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Authors

Nelson, Karin
Geiger, Ann M
Mangione, Carol M

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POPULATIONS AT RISK

Effect of Health Beliefs on Delays in Care for Abnormal Cervical Cytology in a Multiethnic Population

Karin Nelson, MD, MSHS, Ann M. Geiger, PhD, Carol M. Mangione, MD, MSPH

CONTEXT: Women from racial and ethnic minorities in the United States have higher rates of cervical cancer and present with later stage disease compared to whites. Delays in care for abnormal Papanicolaou (Pap) smears can lead to missed cases of cervical cancer or late-stage presentation and may be one explanation for these differences.

OBJECTIVE: To determine if race and ethnicity, health beliefs, and cancer knowledge are associated with delays in care for abnormal Pap smears.

DESIGN, PARTICIPANTS, AND SETTING: We conducted a mailed survey with telephone follow-up of all women with an abnormal Pap smear who received care at Kaiser Permanente Los Angeles Medical Center between October 1998 and October 1999 (n = 1,049).

MEASUREMENTS AND MAIN RESULTS: A delay in care was defined as not attending the first scheduled clinic visit to follow up on an abnormal Pap smear, or requiring multiple contact attempts, including a certified letter, to schedule a follow-up visit. Our response rate was 70% (n = 733) and the sample was 51% Latina. Spanish-speaking Latinas and women of Asian descent were more likely to endorse fatalistic beliefs and misconceptions about cancer. Thirteen percent of the sample delayed follow-up on their abnormal Pap smear. Women who delayed care were more fatalistic and endorsed more misconceptions about cervical cancer. Delays in care were not independently associated with race and ethnicity.

CONCLUSIONS: Health beliefs and cancer knowledge differed by race and ethnicity among women in a large managed care organization. Fatalistic health beliefs and misconceptions

about cancer, but not race and ethnicity, were independently associated with delays in care.

KEY WORDS: Papanicolaou smear; health beliefs; patient adherence.

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Although the routine use of Papanicolaou (Pap) smear screening has decreased rates of cervical cancer in the United States,¹ this reduction has not been equally distributed among all racial and ethnic groups.² Latinas, African-American women, and Vietnamese women have higher rates of cervical cancer and present with later stage disease compared to whites.^{3,4} Delays in care for abnormal cervical cytology can contribute to a later stage at diagnosis and the need for more aggressive treatment. In retrospective analyses, delays in care have been cited as a cause of approximately 15% of cervical cancer cases.^{5,6} On average, 30% to 40% of women do not complete follow-up for an abnormal Pap smear, with higher rates reported in some populations.⁷⁻¹⁶

Previous studies have identified many patient and organizational factors associated with delays in care for abnormal cervical cytology.⁷⁻²¹ Beliefs about health and cancer have also been identified as predictors of adherence among white women with abnormal Pap smears.²² These results may not be applicable to other groups because health beliefs can vary by race and ethnicity.²³⁻²⁶ In several studies, Latinos endorsed more misconceptions about cancer and fatalistic beliefs than whites.^{25,26} Fatalism and other health beliefs have been associated with lower Pap smear screening rates among Latinas.²⁷⁻³⁰ It is not known if these culturally specific beliefs have a similar effect on adherence to follow-up of abnormal Pap smears.

The purpose of this study was to determine (1) if health beliefs differ by race and ethnicity among women in a large managed care organization, and (2) if health beliefs and cancer knowledge are associated with delays in care for abnormal Pap smears in a predominantly Latina population. The tracking system for abnormal Pap smears used by this managed care organization has removed many organizational barriers to follow-up. In this setting, exploring patient-level factors of adherence is important in order to target patient education and intervention strategies to decrease delays and improve care.

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Address correspondence and requests for reprints to Dr. Nelson: VA Puget Sound Medical Center, S-111-GIMC, 1660 South Columbian Way, Seattle, WA 98108-1597 (e-mail: karin.nelson@med.va.gov).

