

Poor Knowledge Regarding the Pap Test Among Low-Income Women Undergoing Routine Screening

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CONTEXT: Many women undergoing cervical cancer screening lack appropriate understanding of the Pap test. It is important to evaluate knowledge and informational needs about Pap testing among groups who may have difficulty accessing care or a relatively low likelihood of obtaining follow-up for an abnormal result, such as minority and low-income women.

METHODS: A sample of 338 women undergoing cervical screening at two clinics in Texas completed a questionnaire measuring their knowledge of Pap testing and asking what specific information they would like to know about the test. Group comparisons and qualitative analyses were conducted.

RESULTS: Women correctly answered an average of 8.7 out of 20 questions; the range was 0–17. Mean scores were higher among white women (10.2) than among blacks (8.4) and Hispanics (7.4), among women with more than a high school education than among their less educated counterparts (10.0 vs. 7.9) and among women with an annual household income of at least \$10,000 than among those with a lower income (9.3 vs. 8.4). Knowledge scores did not differ according to Pap history. Open-ended questioning identified a need for information on the purpose of the test, exam procedures, abnormal test results and prognosis.

CONCLUSIONS: Minority women and those of low socioeconomic status had poor understanding of Pap testing. Identifying misunderstandings in this vulnerable population and improving patient education on the most basic aspects of Pap testing may increase adherence to follow-up when abnormalities are detected.

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Women widely recognize cervical cancer screening via the Pap test as an important health behavior. In 2000, 81% of U.S. women aged 18 and older had received a Pap test within the preceding three years, although screening rates were lower among Hispanic, poor and less educated women.¹ Women's undergoing cervical cancer screening suggests that they are aware that they should be screened; however, they may lack basic understanding of the process, limitations and results of the Pap test. The more knowledgeable women are about Pap testing, the more likely they are to make a screening visit² and to adhere to recommended follow-up for an abnormal result.³

Little research has explored knowledge regarding Pap testing among socioeconomically disadvantaged women, and even less has focused on women undergoing routine screening in the general clinic setting (i.e., not for follow-up for an abnormality). Studies of knowledge and understanding among women experiencing an abnormal Pap test result have found that women had insufficient knowledge about abnormal results and follow-up procedures such as colposcopy, and that many were dissatisfied with the type and amount of information they received about their result.⁴ Research on adolescents⁵ and college students⁶ has suggested that general understanding of cervical cancer screening and human papillomavirus (HPV) in these groups is poor.

It is important to evaluate the knowledge base and informational needs of women of lower socioeconomic status, to ensure that they will continue screening as recommended (despite financial hardship), understand changing guidelines in screening intervals and adhere to follow-up recommendations. In addition, women belonging to racial or ethnic minority groups and those who are poor or lack health insurance yet undergo cervical cancer screening represent an important and understudied group. These women are at increased risk for cervical cancer,⁷ have sought out health care for routine screening and are ultimately accessible for educational efforts. The purpose of this study was to evaluate knowledge regarding Pap testing among a multiethnic sample of socioeconomically disadvantaged women undergoing routine cervical cancer screening and to elicit their specific informational needs.

METHODS

Study Design and Sample Selection

The data reported here were derived from the final phase of a three-phase investigation on adherence to follow-up of abnormal Pap test results. Data from the first phase, a qualitative study, are reported elsewhere.⁸ The second phase was dedicated to the development and psychometric evaluation of a survey instrument designed to examine theory-derived predictors of adherence to follow-up of abnormal Pap results.

Women aged 18–50 who visited one of two university-affiliated clinics in southern Texas for routine cervical screening between October 25, 2002, and June 19, 2003, were eligible for the study. To ensure that a balanced sample was achieved, we constructed a priori a recruitment grid that specified three racial and ethnic groups (Hispanic, non-Hispanic white, non-Hispanic black) and five age-groups (18–24, 25–31, 32–38, 39–45 and 46–50 years) of interest. We sought to fill each cell in the grid with 20 women, for a total sample size of at least 300; all potentially eligible women were approached to participate until each cell reached the desired size.

All women provided written consent before participation. The women were asked to complete a self-administered paper-and-pencil survey in English or Spanish while waiting for their appointment.

