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Perceived Risk of Cervical Cancer in Appalachian Women

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Abstract

Objective—To examine perceptions of cervical cancer risk in elevated-risk Appalachians.

Methods—Appalachian women (n=571) completed interviews examining self-regulation model factors relevant to perceived risk of cervical cancer.

Results—Women with good/very good knowledge of cervical cancer, greater worry, and history of sexually transmitted infection had higher odds of rating their perceived risk as somewhat/much higher than did other women. Former smokers, compared to never smokers, had lower risk perceptions.

Conclusions—Self-regulation model factors are important to understanding perceptions of cervical cancer risk in underserved women. The relationship of smoking and worry to perceived risk may be a target for intervention.

Keywords

cervical cancer; risk factors; risk perception

Much attention has been given to vaccination for the human papilloma virus (HPV) to prevent cervical cancer; however, in spite of the availability of the vaccine, a number of women are not eligible to receive, uninterested in, or unable to obtain vaccination.^{1–3} Screening through Papanicolaou Test (Pap smear) has been shown to decrease cervical cancer incidence by identification of cervical dysplasia and removal of these precancerous lesions.^{4,5} Further, a variety of treatment options exist depending on stage, with treatments for early-stage cervical cancer associated with 5-year survival rates greater than 90%.^{6–8} In spite of the availability of vaccination, routine screening with Pap smear, and a variety of treatment modalities, it is estimated that over 12,000 women developed cervical cancer and over 4000 women died of cancer in the year 2010 in the United States alone.⁸ Further, some

populations suffer a disproportionate burden of cervical cancer. In the period 1998–2003, Appalachians had a higher incidence rate of cervical cancer than the United States as a whole (9.5 vs 8.4 per 100,000), with Appalachian Ohio having a much greater incidence of cervical cancer than non-Appalachian Ohio (10.6 vs 7.8 per 100,000), the greatest disparity in any state.⁹ Data from 2000–2004 of regions in rural, southwestern Appalachian Ohio evidence incidence rates ranging from 9.7–11.7 per 100,000, much higher than the United States as a whole.¹⁰ Educating women from Appalachian Ohio about their elevated risk status and the contribution of risk factors may be helpful in reducing the burden of cervical cancer in this region.

Risk factors are a key component of objective risk, and for this population, 2 types of overlapping risk factors are important: those related to demographics and those related to behaviors. Clearly, Appalachians are at elevated risk for cervical cancer. In addition, other demographic factors such as having lower socioeconomic status, not being married, being nonwhite, and not having insurance coverage are also associated with elevated risk.^{11,12} In addition, many of the reported risk factors for cervical cancer are linked to sexual behaviors and likely represent exposure risks to HPV, and HPV fulfills all of the established criteria for cervical cancer causality.¹³ These include having an early age of first sexual intercourse,¹⁴ having multiple sexual partners,¹⁵ and having sexual partner(s) with multiple partners.¹⁶ Other sexually transmitted infections,¹⁷ no or infrequent screening for cervical cancer, and tobacco use¹⁸ represent other independent risk factors.

In spite of awareness in the scientific community of factors that increase the risk of cervical cancer and the development of a personalized risk tool from the National Cancer Institute, which provides objective information about developing cervical cancer,¹⁹ lay individuals may have perceptions of risk that differ from scientific, objective estimates of risk. Consistent with this, studies have found that perceived risk of cancer differs, sometimes drastically, from objective estimates of risk.^{20,21} Many studies note that women have low perceived risk of cervical cancer;^{22–25} however, without objective risk information for comparison, it is difficult to know how accurate individuals are. Several studies have examined comparative risk of cervical cancer (ie, risk compared to others of their age and race) and have generally found that individuals believed their risk was average or below average.^{26–29} Thus, it appears that individuals may have underestimated their risk; yet, such a conclusion is unclear without having objective estimates of risk. Meanwhile, the few studies that compare perceived and objective risk of cervical cancer tend to focus on a few individual risk factors, rather than examine a more global estimate of objective risk. As one might expect, women's knowledge of risk factors is at best limited.^{27,30–35} Although studies of smokers tend to find that they underestimate risk of cervical cancer,^{26–28} studies examining sexual risk factors have found that either they have little association²⁶ or they are positively associated with perceived risk.²³