METHODS

We performed a retrospective cohort study of all women aged 18 or older with an abnormal Pap smear who received care at Kaiser Permanente Los Angeles Medical Center from October 1998 through October 1999 ($n = 1,049$). A central lab analyzes all Pap smears performed at this facility, and all abnormal cytology results are reported to an on-site Dysplasia Registry. The Dysplasia Registry tracks care for women with abnormal results and maintains a database containing patient contact information, Pap smear results, and appointment scheduling. The staff at the Dysplasia registry use a protocol to schedule women for follow-up of abnormal Pap smears. In addition, they attempt to reschedule missed appointments by making at least 3 attempts to contact women by telephone and then sending a letter by certified mail.

Participants and Recruitment

A mailed survey with telephone follow-up for nonresponders was administered between April and August 2000. Potential participants were mailed an introductory letter and survey questionnaire in English and Spanish with a self-addressed stamped return envelope. If no response was obtained within 3 weeks, a second introductory letter and survey questionnaire were mailed. If no response to the second mailing was received within 3 weeks, a trained bilingual interviewer attempted to call the potential participant to complete the interview over the telephone. The survey was available only in Spanish or English. On average, 5 follow-up calls were made to each nonresponder. Participants were offered a 20-minute long-distance phone card as an incentive to complete the telephone survey. We were unable to contact 16% ($n = 165$) of the potentially eligible sample either by mail or by phone. Thirty-nine (12%) of those contacted by phone refused to participate. The Institutional Review Boards at the University of California, Los Angeles and Kaiser Permanente Southern California approved this study.

Survey Instrument

We designed our survey instrument using questions from the Center for Disease Control (CDC) Behavioral Risk Factor Surveillance System,³¹ the National Health Interview Survey (NHIS) Cancer Risk Factor Supplement,³² and from questions and constructs identified by a literature review.^{24,27-30} The survey instrument was 5 pages long and required approximately 20 minutes to complete. Self-reported socioeconomic variables included age, annual household income, educational level, and marital status. We asked respondents to identify themselves as white or Caucasian (non-Hispanic), Hispanic or Latino, Black or African American, Asian or Pacific Islander, or other. Level of acculturation was assessed by preferred language for reading and speaking, language used for the survey, and country of origin.³³

Survey items were reviewed by the study team and by an expert in psychometric testing. The survey instrument was translated from English to Spanish and back-translated into English. The English and Spanish versions were compared to correct for discrepancies. Delays in care and type of Pap smear abnormality were obtained from the computerized Dysplasia Registry database at Kaiser Permanente Los Angeles Medical Center.

Data Analysis

Development of Scales to Assess Health Beliefs and Cancer Knowledge. We constructed 4 scales using multi-trait scaling methods³⁴: satisfaction with care, fatalism, misconceptions about cancer, and knowledge of cervical cancer risk factors using previously validated items.^{29,30} Although many of the questions regarding fatalism and health beliefs were derived from previous studies of Pap smear screening among Latinas, we used all individuals surveyed to create our scale scores. Each scale consists of 2 to 7 items that were answered using a Likert response format (see Appendix A for individual items). For each scale, a higher score signifies more of the measured construct. Within each scale, items were combined using generally accepted criteria.³⁴ We imputed the mean score for missing individual items to compute the scale score if less than half of the items in the scale were missing. To estimate internal consistency reliability, Cronbach's coefficient α was calculated for each multi-item scale.³⁵ Several items that measured knowledge about Pap smears and cervical cancer did not meet criteria for inclusion into a scale and were analyzed as single items. These items included the statements: "A woman can tell if she has cervical cancer without going to the doctor for tests" and "Women need to get a Pap smear only if they have abnormal bleeding."

Correlates of Health Beliefs and Delays in Care. We used bivariate analysis and multivariate regression models to assess the effect of sociodemographic characteristics on health beliefs and cancer knowledge. The primary study outcome was a delay in care, defined as not attending the first scheduled clinic visit to follow up on an abnormal Pap smear, or requiring multiple attempts, including certified letters, to contact. We used multivariate logistic regression models to determine if health beliefs, cancer knowledge, and race and ethnicity were significantly associated with delays in care, after controlling for the independent effects of age, income, education, and language preference. Country of origin was closely correlated with language preference and was not included in the multivariate models.