Measures

To assess knowledge of Pap testing, we developed a questionnaire that was based on a cervical dysplasia instrument developed for adolescents⁹ and augmented with questions reflecting knowledge areas identified by participants in the qualitative phase of this investigation. To assess the reliability of the questionnaire, we pilot-tested it among 120 women over a three-week period; it had adequate internal consistency (Cronbach alphas, .82 at test and .83 at retest) and temporal stability. The mean overall score was 8.8 (standard deviation, 3.2) at test and 9.0 (standard deviation, 3.1) at retest, and fewer than 2% of responses were missing. In the present study, the questionnaire again had adequate internal consistency (Cronbach alpha, .88).

The final questionnaire included 20 true-false questions about Pap testing that measured knowledge in four domains: purpose of the Pap test (five questions), symptoms among women with an abnormal test result (six questions), implications of an abnormal result (four questions) and follow-up procedures for such a result (five questions). For each question, “don’t know” was a possible response. To derive an overall knowledge score, we summed the correct responses; the small proportion of missing responses (less than 2% for each question) were assigned a score of zero. Possible overall knowledge scores thus ranged from zero to 20. We used the same approach to derive subscores for the four domains; possible subscores ranged from zero to 4–6, depending on the domain.

The questionnaire also included an open-ended question to elicit informational needs related to the Pap test. Specifically, women were prompted to “write down 1 or 2 things about the Pap smear you would most like someone to explain or talk to you about.” On average, women completed the entire survey in 34.0 minutes (standard deviation, 7.0); however, the length of time required to complete only the knowledge questions is unknown.

Women provided information about their race and ethnicity, age, education and household income. Source of payment for women’s health care, as indicated on the medical record, was used as a proxy for financial status when self-

TABLE 1. Percentage distribution of women undergoing routine cervical screening, by selected characteristics, southern Texas, 2002–2003

Characteristic	% (N=338)
Race/ethnicity	
Hispanic	31.7
White	34.3
Black	34.0
Marital status	
Married	30.2
Unmarried	69.2
Missing	0.6
Education	
≤high school	60.6
>high school	37.6
Missing	1.8
Employment	
0–20 hours/week	60.9
≥21 hours/week	37.0
Missing	2.1
Annual household income	
<\$10,000	47.3
≥\$10,000	47.3
Missing	5.4
Source of payment†	
Medicaid	19.8
Indigent	59.5
Private insurance/self-pay	20.4
Medicare	0.3
Pap test history‡	
Abnormal	22.8
Normal	51.8
No prior test	25.4
Total	100.0

†Obtained from the medical record; used as a proxy for financial status.

‡Determined from medical chart review.

reported income was not available; women were classified as indigent if they were categorized as such by financial counselors using standard criteria. Pap test history was obtained from medical records and classified as abnormal, normal or no prior testing. The study was approved by the institutional review board at the University of Texas Medical Branch, Galveston.

Statistical Analysis

We used the Pearson chi-square test and one-way analysis of variance to conduct group comparisons of proportions of correct responses and knowledge scores, respectively. Test statistics, means (along with standard deviations) and Bonferroni-adjusted 95% confidence intervals are presented. Independent groups t tests were used to compare mean differences in knowledge scores according to level of education and household income. Pearson correlation was used to examine the relationship between knowledge scores and age. Descriptive and comparative statistics were generated using SPSS, version 12.1. A two-tailed alpha level of .05 was considered statistically significant.

We used The Ethnograph software, version 5.1, to summarize responses to the open-ended question. Each author

TABLE 2. Percentage distribution of women, by responses to true-false questions measuring knowledge about Pap testing, by question, according to response