In addition to risk factors, psychosocial factors may serve as predictors of perceived risk, and consideration of psychosocial factors may improve future intervention efforts. Although a number of models indicate that perceived risk is a critical determinant of appropriate risk reduction behavior,^{36–40} models (eg, heuristics,⁴¹ expressed preference⁴²) are increasingly examining factors playing a role in risk perception. The self-regulation model (SRM) posits that a number of factors play a role in an individual's perception of risk, including self-system factors, cognitive and affective representations, and health-related behaviors.⁴³ The self-system is the combination of self and social environment factors (eg, demographic risk factors) essential to the perception of the health threat,^{43,44} which in this case is risk of cervical cancer. In addition to the self-system, the SRM posits an individual forms 2 parallel and interacting psychosocial representations in response to the threat of cancer: cognitive (ie, what the health threat is) and affective (ie, how the individual feels about the

health threat) representations.^{44,45} Thus, based on the SRM, psychosocial factors such as knowledge, beliefs, and worry may play an important role in the perception of cervical cancer risk. In addition to self-system factors and representations, an individual may engage in health-related behaviors to modify risk of cervical cancer; and as this is a self-regulatory model, engaging in a behavior would then influence an individual's perception of risk. Perhaps the best known health-related behavior to decrease risk is the Pap smear, and the extent to which one engages in routine cervical cancer risk may play a role in one's perception of risk. The novel combination of the self-system (eg, demographic risk factors), cognitive and affective representations (eg, psychosocial factors), and health-related behavior (eg, behavioral risk factors) combine to determine the extent to which an individual perceives her "self-at-risk" for cervical cancer.²⁰

Understanding how women in Appalachia perceive their risk status is critical to future intervention efforts to increase appropriate health behaviors and decrease the burden of cervical cancer. The purpose of this study was to examine perceived risk of cervical cancer: how risk factors and psychosocial factors predict perceived risk.

METHODS

Participants

Institutional review board approval was received. Eligible individuals were women over 18 years of age, who resided in an Appalachian county in Ohio⁴⁶ and attended a participating clinic in the past 2 years. Further, individuals could not be pregnant (as confirmed by pregnancy test) or have had invasive cervical cancer or a hysterectomy. Based on a priori power calculation for the parent study,⁴⁷ a larger study of Pap screening and smoking prevalence, over 415 women were sought for participation in this observational study.

Procedure

Fourteen clinics in Appalachian Ohio were selected, including 4 regions and both rural and nonrural areas. From participating clinics, charts were reviewed, and a random sample of eligible women was selected. After selection, patients were sent a letter inviting them to participate in the cross-sectional survey and included a postcard to return for participation. Women who did not return the postcard were contacted by phone. At least 10 attempts were made to contact potential participants by phone to evaluate eligibility and determine interest in participating. Women who were eligible and agreed to participate were contacted by a study interviewer, who then obtained written consent and conducted the interview.

The interview was designed to gather information regarding perceived risk, worry, knowledge, barriers, and beliefs about cervical cancer and Pap screening, health and sexual history, and smoking behavior. The interviews were conducted in person and were administered using a computer-assisted system. An audio portion was included to collect sensitive data. Time to complete the interview averaged 1.5 hours.

Measures

Self, cognitive and affective representations and health behaviors were assessed. Self-system factors included demographic risk factors: age, education, race, marital status, rurality,⁴⁷ poverty income ratio,⁴⁷ income, and health care insurance. Cognitive and affective representations of cervical cancer were also assessed. Cognitive factors included knowledge of and beliefs about cervical cancer, as well as benefits/barriers of cervical cancer screening, consistent with previous studies.^{48–50} The affective representation was assessed with an item to assess worry about cancer.⁵⁰

Health-related behavioral risk factors (age at first sexual intercourse, lifetime number of sexual partners, male sexual partners with a history of sex with other men, history of sexual intercourse in exchange for money, male sexual partners with a history of intravenous drug use, condom use, male sexual partners with a history of sexually transmitted infection (STI), personal history of STI, history of abortion) were considered individually, and as a risky sexual behavior index⁵¹ (an estimate of overall objective risk). Other health-related behavioral risk factors were considered (smoking and cervical cancer screening) as well. Both history of abnormal Pap smear and whether the woman was within screening guidelines were included. Whether the woman was within risk-appropriate screening guidelines was defined consistent with Paskett et al.⁴⁷ These questions were developed for the study.⁴⁷

Finally, comparative perceived risk of cervical cancer was considered. Participants were asked their perceived risk of cervical cancer compared with other women their age in the general population, consistent with previous research.⁵⁰ The response scale for this item ranged from 1=much lower than the general population, 2=lower than the general population, 3=same as the general population, 4=higher than the general population, and 5=much higher than the general population.

