

HEALTH LITERACY, CERVICAL CANCER RISK FACTORS, AND DISTRESS IN LOW-INCOME AFRICAN-AMERICAN WOMEN SEEKING COLPOSCOPY

Objectives: To describe the relationship between health literacy, distress, and cervical cancer risk factors in women at high risk for developing cervical cancer.

Design: Cross-sectional, prospective cohort design.

Setting: Two university-based gynecological oncology colposcopy clinics and 3 Planned Parenthood community clinics.

Patients/Participants: One hundred-thirty English-speaking African-American women ≥ 18 years referred for colposcopy following abnormal Pap testing.

Main Outcome Measures: Avoidance and Intrusion subscales of the Impact of Events Scale (IES), Rapid Estimate of Adult Literacy in Medicine (REALM), and demographics.

Results: Forty-five percent of women had a low level of health literacy (<9th grade). Low health literacy was related to fewer risk factors ($P < .01$) and higher levels of distress on the Impact of Events avoidance subscale ($P < .05$) after controlling for covariates. Forty-three percent of women with low literacy had excessive levels of distress as compared to 25% in women with high literacy ($P < .05$).

Conclusions: A low level of health literacy is associated with increased levels of distress among women at high risk for developing cervical cancer. To the extent that distress serves as a barrier to treatment, culturally informed, effective interventions are needed. (*Ethn Dis.* 2002;12:541–546)

Key Words: Health Literacy, Cervical Cancer, Colposcopy, Disparities, African-American

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INTRODUCTION

Cervical cancer is a highly preventable neoplasm; however, it represents the third most common cancer worldwide.¹ In the United States, cervical cancer is the ninth most deadly neoplasm.¹ Disturbing disparities are evident for African-American women who have cervical cancer mortality rates more than double the rates for White women in the United States.² Disparities in cervical cancer outcome have been attributed to poor access to health care; inadequate patient knowledge or poor physician-patient communication; lack of transportation or childcare; and poor adherence to follow-up recommendations.^{3,4} Recent evidence from the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) suggests that increased rates of cervical cancer mortality among African-American women may be related to a lack of appropriate follow-up care for high grade lesions.⁵ Although not adequately studied, two factors that may relate to this increased risk for cervical cancer among African-American women are poor health literacy skills and emotional distress associated with receiving abnormal Papanicolaou (Pap) results.

Health literacy is a specific form of literacy relevant to medical or health contexts. Health literacy reflects the ability to read and comprehend medical terminology, to understand instructions for taking medications, to read an appointment slip or medication label, to complete health-related forms, and to navigate medical settings.⁶ A study conducted within 2 public hospitals found that 35% of English-speaking patients had inadequate health literacy skills.⁷

Furthermore, approximately 50% of people living in poverty have inadequate literacy skills. A low level of health literacy is often an unnoticed factor in health independent of socioeconomic status and education.⁸ For example, men with low health literacy levels have been shown to present with more advanced stages of prostate cancer at diagnosis, and women with low health literacy levels have been shown to know less about mammography as compared to groups with high levels of health literacy.^{9,10}

In Ecuador, a country where rates of cervical cancer are extremely high, a study found that the incidence of cervical cancer was 6 times greater in women who were illiterate and 2 times greater in women with little formal education, as compared to women with a university education.¹¹ The mechanism(s) accounting for the disparity was not directly explored. The impact of low health literacy has not been explored in relation to cervical screening or exposure to risk factors for cervical cancer within the United States.

Prevention of cervical cancer has been largely attributed to the Pap test as a primary screening tool for cervical cancer, coupled with colposcopy and biopsy when abnormalities are identified.¹² Despite clear benefits of Pap testing and colposcopy, studies indicate that approximately 25% of women who receive abnormal Pap results experience adverse emotional reactions severe enough to impair their daily functioning.^{13,14} Some studies found that the distress served as a barrier to compliance for cervical screening and followup.^{15,16} Little research has focused on distress among those with greater rates of cervical cancer such as low-income, Afri-

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can-American women. Focusing upon the experiences of women of color is important because their experiences within the healthcare system differ from those of White women and their reactions to health threats are also likely to differ. For example, women of color are more likely to have a race-discordant physician relationship, which alters the psychosocial context of their health care.^{17,18}

This exploratory study addresses the relationship between health literacy skills and distress experienced by a group of low-income African-American women seeking colposcopy as a follow-up for an abnormal Pap test. The primary goals of this study were to determine whether: 1) distress differed by the literacy level of women, after controlling for years of education and severity of Pap results; and 2) the type and number of risk factors differed for women based upon their literacy level.