Question (and correct response)	Correct	Incorrect	Don't know	Missing	Total
The purpose of the Pap smear test is to:					
Check your ovaries (False)	20.4	61.2	17.8	0.6	100.0
Scrape cells to look for cancer (True)	85.5	4.1	10.4	0.0	100.0
Treat cancer (False)	43.2	32.8	23.4	0.6	100.0
Test for sexual disease (False)	12.1	73.1	14.8	0.0	100.0
Check your urine (False)	43.2	31.1	25.1	0.6	100.0
Symptoms of an abnormal Pap smear are:					
Vaginal itching/irritation (False)	20.1	49.1	30.5	0.3	100.0
Pain with sexual intercourse (False)	14.5	54.7	30.5	0.3	100.0
A frequent need to urinate (False)	29.3	31.4	37.6	1.7	100.0
Unnoticeable/no symptoms (True)	50.9	12.4	34.6	2.1	100.0
Unusual vaginal spotting/bleeding (True)	58.9	12.7	28.1	0.3	100.0
Genital warts (True)	42.0	20.4	36.7	0.9	100.0
If you have an abnormal result on the Pap test:					
You should tell your partner (True)	89.3	2.7	6.5	1.5	100.0
It means you have cancer (False)	68.0	5.9	25.4	0.7	100.0
The problem could go away on its own (True)	10.9	69.2	18.9	1.0	100.0
You may need more frequent Pap smears (True)	75.1	7.1	16.6	1.2	100.0
Follow-up for an abnormal Pap smear can involve:					
A blood test (False)	12.7	63.9	23.1	0.3	100.0
Biopsy (True)	51.2	11.8	36.4	0.6	100.0
Another Pap smear test (True)	86.4	1.5	11.8	0.3	100.0
Colposcopy (True)	21.6	14.8	62.7	0.9	100.0
HPV testing (True)	34.0	10.7	54.4	0.9	100.0

Note: HPV=human papillomavirus.

independently performed qualitative analysis, generating a set of code words to characterize themes within the responses. We then discussed and merged our individual code words and themes to arrive at a final set of seven themes that adequately described the qualitative data.

RESULTS

Sample Characteristics

Of the 429 women who were eligible and invited to participate in the study, 83% initially agreed to participate, while the rest refused. The refusal rate did not differ significant-

ly by age, but it did differ with respect to other characteristics. Twenty-seven percent of married women refused to participate, compared with 13% of unmarried women ($\chi^2=11.05$, $df=1$, $p<.01$); 34% of Hispanic women declined, compared with 5% of whites and 9% of blacks ($\chi^2=48.85$, $df=2$, $p<.001$); and 20% of women who were indigent or received Medicaid refused, compared with 7% of privately insured or self-paying women ($\chi^2=7.48$, $df=1$, $p<.01$).

Of the 356 women who initially agreed to participate, 338 (95%) completed the survey, while the rest left the clinic before completing it, primarily because of time constraints. Women who did and did not complete the survey did not differ with respect to age. However, whereas the final sample was made up of roughly equal proportions of Hispanics (mainly women of Mexican descent), whites and blacks (Table 1, page 79), Hispanic women made up 78% of the group who did not complete the survey, and whites the remainder ($\chi^2=17.56$, $df=2$, $p<.001$).

On average, women in the final sample had a mean age of 29.9 years (standard deviation, 8.6). The majority of women were unmarried (69%), had at most a high school education (61%) and worked half-time or less (61%). Roughly half had an annual household income of less than \$10,000, and 60% were indigent. In the past, 23% had had an abnormal result on a Pap test.

Knowledge

Whether women answered questions about Pap testing correctly varied considerably by question (Table 2). Large proportions answered “don’t know” to the questions pertaining to colposcopy (63%) and HPV (54%), terms commonly associated with abnormal Pap results. Large proportions (61–73%) gave incorrect responses to questions pertaining to the purpose of the Pap test (i.e., checking ovaries, testing for sexual disease), blood testing for follow-up and the potentially transient nature of an abnormal result. Only one-half of respondents knew that a woman with an abnormal Pap smear might not have any symptoms, while one-third incorrectly indicated that the purpose of the test was to treat cancer. However, the majority knew that the purpose of the Pap test is to check for cancer, that women with abnormal Pap results should tell their partner and may need more frequent testing, that an abnormal result does not necessarily mean that a woman has cancer and that follow-up for an abnormal result may include a repeat test (68–89%). Women with a history of an abnormal result did not have a significantly higher proportion of correct responses on the questions regarding colposcopy and HPV than women with a normal history or previously unscreened women (not shown).

Overall, women answered from zero to 17 of the 20 questions correctly, but scores were generally low, averaging 8.7 (standard deviation, 3.6). Scores differed by race and ethnicity (Table 3): White women scored higher (10.2) than blacks (8.4) and Hispanics (7.4). Scores also were higher among women who had more than a high school education than among their less educated counterparts (10.0 vs.

