel more prepared to deal with the impending follow-up care. Participants’ reported that they appreciated it when providers gave them accurate, simple information that was easy to understand and follow.

In general, participants reported an overwhelming need and desire for better information about the meaning of an abnormal Pap test result, the next steps in care and resources of financial support. Many women stated that they would like an honest talk with their provider, rather than to be handed brochures with generic information.

“I would want more information, more time to speak to the doctor about it. And just more input from them to us, as a patient. To what they think could be done or what we could do”.

Participants also discussed the need for support groups or the opportunity to be connected with women who had experienced a similar situation, including Spanish-speaking women.

Payment options

The majority of women stated that payment options or free exams would be great incentives for getting their follow-up care, since the assurance of such economic support would help them follow through with the recommended care (Table 3).

Some participants mentioned knowing about places or programs/clinics that would provide economic aid and having used them. They preferred these facilities even if that meant they would not be as comfortable as in other clinics. Additionally, women reported that they wished more women knew about these programs, because they felt this was not common knowledge.

Discussion

This study highlights the experiences and attitudes towards cervical cancer screening and follow-up care after an abnormal Pap test result, as well as the barriers and facilitators of follow-up care, among rural Latinas. Overall, participants held misconceptions about the purpose of Pap testing and described feeling uncomfortable undergoing a Pap test. Upon receiving an abnormal Pap test result, women reported feeling anxious and afraid of a possible cancer.
diagnosis and its implications. The most commonly cited barriers to follow-up care included fear and stigmatization, lack of information and cost of care, whereas the facilitators included personal motivation, social support, availability of payment options and patient-provider communication.

We found that participants reported feelings of anxiety and fear after receiving news of an abnormal Pap test result, followed by subsequent emotions of guilt and blame, as well as the need for information about the meaning of their abnormal Pap test result. Similar processes have been described where participants’ anxiety of a possible cancer diagnosis and struggle dealing with the stigma associated with a sexually transmitted disease resulted in a sense of guilt, feeling contaminated, and reluctance to share results with their male partners and family members [24,25]. The role of the male partner in screening and follow-up has been less described in Latino populations [26,27]. Even if women in our sample mentioned that their partners did not oppose their screening and follow-up care, it is also true that most participants did not share their screening history or results with them. The lack of knowledge of the Latino male regarding cervical cancer screening has been described in previous literature [26,27].

Male infidelity as cause of an abnormal Pap test result emerged as an interesting concept not mentioned before in other similar studies. It is well known that Latinas have fewer sexual partners and are more conservative than NLW women, yet they still suffer from a disproportionate cervical cancer burden [15]. Many women in our sample were sure about their own sexual behavior, but questioned whether their partners’ infidelity could have led to their abnormal Pap test results.

Information seeking was a primary concern after receiving an abnormal Pap result, as women described a lack of clear information about the meaning of their abnormal result and its consequences. Importantly, in our study, such lack of clarity about their results and the overall prognosis was reported as one of the main barriers to follow-up care. Likewise, participants discussed wanting an honest, direct, culturally appropriate conversation with their provider, rather than pamphlets or brochures of information that explained the implications of their Pap results. Latinas highly admire personal relationships (personalismo) and have admiration respect for power figures (respeto); hence, a close relationship with their provider may be a powerful facilitator of follow-up care among Latinas [28-31].

Latinas in our sample were reluctant to disclose their abnormal result to other people, referring to the fear of stigmatization and gossip about them having a sexually transmitted infection, and not wanting to burden their families with an unclear diagnosis. Yet, our participants were unwavering about stressing the importance of family support (both moral and practical) in their decision to follow-up. Familism is a well-known cultural trait in Latino populations [32,33]. While rural communities tend to be close-knit, where family and friends support each other, others’ opinions may also be very influential on Latinas behaviors. This is particularly important in regard to facilitators of follow-up care, since strategies should aim to utilize patients’ social networks or create new networks for patients (such as patient navigation programs, mentoring programs, support groups etc.) in order to address the different aspects of this cultural trait.

Cost and transportation were also mentioned as influential factors to follow-up care. Our participants reported the willingness to sacrifice quality of care for access to less expensive services. Furthermore, women reported delaying and foregoing care, or willingness to, when faced with choosing between paying for their recommended medical care and their family’s basic needs. Interestingly, even though the Breast and Cervical Health Program referred many participants to our study, a federally funded aid program, most women didn’t know about funding opportunities available for follow-up of abnormal Pap test results, suggesting there is need for better communication of these resources to the community.

Finally, our participants had very different personal motivations to obtain follow-up; whether it was peace of mind, love for their children or the fact that cervical cancer is preventable, most women in our sample felt it was within their control to follow-up their abnormal result. Even though some participants described fear and anxiety as barriers to follow-up, others described these factors as motivators. Evidence has shown that some level of anxiety about the uncertainty of the test may increase the likelihood of following up with medical care recommendations [13]. Researchers and health care professionals should identify and foster personal motivators, since there is evidence suggesting that having a sense of control and self-efficacy can increase compliance to cancer screening services [34].

Limitations

Our study has some limitations that should be noted. Our sample was comprised of women aged 22 to 69 years, who lived in a rural setting, had low income and were mostly foreign-born individuals from Mexico; thus, our findings are most generalizable to similar populations. Second, the purposive sampling of participants may have led to the inclusion of individuals who were committed to or interested in cancer screening and follow-up care, leading to sampling bias. Nevertheless, our goal was to retrieve in-depth information about Latinas’ experiences with Pap test screening and follow-up care after receiving abnormal results. Although the majority of women in our sample were compliant with follow-up care recommendations, attempts were made to reach more women who had not complied with follow-up care; this population may have different characteristics and experiences with Pap testing and follow-up care compared to compliant women.

Implications for Practice

Latinas have misconceptions about receiving an abnormal Pap test result. Important cultural barriers that arise from these misconceptions may affect the uptake of cervical cancer screening and follow-up care in this population. Fear of the diagnosis and procedure, high costs of care, stigmatization and being ashamed to ask their families and health care providers for information are among the barriers reported in this study. These factors should be taken into consideration when efforts are made to motivate women to obtain cervical cancer screening.

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