Risk factors for cervical cancer included: presence of sexually transmitted diseases (STDs), history of nicotine use, early age at first intercourse, greater number of sexual partners, and use of oral contraceptives. Human papillomavirus (HPV), the primary cause of cervical cancer, was not included as a variable in this study because the clinics do not routinely conduct HPV testing.

METHODS

Participants

Women were prospectively recruited during a 12-month period from 2 university-based gynecological oncology colposcopy clinics and 3 Planned Parenthood community clinics. The 5 sites provide care for many African-American women from diverse geographic areas in Chicago. One hundred-thirty women, self-identified as African-American, completed the study between November 1999 and December 2000.

Consecutive women referred for colposcopy as medical follow-up for an abnormal Pap test in each clinic were eligible. Women who were eligible, but who failed to keep their scheduled appointment were contacted to reschedule and remained in the study group if they presented to the clinic during the study period. Women were excluded if they were: 1) younger than 18 years; 2) referred for colposcopy for reasons other than abnormal Pap tests; or 3) seeking follow-up for prior colposcopy or other procedures.

The study protocol was approved by human subjects Institutional Review Boards at each participating institution. All participants signed consent forms. No compensation was offered for participation.

PROCEDURES

This exploratory study used a cross-sectional design with a convenience sample of women recruited as they presented for a regularly scheduled colposcopy appointment. One of 2 White, female research assistants approached eligible patients in the waiting area prior to meeting with the physician. Women who agreed to learn more about the study were taken to a private room, where they signed informed consent forms. Demographic information and 2 interviewer-administered questionnaires were collected. Following the interviews, women returned to the waiting area for

their colposcopy. Medical information regarding colposcopy results and Pap tests were collected from charts and lab results. No attending physicians in this study were African-American and 6 out of 7 were male.

MEASURES

Participants completed all measures in a private room within the colposcopy clinic prior to the procedure and prior to meeting the physician. Demographic information was collected in addition to the administration of the measures described below.

Rapid Estimate of Adult Literacy in Medicine (REALM)

Health literacy was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM), which consists of 66 health/medical-related words that patients are asked to read aloud.¹⁹ The questionnaire can be completed within 2 to 3 minutes and results are in the form of a raw score based upon the number of correctly pronounced words. Raw scores can be converted into 4 reading levels. In this study, high health literacy was defined as the top reading level reflective of a ninth grade or higher reading ability. Low health literacy was defined as the 3 lowest levels reflective of an eighth grade or lower reading ability.

Impact of Events Scale (IES)

The IES is a 15-item measure of subjective psychosocial distress related to a specific stressful event.²⁰ In this study, the event was defined as "needing a colposcopy due to an abnormal Pap test." Participants were asked to rate how often they had experienced each item in the past 7 days on a scale from 0 (not at all) to 5 (often). Scoring yielded 2 subscale scores, intrusion and avoidance, with higher scores indicating greater stress. A score ≥ 20 on either

subscale is suggestive of a significant stress response.^{20,21}

DATA ANALYSIS

Data analyses were performed using SPSS for Windows (version 10.0). Differences in risk factors of women with high and low health literacy levels were analyzed using the Mann-Whitney test for categorical data and *t* test for continuous data. Univariate *t* tests were conducted on the entire group to identify covariates of distress. Variables that reached significance in the univariate analyses were included as covariates in a hierarchical analysis of covariance to evaluate the impact of health literacy upon distress. All testing of hypotheses was based upon 2-tailed significance levels.

RESULTS

The response rate for this study was 96%, resulting in a sample of 130 African-American women. Forty-five percent of the sample had health literacy levels at or below the 8th-grade level. Table 1 displays the demographic characteristics of the 130 participants grouped into literacy levels. Approximately 11% of the entire sample were married or lived with a partner, 29% were single parents, and 49% were single, living with extended family. As expected, the group of women with high levels of health literacy had more education than did the group with low levels. The age of the participants did not differ by literacy level. Approximately 20% of the women knew someone whom they believed had cervical cancer.

The time each woman allowed to elapse between learning of the abnormal Pap test and obtaining a colposcopy was collected from lab reports. Over 50% of the women obtained a colposcopy within 2 months of notification of the abnormal Pap. Over 70% of the sample kept the first appointment for colpos-

Table 1. Demographic characteristics and follow-up behavior of sample by health literacy level