TABLE 3. Overall scores and subscores (and 95% confidence intervals) on the questionnaire measuring knowledge of Pap testing, by selected characteristics

Characteristic	Overall score	Subscore			
		Purpose	Symptoms	Implications	Follow-up
Race/ethnicity†					
Hispanic	7.4 (6.7–8.1)	1.7 (1.4–1.9)	1.7 (1.4–2.0)	2.1 (1.9–2.3)	ns
White	10.2 (9.6–10.8)	2.7 (2.4–2.9)	2.6 (2.3–2.9)	2.7 (2.5–2.8)	ns
Black	8.4 (7.8–9.0)	1.7 (1.5–1.9)	2.1 (1.8–2.4)	2.5 (2.3–2.6)	ns
F(2,335)	18.8***	22.1***	10.8***	10.0***	2.2
Education					
≤high school	7.9 (7.4–8.4)	1.8 (1.6–2.0)	2.0 (1.8–2.2)	2.2 (2.1–2.4)	1.9 (1.7–2.0)
>high school	10.0 (9.4–10.6)	2.4 (2.0–2.6)	2.5 (2.2–2.7)	2.7 (2.6–2.9)	2.4 (2.2–2.6)
t(330)	-5.4***	-3.6***	-3.1**	-4.9***	-3.9***
Annual household income					
<\$10,000	8.4 (7.9–9.0)	ns	ns	ns	1.9 (1.7–2.1)
≥10,000	9.3 (8.7–9.8)	ns	ns	ns	2.3 (2.1–2.4)
t(318)	-2.2*	-0.7	-1.8	-0.9	-2.6**

*p<.05. **p<.01. ***p<.001. †For race/ethnicity, significance levels apply to differences between white women and each of the other groups or, for the implications subscore, between Hispanic women and each of the other groups. Notes: The possible range of scores (low–high) was 0–20 overall, 0–5 for purpose and follow-up, 0–6 for symptoms and 0–4 for implications. ns=non-significant.

7.9). Finally, higher scores were observed among women with an income of at least \$10,000 than among those with a lower income (9.3 vs. 8.4). Knowledge scores increased with age ($r=.14$, $p<.01$ —not shown), and this association remained significant after Pap history was controlled for (partial $r=.14$, $p<.05$). Mean knowledge scores did not differ among women who had experienced an abnormal result (9.3), those who had not (8.3) and those who had not had a prior Pap test (8.9).

Where we found associations between demographic factors and overall knowledge scores, we examined the associations between these factors and the four subscores, to describe specific differences in the domains of knowledge (Table 3). White women scored higher than others on questions regarding the purpose of the Pap test and symptoms of an abnormality, whereas Hispanic women scored lower than others on questions regarding implications of an abnormal result. There were no racial or ethnic differences on questions regarding follow-up procedures. Women with no more than a high school education had lower scores on all of the subscales than their more educated counterparts. Women with incomes of less than \$10,000 per year scored lower than their counterparts reporting higher incomes only on the subscale measuring knowledge of follow-up procedures. Finally, age was positively associated with knowledge about the purpose of the Pap test ($r=.16$, $p<.01$) and follow-up ($r=.12$, $p<.05$) but not with knowledge about symptoms or implications.

Informational Needs

In response to the open-ended question measuring women's informational needs, 210 women (62%) provided 340 statements that could be coded. Of the women who did not provide codable responses, 90% left the question blank, while the rest gave responses that were unrelated to the question.

Seven themes emerged from responses to the open-ended question (Table 4). More than one-fourth (29%) of responses reflected a need to know the Pap test results, the prognosis and the test's accuracy. A similar proportion (26%) indicated a desire to know more about abnormal Pap tests, including information on prevention, causes, symptoms, severity, treatment, follow-up and multiple abnormal tests. Some 14% of responses reflected a need to know more about the mechanics and procedures of the Pap exam, including risks of the test and discomfort during the exam, and 13% indicated a desire to know more about the purpose and importance of the test. Nine percent of responses reflected a desire to know more about general women's health conditions, including cancer and other diseases, as well as sexually transmitted diseases that may be related to abnormal Pap test results. A small proportion (5%) of responses indicated a need to know more about the timing of the Pap test, specifically, the timing of receiving the results and of detecting cancer and other abnormalities, and when and how often to have the test. Finally, 3% reflected concerns about doctor-patient communication.