Statistical Analysis

Means, standard deviations, and other statistics were computed to describe the sample. A mixed model was fit because of the clustered nature of the data; participants were clustered within clinics. Clinic was modeled as a random effect. Univariate analyses were conducted for comparative perceived risk. In the univariate models, the outcome was perceived risk level “somewhat or much higher” versus “about the same, somewhat or much lower.” We opted to dichotomize the perceived risk variable when it was determined that “about the same” and “lower than average” were not significantly different. Variables considered were self (ie, demographics, objective risk factors), cognitive (ie, knowledge, beliefs), and affective (ie, worry) representations, and health behaviors (ie, Pap Smear, smoking). Individual variables that were significantly associated with perceived risk were entered into a mixed logistic regression model.⁵² A combination of forward selection and backward elimination was used. The variables were entered in blocks (self, cognitive and affective, sexual behavior, etc) and then nonsignificant variables were removed one by one. The final model was examined for fit and discrimination. We opted to dichotomize the perceived risk variable when it was determined that “about the same” and “lower than average” were not significantly different. Proc GLIMMIX (SAS Institute, Cary, NC) was used for the analyses because of the clustered nature of the data (participants were clustered within clinics). Clinic was considered a random effect. Variables that were not significant in the binary logistic regression model were removed from the final model.

RESULTS

The details about the participant recruitment are outlined in Paskett et al.⁴⁷ In brief, 4585 patients were sampled from the 14 clinics. Of these women, 2903 were determined to be potentially eligible and sent an invitation to participate in the study. Of the 801 women who were contacted and determined to be fully eligible, 571 completed the interview, yielding a cooperation rate of 71%.⁴⁷ Most women felt their risk was about the same as other women in the general population for cervical cancer (56%) or lower/much lower than that of other women (25%). Only 19% felt their risk was above/ much above that of other women in the general population.

In the univariate analyses, the following variables were significant for comparative perceived risk: age, income (both poverty income ratio and income category), insurance

type, perceived barriers to getting a Pap, knowledge of cervical cancer, worry about cervical cancer, age at first intercourse, lifetime sexual partners, personal history of STI, history of abnormal Pap, risky sexual behaviors index, history of abortion, and smoking status (Table 1).

These variables were then entered into the binary logistic regression model. In the final model, women with good or very good knowledge of cervical cancer, those who worried about cervical cancer, and those with a personal history of STI or abnormal Pap had a higher odds of rating their cervical cancer risk as somewhat or much higher (Table 2). Former smokers, compared to never smokers, had lower odds of rating their cervical cancer risk as somewhat or much higher.

Discussion

The vast majority of these Appalachian women felt their risk was the same as or below the risk of other women their age. This result may reveal (1) an optimistic bias,⁵³ particularly in women who believe their risk to be much below that of other women or (2) an availability heuristic,⁴¹ such that women considered only the people around them in Appalachia, rather than the larger US population. However, this perception of risk can be further clarified by examining the factors associated with perceptions of elevated risk.

To be most accurate and to engage in the most appropriate risk behaviors, individual's perceptions of risk should be based on risk factors, both demographic risk factors and behavioral risk factors. Although self-factors/demographic risk factors were associated with perceived risk of cervical cancer in univariate analyses, they did not appear in the final model. This was unexpected as lower socioeconomic status and other barriers to Pap Smear use are associated with higher risk of cervical cancer.⁵⁴ Thus, it appears that these women do not give appropriate consideration to these established risk factors, indicating some inaccuracy in their perception of risk.

Rather than self-factors/demographic risk factors, psychosocial factors and health-related behavioral risk factors were associated with perceived risk of cervical cancer in the final model. This is consistent with the Self-regulation Model, which posits cognitive (ie, what the health threat is) and affective (ie, how the individual feels about the health threat)^{44,45} representations, along with the practice of health-related behaviors, impact perceived risk.⁴³ Specifically, the cognitive factor (greater knowledge of cervical cancer—except excellent knowledge), the affective factor (greater worry about cervical cancer), risky health behaviors (having a personal history of STI or abnormal Pap), and being a never smoker (as opposed to being a former smoker) were associated with greater perceptions of risk of cervical cancer. Thus, the association of cognitive (knowledge) and affective (worry) factors, as well as behavioral factors (risky sexual behavior—history of STI and abnormal Pap—and smoking) with perceived risk of cervical cancer would be predicted by the self-regulation model and indicate critical intervention needs in the areas of improved education about cervical cancer and management of cancer-related distress.