RESULTS

Study Population

From 1,049 eligible women with abnormal Pap smears, we received 733 survey questionnaires, for a

response rate of 70%. Sixty-two percent of women who delayed care completed the survey questionnaire, as compared to 71% of those who did not delay care ($P = .03$). Forty-four percent ($n = 322$) of the survey questionnaires were completed by telephone. Population characteristics are displayed in Table 1. The sample was 51% Latina, 24% white, 13% African American, and 12% Asian. We excluded individuals who identified themselves as other race ($n = 6$). Fifteen percent of respondents had less than a high school education and 38% had an annual income of less than \$30,000. Twenty percent of respon-

dents reported that they preferred to read and speak mostly in Spanish. Among Latinas, 36% ($n = 130$) were born in Mexico, and 29% ($n = 105$) were born in Central America. Eighty-six percent ($n = 73$) of Asian women were born outside of the United States. The majority of Pap smears were ASCUS (atypical squamous cells of undetermined significance), with the remainder being low-grade (23%) or high-grade (4%) intraepithelial lesions. Thirteen percent ($n = 97$) of women had a delay in care, defined as missing the first follow-up visit for an abnormal Pap smear ($n = 56$) or requiring multiple attempts, including certified letters, to contact to schedule a follow-up appointment ($n = 41$).

Table 1. Population Characteristics: Women with Abnormal Pap Smears ($N = 733$)

	<i>n</i>	%
Race/ethnicity*		
Latina	362	51
White	167	24
African American	91	13
Asian	85	12
Education		
Less than high school	112	15
High school/tech school	347	48
College graduate	264	37
Age, y		
<40	342	47
≥40	391	53
Annual income†		
<\$30,000	261	38
\$30,000–\$60,000	276	41
>\$60,000	143	21
Country of origin		
United States	365	50
Mexico	130	18
Other	230	32
Language preference		
English	319	44
English and Spanish	194	27
Spanish	145	20
Other	73	10
Pap smear abnormality		
ASCUS	533	73
LGSIL and HGSIL	200	27
Delay in care‡	97	13
Treatment for cancer is worse than the disease	305	44
Little a person can do to reduce risk of cancer§	219	31
Cutting into cancer makes it spread§	258	38
A bump or a bruise can cause cancer§	183	26

* Data available for $n = 705$.

† Data available for $n = 680$.

‡ A delay in care is defined as not attending the first clinic visit to follow up for an abnormal Pap smear and/or requiring multiple attempts, including certified letters, to contact to reschedule a follow-up visit.

§ n (%) of individuals who strongly or somewhat agreed with the statements.

Column totals may vary due to missing data or rounding error. ASCUS, atypical squamous cells of undetermined significance; LGSIL, low-grade squamous intraepithelial lesions; HGSIL, high-grade squamous intraepithelial lesions.

Health Beliefs and Cancer Knowledge

The Cronbach's coefficient α for the scale scores are 0.9 for satisfaction, 0.6 for fatalism, 0.8 for misconceptions about cancer, and 0.8 for cervical cancer risk factor knowledge. The mean score for the fatalism scale is 10 (SD, 3.4; range, 5 to 25) and the mean score for the misconceptions about cancer scale is 18 (SD, 6.2; range, 7 to 34). Table 1 displays 4 items included in either the fatalism or misconceptions about cancer scales. Forty-four percent of respondents strongly or somewhat agreed that "the treatment for cancer is worse than the disease," and 31% endorsed the statement that "there is very little a person can do to reduce their risk of cancer." Thirty-eight percent of respondents agreed that "cutting into cancer makes it spread" and 26% agreed that "a bump or a bruise can cause cancer."

Correlates of Fatalism and Misconceptions about Cancer

Linear regression models were used to identify correlates for both the fatalism and misconceptions about cancer scores (Table 2). A higher score corresponds to endorsing more fatalistic beliefs or more misconceptions about cancer. The coefficients displayed in Table 2 represent the difference in score compared to the reference group. Individuals of Asian descent, Spanish-speaking Latinas, those with less education, and those with lower incomes endorsed more fatalistic beliefs and more misconceptions about cancer. We did not find significant differences in scores on the knowledge of cervical cancer risk factor scale or the satisfaction scale by sociodemographic characteristics (data not shown).