TABLE 4. Percentage distribution of responses to the open-ended question about women's informational needs regarding Pap tests, and sample responses, by theme

Theme and sample responses	% (N=340)
Pap test results and prognosis	29.1
"Can I know if it's good or bad"—Hispanic woman, aged 30	
"What the results are, did I pass/fail"—black woman, aged 18	
"What effect will it have on my body"—white woman, aged 41	
"Corect [sic] testing, mis reading [sic] tests or missing something" —white woman, aged 39	
Abnormal Pap test results	26.2
"What can we [sic] done to fix it"—Hispanic woman, aged 42	
"How does it become abnormal"—white woman, aged 37	
"The seriousness of an abnormal Pap"—Hispanic woman, aged 36	
"If I have an abnormal exam and it's repeated 30x and it's still abnormal, why don't I get anything for treatment?" —Hispanic woman, aged 24	
"What can I do to help myself or to help prevent it again" —Hispanic woman, aged 30	
"What are the possibilities of me having to come back" —black woman, aged 20	
"I would like to know about the side effects or symptoms" —black woman, aged 21	
Mechanics and procedures of the Pap exam	13.8
"What is it that they take from inside me in the exam" —Hispanic woman, aged 25	
"I would like to know more about scraping the sides with the rough object"—black woman, aged 33	
Purpose and importance of the Pap test	12.9
"What exactly there [sic] are looking for"—white woman, aged 21	
"The reason why it is necessary to get a Pap smear" —black woman, aged 34	
"Why are they so important?"—white woman, aged 35	
General women's health conditions	9.4
"What if I have cancer?"—Hispanic woman, aged 24	
"Tilted uterus, endometriosis [sic]"—black woman, aged 45	
"Ulcers, infections and everything about cancer" —Hispanic woman, aged 39	
"Does sex have anything to do w/my adnormal pamp smear [sic]?" —black woman, aged 29	
Timing of the Pap test	5.3
"How early are abnormalities detected"—white woman, aged 20	
"Why do we have to take a Pap smear every year" —black woman, aged 25	
"When will you be able to tell if something is wrong if it is abnormal?"—white woman, aged 18	
"When should I get an exam"—Hispanic woman, aged 37	
"To have the results more quickly"—Hispanic woman, aged 48	
Doctor-patient communication	3.2
"Use clear and simple words; in person, doctor to patient" —Hispanic woman, aged 31	
"If there was something wrong I would like it explained in English not doctor terms"—white woman, aged 40	
Total	100.0

Note: A total of 210 women provided the 340 responses on which the percentages are based.

DISCUSSION

Women who undergo cervical cancer screening may lack appropriate understanding of the Pap test. Our data show considerable knowledge deficits among socioeconomically disadvantaged women awaiting screening.

Notably, the question referring specifically to HPV had

one of the highest proportions of “don’t know” responses. A large majority of the women indicated that the purpose of the Pap test is to test for sexual disease and affirmed that one should tell her partner of an abnormal test result. These responses suggest that women suspect a linkage between a sexually transmitted pathogen and an abnormal result.

The poor knowledge surrounding HPV found in our study and, similarly, in research conducted outside of the United States¹⁰ suggests a need to improve women’s understanding of the linkage between sexual behavior, HPV, Pap testing and cervical cancer. This may become increasingly important as HPV DNA testing takes on a more prominent role in cervical screening efforts and the possibility of developing a vaccine for cervical cancer gains attention in the media.

In our study, white women scored higher than blacks and Hispanics on overall knowledge. Racial and ethnic disparities have been identified in previous investigations of knowledge regarding cervical cancer screening. Lindau et al.¹¹ reported that black and Hispanic women were half as likely as white women to know the purpose of the Pap test; however, this association did not remain after the authors accounted for health literacy. Thus, the knowledge differences we observed by ethnicity may have been due to differences in health literacy. Black and Hispanic women in our study scored lower than whites on questions pertaining to the purpose of the Pap test and symptoms in women with an abnormality. These findings suggest ways in which educational approaches might be tailored to meet specific informational needs of minority patients, while keeping issues of health literacy at the forefront.¹² Effective educational techniques to tailor such information to populations with low literacy include the use of pictures and videos, as well as clarifying with patients what particular words mean to them.¹³

Our finding that women’s knowledge about Pap testing increased with age is important because younger women are at greater risk for contracting HPV than are their older counterparts. Younger women may be more amenable to educational efforts, as they may be less embarrassed about not knowing about Pap testing. At the same time, it would be incorrect for providers to assume that older women have greater knowledge about Pap testing than their younger counterparts—even though older women may themselves assume that they understand the test and the implications of an abnormal result—as age relationships were observed in some knowledge domains but not in others. The association between age and knowledge regarding the Pap test is therefore worthy of further study.