Demographics	Low Levels of Health Literacy (N=58) N (%)	High Levels of Health Literacy (N=72) N (%)	P Value
Living situation			NS
Live with partner/husband	9 (15.5)	6 (8.3)	
Not married, single parent	21 (36.2)	17 (23.6)	
Not married, live with extended family	26 (44.8)	38 (52.8)	
Single or widowed, live alone	1 (1.7)	9 (12.5)	
Other	1 (1.7)	2 (2.8)	
Age			
Mean ± SD	26.0 ± 9.5	26.3 ± 11.0	NS
Education			
9th grade or less	4 (6.9)	0 (0.0)	
10th–11th grade	21 (36.2)	9 (12.5)	
High school	14 (24.1)	26 (36.1)	
1–3 years college	19 (32.7)	27 (37.5)	
College graduate	0 (0.0)	8 (11.1)	
Post-graduate degree	0 (0.0)	2 (2.8)	
Mean ± SD	11.7 ± 2.2	13.1 ± 1.7	.000
Insurance status			NS
Medicaid	35 (60.3)	36 (50.0)	
Uninsured	17 (29.3)	24 (33.3)	
Private insurance	2 (3.4)	4 (5.5)	
Medicare	1 (1.7)	2 (2.8)	
Time since abnormal Pap test			NS
Within last 1 month	17 (29.3)	21 (29.2)	
Within last 2 months	4 (24.1)	16 (22.2)	
Within last 3 months	7 (12.1)	9 (12.5)	
Within last 4 months	7 (12.1)	11 (15.3)	
More than 4 months	10 (17.2)	14 (19.4)	
Adherence to colposcopy appointments			NS
First scheduled appointment	44 (75.9)	52 (72.2)	
Second scheduled appointment	6 (10.3)	13 (18.1)	
More than 2 appointments	3 (5.2)	7 (9.2)	

copy. Literacy was not significantly related to time elapsed between notification of Pap results and presentation for colposcopy. One-third of the sample had obtained a colposcopy in the past.

The number of risk factors differed significantly with the low literacy level group reporting an average of 1.8 (SD=0.89) and the high literacy level group reporting 2.3 (SD=0.96; $P<.01$). Types of risk factors differed by literacy levels as shown in Table 2. Women with high levels of health literacy were more likely to use oral contraceptives ($P<.01$) and to report having more than 5 lifetime sex partners

($P<.01$). Women with low levels of health literacy had greater parity ($P<.05$), despite being of similar age. Literacy was not related to having intercourse prior to the age of 18, STDs other than HPV, current use of tobacco, or number of prior abnormal Pap tests or past colposcopies.

Levels of distress on the intrusion subscale were significantly higher for women having their first colposcopy as compared to those with prior colposcopies ($P<.05$). The intrusion and avoidance subscales were both significantly higher for women who knew someone diagnosed with cervical cancer

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($P < .01$). Distress and severity of Pap results were not significantly related.

In the multivariate analyses, the mean levels of distress on the avoidance subscales were significantly higher ($P = .02$) for the group with low literacy level after controlling for years of education, for knowing someone with cervical cancer, and for past colposcopy as shown in Table 3. The percentage of women scoring above the cutoff of 19 on the avoidance subscale was significantly larger in the low health literacy level group (43% vs 25% in the high literacy level group [$P = .03$]).

DISCUSSION

Our study is the first to explore the relationship between health literacy and distress in a group of women at high risk for developing cervical cancer. The sample was highly motivated to seek colposcopy with over 50% of women appearing within 2 months of being referred, and only 22% missing one or more appointments.

Our study is among the first to include information on exposure to cervical cancer risk factors based upon health literacy levels. Interestingly, women with low levels of health literacy exhibited fewer risk factors and the types of risk factors differed slightly by health literacy level. Women with low levels of health literacy were less likely to use oral contraceptives, and had fewer lifetime sex partners, compared to those in the high literacy level group. However, women with low levels of health literacy had greater parity, despite being of similar age. Use of tobacco, one of the greatest modifiable risk factors for cancer, was comparable in both groups.

In our sample of African-American women, psychosocial distress was significantly higher in women with low levels of health literacy compared to those with higher levels. Unadjusted scores for our sample of high and low literacy level groups on the intrusion subscale were

Table 2. Cervical cancer risk factors and prior cervical testing of sample by health literacy level