Correlates of Delays in Care

Thirteen percent of the sample had a delay in care for their abnormal Pap smear. Table 3 displays characteristics of women who delayed care. In bivariate analysis, Asian women and older women were less likely to delay care. Respondents who agreed that "a woman can tell if she has cervical cancer without going to the doctor" and "a woman needs a Pap smear only with abnormal bleeding" were also

more likely to delay care. Individuals who agreed with these 2 items were from lower income groups, but did not differ significantly by race or ethnicity (data not shown). In this insured cohort, barriers to care such as cost, transportation, childcare, and making time for doctors' appointments were not associated with delays in care (data not shown). Women who delayed care had a higher mean score on the fatalism scale than those who did not delay care (mean [SD], 11.0 [3.8] vs 9.8 [3.4]; $P < .05$, Student's t test). There were no differences in mean scores on the satisfaction, cervical risk factor knowledge, or misconceptions about cancer scale between women who delayed and did not delay care (data not shown).

In multivariate logistic analysis (Table 4), the strongest associations with a delay in care were a higher score on the fatalism scale and endorsing the view that a woman needs a Pap smear only with abnormal bleeding. Individuals who believe that that a woman can tell if she has cervical cancer without going to the doctor were more likely to delay care, although this result was not statistically significant. When fatalism and health beliefs were included in the multivariate model, race and ethnicity were no longer related to delays in care. Interactions between income, education, and race and ethnicity were assessed and were not found to

Table 2. Multivariate Correlates with Fatalism and Misconceptions about Cancer Scores, Linear Regression*

	β (95% CI)	
	Fatalism Score (N = 646)	Misconceptions about Cancer Score (N = 642)
Race/ethnicity		
White	Reference	Reference
Asian	1.1 (0.2 to 2.0) [†]	3.2 (1.7 to 4.7) [†]
African American	0.4 (-0.5 to 1.3)	0.3 (-0.6 to 2.3)
Latina [‡]		
English	-0.4 (-1.3 to 0.6)	1.2 (-0.3 to 2.7)
English and Spanish	0.2 (-0.6 to 1.1)	0.7 (-0.7 to 2.2)
Spanish	1.3 (0.2 to 2.3) [†]	3.4 (1.6 to 5.2) [†]
Education		
Less than high school	2.2 (1.2 to 3.2) [†]	3.7 (2.1 to 5.4) [†]
High school/tech school	0.7 (0.05 to 1.3) [†]	2.0 (0.9 to 3.0) [†]
College graduate	Reference	Reference
Annual income		
<\$30,000	1.3 (0.5 to 2.1) [†]	3.5 (2.2 to 4.7) [†]
\$30-\$60,000	0.8 (0.1 to 1.5) [†]	1.9 (0.7 to 3.0) [†]
>\$60,000	Reference	Reference
Age, y		
<40	0.3 (-0.3 to 0.8)	0.1 (-0.7 to 0.9)
>40	Reference	Reference

* A higher score corresponds to endorsing more fatalistic health beliefs and misconceptions about cancer. β represents the difference in score as compared to the reference group.

[†] $P < .05$.

[‡] Language that respondent preferred to read and speak.

Table 3. Population Characteristics of Women with Delays in Care

	Population Total (n)	Delay in Care	
		(n)	(%)
Race/ethnicity*			
White	167	22	13 [†]
Latina	362	54	15
African American	91	14	15
Asian	85	5	6
Education			
Less than high school	112	17	15
High school/tech school	347	50	14
College	264	28	11
Age, y			
<40	342	56	16 [†]
≥40	391	41	10
Annual income [‡]			
<\$30,000	261	41	16
\$30,000-\$60,000	276	37	13
>\$60,000	143	12	8
Country of origin			
United States	365	48	13
Mexico	130	23	18
Other	230	26	11
Language preference			
English	319	39	12
English and Spanish	194	28	14
Spanish	145	21	14
Other	73	8	11
Pap smear abnormality			
ASCUS	533	67	13
LGSIL and HGSIL	200	30	15
A woman can tell if she has cervical cancer without going to the doctor			
Agree	35	9	26 [†]
Disagree	675	85	13
A woman needs a Pap smear only with abnormal bleeding			
Agree	23	9	39 [†]
Disagree	695	87	13
For your last doctor visit, difficult to [§]			
Get out of work (n = 602)	173	23	13
Make time for MD appointment (n = 714)	246	36	15
Get transportation (n = 693)	73	11	15
Pay for appointment (n = 632)	82	12	15
Arrange childcare (n = 329)	71	11	15 [¶]

* Data available for n = 705 of 733 participants, Pearson χ^2 test for Asian versus white women.