It is not surprising that, in general, those who were more knowledgeable about cervical cancer had higher perceived risk—as the women in the study were at higher objective risk of cancer. The only anomaly was that those with excellent knowledge did not believe they were at elevated risk. It is possible that those with the highest level of knowledge may have taken purposeful actions to decrease their risk and be truly aware of their risk status. Another explanation is that these women are no longer engaged in risky behaviors so their risk perception is based upon current rather than past behaviors. Additional research is needed to clarify this finding.

Further, beliefs about cervical cancer, a cognitive factor, were not associated with risk of cervical cancer, which would seem to be contrary to the self-regulation model.⁴⁵ The belief items focused largely on beliefs about Pap Smear and Pap Smear use was also not associated with risk perception in our analysis. On the other hand, history of abnormal Pap and STI were associated with elevated perceived and objective risk of cervical cancer, indicating that these factors may have been more informative to women about risk status. All other risky sexual behaviors were not associated with elevated perceptions of cervical cancer risk. This may be partly due to the small number of women reporting some behaviors (eg, history of male sexual partners who used drugs intravenously), or to some risk factors' being closely related to one another (eg, a person who had sex for money may have also had a male sexual partner who used drugs intravenously). Efforts to increase awareness of the preventative role of Pap Smear in cervical cancer risk, along with other sexual behavior risk factors, may be helpful before women engage in risky behaviors and, in turn, receive abnormal results.

The relationship between smoking and perceptions of cervical risk is somewhat puzzling. From an objective risk standpoint, being a current smoker would be associated with highest risk followed by being a former smoker. That former smokers were less likely to believe that they were at elevated risk than never smokers is inconsistent with objective risk. Those who never smoked should be at the lowest risk. Previous research has shown smokers tend to underestimate risk of cancer.^{26–28,53} This is the first study to our knowledge to show that former smokers discounted risk of cervical cancer as compared to never smokers, whereas current and never smokers did not differ in perceptions of risk. It may be that awareness of the negative consequences, such as cancer, was a key motivator to quit smoking, and thus, because they had stopped smoking, former smokers overly discounted their objective risk of cancer; or former smokers discount their risk since they have stopped smoking and perceive themselves at lower risk. In any event, interventions to improve awareness of the link between smoking (whether current or former) and cervical cancer are needed (eg,⁵⁵).

In addition, a factor that does not contribute to objective estimates of risk but that is hypothesized to play a critical role in perceived risk is affect.^{42,43,56} Specifically, we examined the role of worry about cervical cancer in perceived risk. Higher anxiety and worry have been associated with greater perceived risk of cervical cancer.^{57,58} and our results are consistent with these studies, adding further support for the importance of negative affect in perceived risk of cancer. Thus, although women appear to have understood some factors that elevated their risk of cervical cancer, affect and smoking status indicate that individuals have room for improvement in their understanding of risk for cancer. In addition to education, interventions need to address cancer-related worry to motivate appropriate health-related behaviors.

Strengths and limitations to this study should be noted. Only comparative perceived risk of cervical cancer was assessed. The study could be strengthened by having multiple assessments of perceived risk, examining short- and long-term risk and to whom they were comparing their own personal risk. Further, there was no assessment of personal or family history of cancer. These may play a role in individual's perceptions of risk although they do not seem to play as critical a role in objective risk as they do in other cancers. Further, a number of measures in the study were single items, such as worry. Additional items would have given a clearer picture of the role of negative affect in perceived risk. These concerns about assessment notwithstanding, having a longer survey would have likely decreased the response rate and would have been cost prohibitive for over 500 individuals. Another limitation is the cross-sectional nature of the study, making it difficult to know the direction of causality in the relationship between risk factors and perceived risk. Lastly, the sample included women who were regular patients at 14 clinics in Appalachia Ohio and, thus, were not a representative sample of women from Appalachia. Moreover, our cooperation rate

overestimates the response rate, again suggesting a biased sample. This is, however, an important first step in learning about risk perceptions of cervical cancer in the Appalachian population.

Conclusion

In sum, considering factors such as worry, knowledge, and past behaviors is critical in understanding how an individual perceives her risk of cervical cancer. Underserved women need to understand the risk factors for cervical cancer and how it influences their own personal risk. Understanding these relationships could be helpful to interventions to improve risk-appropriate health behavior, such as encouraging Pap Smear use. Although women did not report engaging in a number of risk factors associated with cervical cancer, smoking is very common in Appalachia, and women need to understand the link of smoking behavior to elevated cervical cancer risk. Finally, worry about cervical cancer and perceived risk of cervical cancer are closely related. Women high in worry with no objective risk factors need to understand that risk-adjusted Pap Smear screening is adequate, to avoid negative psychological sequelae and unnecessary use of health care services in the Appalachian region. Thus, interventions are needed to improve the understanding of factors that contribute to elevated risk of cervical cancer in underserved women both to increase healthy behavior and improve psychological well-being.