	Low Levels of Health Literacy (N=58) N (%)	High Levels of Health Literacy (N=72) N (%)	P Value
Current oral contraceptive use	7 (12.1)	25 (34.7)	.005
Sex prior to 18 years of age	40 (69.0)	65 (90.3)	.002
Number of lifetime partners			
0-1	5 (8.6)	3 (4.2)	.009
2-3	13 (22.4)	17 (23.6)	
4-5	25 (43.1)	15 (20.8)	
>5	15 (25.9)	37 (51.4)	
Parity			
Mean \pm SD	1.9 \pm 2.1	1.2 \pm 1.4	.047
History of STD			
Yes	32 (55.2)	44 (61.1)	NS
Smoked in last 30 days			
0 days	42 (72.4)	54 (75.0)	NS
1-4 days	0 (0.0)	4 (5.6)	
5 days or more	16 (27.6)	14 (19.4)	
Regular smoker ever			
Yes	18 (31.0)	21 (29.2)	NS
Other abnormal Paps			
Yes	20 (34.5)	34 (47.2)	NS
Don't know	0 (0.0)	2 (2.8)	
Prior colposcopy			
Yes	15 (25.9)	22 (30.5)	NS
Results of testing			
Pap leading to colposcopy			
ASCUS	20 (34.5)	11 (15.3)	NS
LSIL	21 (36.2)	26 (36.1)	
HSIL	13 (22.4)	15 (20.8)	
Results not available	4 (6.9)	20 (27.8)	
Biopsy results			
WNL	15 (25.9)	19 (26.4)	NS
CIN1	13 (22.4)	24 (33.3)	
CIN2	6 (10.3)	6 (8.3)	
CIN3	2 (3.4)	0 (0.0)	
CIS	1 (1.7)	1 (1.4)	
VAIN	0 (0.0)	1 (1.4)	
No biopsy done	18 (31.0)	12 (16.7)	

8.6 (high) and 12.2 (low); on the avoidance subscale, the scores were 11.7 (high) and 17.4 (low). A British study conducted by Palmer et al offers comparison using the IES with 2 groups of women—one group with normal Pap results, and one group with abnormal Pap results requiring colposcopy.²²⁻²³ Distress levels in our sample were similar to those of the British women seek-

ing colposcopy whereas our high literacy level group was similar to the British women with normal Pap results. It is difficult to make comprehensive comparisons between the studies because the demographic characteristics of the British women are not adequately described.

From a clinical perspective, the percentage of women reporting excessive levels of distress is meaningful. Twenty-

Table 3. Descriptive characteristics for impact of events by health literacy level

IES Subscale	Low Levels of Health Literacy (N=53)	High Levels of Health Literacy (N=68)	P Value
Intrusion			
Unadjusted mean \pm SD	12.2 \pm 8.4	8.6 \pm 8.5	.05
Adjusted mean*	11.5	9.1	NS
N (%)>19	12 (23)	8 (12)	NS
Avoidance			
Unadjusted mean \pm SD	17.4 \pm 11.0	11.7 \pm 9.8	.000
Adjusted mean*	16.8	12.2	.02
N (%)>19	23 (43)	17 (25)	.03

* Adjusted to control for education, knowing someone with cervical cancer, and prior colposcopy.

five percent of the high literacy level group were extremely distressed, while 43% of the low literacy level group were similarly distressed. These results are comparable to other studies. For example, Lerman¹⁴ found that 25% of a low income, mixed ethnic group of women referred for colposcopy reported impairment in daily functioning due to anxiety or worry, and 30% worried about cervical cancer. Lerman's study included a control group (ie, women with normal Pap results), of which 11% had impaired functioning and 14% had cancer worries.¹⁴

By design, this exploratory study raises several questions. The results suggest that low levels of health literacy are contributing to distress associated with a colposcopy, independent of prior colposcopy experience; knowing someone with cervical cancer; and education. However, the cross-sectional design limits our understanding of the direct psychological impact of the need for a colposcopy. Perhaps women with low literacy levels respond to health threats, such as abnormal Pap results and colposcopy differently than do women with higher literacy levels. One might hypothesize that women with low literacy levels have fewer resources, limited coping skills, and/or more demands upon their limited resources, thus making them more vulnerable to health threats.

A strength of this study was the 96%

response rate. With few exceptions, the women were eager to talk about their distress and fears. Many verbalized their relief at being asked directly about their emotional experiences and appeared more relaxed following the interview. Over half of the women expressed interest in learning more about the causes or consequences of cervical abnormalities, and many commented on their preference for face-to-face contact as compared to receiving written material.

In conclusion, the results for our sample of African-American women with high levels of health literacy were consistent with prior published reports on predominantly White or mixed ethnic populations, which found that approximately 25% of women with cervical abnormalities experience severe distress. Our results found that significantly more women with low levels of health literacy experienced high levels of distress, a finding not reported to date. This increased psychological distress is likely to interfere with future compliance for follow-up and, treatment is of serious concern and demands intervention. Prior studies have relied upon supportive and informative interventions. Future research should explore more innovative interventions aimed at improving communication between physicians and patients with low literacy levels and within race discordant relationships. Longitudinal studies are needed to understand if low levels of health literacy

The results suggest that low levels of health literacy are contributing to distress associated with a colposcopy, independent of prior colposcopy experience; knowing someone with cervical cancer; and education.

and distress are contributing directly or indirectly to cervical cancer rate disparities.

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DISCLAIMER

The opinions expressed in this article do not necessarily reflect those of Planned Parenthood Federation of America, Inc.

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