[†] $P < .05$, Pearson χ^2 test.

[‡] Data available for n = 680 of 733 participants.

[§] Data available for (n) after each listed barrier; population total endorsed the listed barrier to care.

^{||} Only asked if children at home.

[¶] No significant difference from women who did not endorse these barriers to care (data not shown).

Column totals may vary due to missing data; percentages displayed are row percentage of total population. ASCUS, atypical squamous cells of undetermined significance; LGSIL, low-grade squamous intraepithelial lesions; HGSIL, high-grade squamous intraepithelial lesions.

Table 4. Multivariate Correlates with Delays in Care (N = 643), Logistic Regression

	Race and Ethnicity, OR (95% CI)	Socioeconomic Covariates, OR (95% CI)	Full Model, OR (95% CI)
Race/ethnicity			
Asian	0.4 (0.6 to 1.1)*	0.4 (0.1 to 1.1)	0.4 (0.1 to 1.1)
African American	1.2 (0.6 to 2.5)	1.2 (0.6 to 2.4)	1.2 (0.6 to 2.9)
Latina	1.1 (0.7 to 2.0)	1.1 (0.7 to 1.9)	1.2 (0.5 to 2.8)
White	Reference	Reference	Reference
Age <40 y		1.6 (1.0 to 2.6)	1.6 (1.0 to 2.6)
Education			
Less than high school		1.3 (0.6 to 2.8)	1.2 (0.6 to 2.5)
High school		1.1 (0.6 to 2.0)	0.9 (0.6 to 1.6)
College		Reference	Reference
Income			
<\$30,000		1.7 (0.8 to 3.6)	1.5 (0.7 to 3.2)
\$30,000–\$60,000		1.4 (0.7 to 2.9)	1.3 (0.7 to 2.8)
>\$60,000		Reference	Reference
Fatalism score (per point increase) [†]			1.1 (1.0 to 1.2) [‡]
Need a Pap smear only with abnormal bleeding (y/n)			4.2 (1.1 to 15.5) [‡]
Can tell if you have cervical cancer without going to the MD (y/n)			2.1 (0.9 to 5.2)*

Odds ratio >1 indicates a greater probability of a delay in care.

*P < .1.

[†]Scores range from 5–25; higher score indicates endorsing more fatalistic beliefs.

[‡]P < .05.

be significantly associated with delays in care (data not shown).

DISCUSSION

We found that health beliefs differed by race and ethnicity among women enrolled at a large managed care organization. Spanish-speaking Latinas and women of Asian descent were more likely to endorse fatalistic beliefs and misconceptions about cancer. However, in analyses that accounted for health beliefs, we did not find any association between race and ethnicity and delays in care. Fatalistic beliefs and knowledge about Pap smears and cervical cancer were the strongest correlates of delays in care. Although previous studies have described an association between health beliefs and adherence to follow-up for abnormal Pap smears,²² this is the first study to show an effect of health beliefs and cancer knowledge in a predominantly Latina population. A study of 279 largely Hispanic women in New York City did not show an effect of health beliefs on follow-up for colposcopy.¹⁹ Our findings may reflect the larger sample size, the greater number of items used to measure specific health beliefs such as fatalism, or the heterogeneity among Latinas who reside in different areas of the United States.³⁶