Knowledge scores were not higher among women who had previously experienced an abnormal result than among women who had previously had only normal results or had never been screened. Complete medical records of Pap test results were available for all women whose testing was performed at our institution, but we may have missed some women who had had Pap tests with abnormal results elsewhere. Nonetheless, because women with confirmed histories of abnormal Pap tests were not more knowledgeable

about testing, it is unlikely that underreporting of abnormal results would have changed our results.

The knowledge deficits that we found suggest that women may not receive adequate information when they undergo a Pap test and when they are told they have an abnormal result. Other data suggest that women may not retain information given to them by clinicians.¹⁴ Unfortunately, patients with the greatest health care needs may have the lowest functional health literacy,¹⁵ and concerted effort among clinicians to use “living room” language and to encourage the most basic questions about Pap testing and cervical cancer may be required to educate vulnerable populations.

Women who were educated beyond high school had higher knowledge scores in all domains. None of the other factors studied (e.g., income, race and ethnicity, age) had this clear pattern. Providers should exercise caution, however, when using reported education level as a guideline for educating and communicating with patients, as many patients have reading levels at least three levels below the grade completed in school.¹⁶

A desire for more information about Pap results was the most frequent theme emerging from responses to the open-ended question. The high-volume clinics in which this study was conducted do not notify patients of Pap results unless the result is abnormal. This practice may conserve resources but may be unacceptable to women. Furthermore, consistent patient notification would provide an opportunity for women to ask questions and clarify their understanding of their test result.

Our qualitative results also reflected concerns about the pain and discomfort of the Pap test, a need for better communication between providers and patients, a desire for more information on the exam procedure, questions regarding the importance of the Pap test and a need for information about the severity and treatment of abnormal results. These themes have been reported in previous studies¹⁷ and suggest a continuing need to identify new mechanisms and opportunities for patient education.

Limitations

Our study is not without limitations. First, our sample was small, which may limit the generalizability of our results and may have resulted in nontrivial sampling errors. The issue of generalizability is particularly important when exploring associations by race and ethnicity, as disproportionately more Hispanic women than other women declined to participate in the study. In addition, refusal rates were disproportionately high among married women and indigent women. However, we found significantly lower knowledge scores for Hispanic women and women with very low incomes, suggesting that inclusion of more women from these populations would likely strengthen our results.

Second, because of our geographic location, most Hispanic women were of Mexican origin; therefore, our findings may not be generalizable to Hispanic women of other backgrounds.

Third, our study is limited by our instrumentation. We used a single questionnaire to measure women's understanding of the Pap test. This questionnaire was carefully pretested among women undergoing cervical screening at the same clinics used in this investigation and was found to have good psychometric properties. Nevertheless, it is not comprehensive, and standardized population data are not available to permit comparisons of our results with those from other, similar populations. Moreover, our results are limited by the potential ambiguity inherent in knowledge-based questions. The possibility that a respondent may misinterpret a question can be minimized by careful pretesting of the questionnaire, but it cannot be eliminated. We assessed knowledge using simple language and a true-false response format, to maximize receptivity in a population that shares many characteristics of populations with low health literacy. Yet, because we did not use precise medical language, women may have misinterpreted questions, and this could have led to bias in our results.

Finally, our data do not address the complex relationships between knowledge and important patient behaviors related to Pap testing, such as adherence to follow-up, partner notification, continued screening and accurate disclosure of medical history to the provider. The impact of knowledge in a particular domain on specific behaviors, such as greater participation in screening, is not within the scope of this article. However, each potential relationship between knowledge and behavior represents an important direction for future research.

Conclusion

Our data demonstrate significant gaps in understanding regarding cervical cancer screening among socioeconomically disadvantaged women. Results from this study indicate the need for intensive patient education among women undergoing Pap testing. Improving knowledge regarding cervical cancer screening may enhance clinical care of the vulnerable population studied.

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