We are not aware of other studies that have examined the effect of health beliefs on adherence among Asian women with abnormal cervical cytology. High rates of misconceptions regarding cervical cancer and Pap smear screening among Vietnamese³⁷ and Korean American women^{38,39} have been previously documented. We found

that Asian women were less likely to delay care than whites in bivariate analysis; however, this relationship was no longer significant when the effects of health beliefs were taken into account. We were unable to perform analysis of the interaction between specific Asian groups and fatalism on delays in care because of a limited sample size. In addition, we did not differentiate among different Asian subpopulations in our sample or survey women who did not speak English or Spanish. Because we were unable to survey non-English-speaking Asian women, we may have excluded less acculturated women from this subgroup. Given the high rates of cervical cancer among some groups of Asian women,⁴⁰ further study of health beliefs and their impact on adherence in these populations may be warranted. We found no difference in health beliefs or cancer knowledge between African-American and white women after adjusting for income and education. Previous studies that are not fully adjusted for income and education have reported that African Americans have less general knowledge^{41–43} and endorse more fatalistic beliefs about cancer.⁴⁴

Previous studies have reported increased rates of delays in care for African-American women and Latinas as compared to whites.^{8–10} These studies were all conducted in poorer, less insured populations. In contrast, all women in our sample had health insurance, thus removing access to care as a potential barrier to care. Because all women were enrolled in a managed care plan that has made cervical cancer prevention an organizational priority, many administrative barriers to adherence have been removed. In addition, cost and transportation issues that

have been noted in more indigent groups were not reported as significant barriers to adherence in our population.

Our study is limited in the ability to make causal inferences about the effect of health beliefs and misconceptions about cancer on adherence behavior. The survey was conducted after women were notified about their abnormal results. The experience of having an abnormal Pap smear may have influenced their health beliefs and cancer knowledge. Previous studies have shown that women experience anxiety and changes in self-perception because of abnormal cervical cytology.⁴⁵⁻⁴⁷ In addition, because our survey questionnaire was primarily self-administered, those who responded by mail are unlikely to include women from low literacy groups. We may have decreased this bias by providing the opportunity to complete the survey questionnaire over the telephone for English and Spanish speakers.

Overall, the rates of nonadherence we report are less than in many studies,^{8,9} but are consistent with those reported for other managed care systems.⁴⁸ As a result of the organized tracking system and the efforts of the dedicated staff at the Dysplasia Registry, very few women are lost to follow-up, but a significant number of women with abnormal Pap smears delay care. Rescheduling appointments requires additional labor for the Dysplasia Registry staff and clinic providers. In less-organized systems where many women from ethnic minorities receive care, failed appointments may result in greater numbers of missed cases of cervical cancer and of women presenting with advanced disease.

The U.S. Department of Health and Human Services has identified reducing racial and ethnic disparities in cervical cancer as a priority area.⁴⁹ Cervical cancer is an almost entirely preventable disease if women are screened and followed up appropriately. As increasing numbers of women receive appropriate Pap smear screening,⁵⁰ additional emphasis should be placed on the timely management of potentially precancerous lesions. Rates for follow-up of abnormal Pap smears improve with active interventions such as mailed reminders, telephone counseling, and educational brochures.⁵¹⁻⁵⁵ Interventions to decrease delays in care for abnormal Pap smears need to address fatalistic health beliefs and misconceptions about cancer, especially in multi-ethnic patient populations.

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APPENDIX A

Scale Items

Fatalism	5 items
1. There is very little a person can do to reduce her risk of getting cancer	25 maximum score
2. I would rather not know if I had cancer.	Scoring: strongly agree = 5 to strongly disagree = 1
3. The treatment for cancer is worse than the disease.	
4. God can punish people by making them sick.	
5. I would be afraid to tell my partner if I had cervical cancer because it would affect our relationship.	
Misconceptions about cancer	7 items
1. Cutting into cancer makes it spread.	35 maximum score
2. A bump or a bruise can cause cancer	Scoring: strongly agree = 5 to strongly disagree = 1
3. Can each of these items cause cervical cancer	
■ Fate or bad luck	
■ Lack of cleanliness or poor hygiene	
■ Sexual activity during menstruation	
■ Having an abortion	
■ Being hit in the vagina or cervix	
Knowledge of cervical cancer risks	2 items
1. Sexual activity at an early age	10 maximum score
2. Many sexual partners	Scoring: strongly agree = 5 to strongly disagree = 1
Satisfaction	2 items
Thinking about your most recent pap smear, colposcopy test, or female exam how satisfied were you:	8 maximum score
1. with the way your health care provider discussed the test before it was done	Scoring: very satisfied = 4 to very dissatisfied = 1
2. with the way the test was performed	