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Table 1

Characteristics of Participants by Perceived Risk of Cervical Cancer Risk in Appalachian Ohio 2005–2008
(n=543)

	Much/somewhat lower (n=137) Percentage Reporting	About the same (n=303) Percentage Reporting	Much/somewhat (n=103) Percentage Reporting
Self Factors			
Age **			
18–30	27.7	30.4	42.7
31–50	44.5	46.5	47.6
51	27.8	23.1	9.7
Education			
Less than High School (HS)	5.8	8.6	7.8
HS diploma or GED	35.8	36.3	30.1
> HS diploma	58.4	55.1	62.1
Race			
White	96.4	94.4	94.2
Other	3.6	5.6	5.8
Marital status			
Never married	12.4	18.1	21.4
Married member of couple	66.4	61.4	56.3
Divorced/widowed/separated	21.8	20.5	22.3
County of residence			
Rural	62.8	64.0	56.3
Urban	37.2	36.0	43.7
Poverty income ratio (n=517) **			
<1	17.1	27.8	27.3
1–1.99	23.1	28.8	42.4
2–2.99	26.2	13.9	11.1
3–3.99	19.2	17.0	9.1
4–4.99	6.9	7.6	6.1
5	6.9	4.9	4.0
Income category (n=517) *			
< \$20,000	23.9	35.8	40.4
\$20 – 50,000	44.6	35.4	41.4
> \$50,000	31.5	28.8	18.2
Medical Insurance (n=540) *			
Private insurance	68.2	62.9	49.5
Medicaid/Medicare	14.8	24.32	30.1
No coverage	17.0	12.9	20.4
Cognitive Factors			
Knowledge **			

	Much/somewhat lower (n=137) Percentage Reporting	About the same (n=303) Percentage Reporting	Much/somewhat (n=103) Percentage Reporting
Poor to Fair (–14 to 4)	25.6	27.1	14.5
Good (5 to 6)	20.4	20.1	28.2
Very good (7 to 8)	24.8	19.8	36.9
Excellent (9 to 14)	29.2	33.0	20.4
Beliefs about cervical cancer			
Negative	34.3	41.3	40.8
Positive	65.7	58.7	59.2
Barriers to getting a Pap (1–10) *			
Mean ± SD	1.7±1.3	1.6±1.3	2.1±1.4
Range	0–5	0–6	0–7
Affective Factor			
Worry about cervical cancer ***			
A lot	1.5	6.0	17.5
Some	23.3	30.0	46.6
Not at all	75.2	64.0	35.9
Risky Sexual Behaviors			
Age at first sexual intercourse (n=529) *			
< 18 years of age	53.0	62.2	71.3
18 years of age	47.0	37.8	28.7
Lifetime # partners (n=492) ***			
5 lifetime sexual partners	35.4	49.1	64.8
< 5 lifetime sexual partners	64.6	50.9	35.2
History of male sexual partners with a history of sex with other men (n=514)			
Yes	62	2.1	5.1
No	93.8	97.9	94.9
History of sexual intercourse in exchange for money (n=539)			
Yes	2.2	1.7	2.0
No	97.8	98.3	98.0
History of male sexual partners with a history of intravenous drug use (n=522)			
Yes	2.2	4.8	5.1
No	97.8	95.2	95.5
Condom use (n=527)			
Inconsistent use	84.7	82.7	82.4
Consistent use	15.3	17.3	17.6
History male sexual partners with an STI (n=495) *			
Yes	8.9	10.6	19.6
No	91.1	89.4	80.4
Personal history of STI (n=531) ***			

	Much/somewhat lower (n=137) Percentage Reporting	About the same (n=303) Percentage Reporting	Much/somewhat (n=103) Percentage Reporting
Yes	11.3	19.9	38.2
No	88.7	80.1	61.8
History of abnormal Pap (n=541) ***			
Yes	24.8	31.9	52.4
No	75.2	68.1	47.8
History of abortion (n=542) *			
Yes	6.6	8.0	15.5
No	93.4	92.0	84.5
Risky Sexual Behavior Index (n=411) **			
Low	39.2	32.6	16.5
Medium	30.4	31.7	29.1
High	30.4	35.6	54.4
Other Health Behaviors			
Within risk-appropriate Pap Smear guidelines (n=535)			
Yes	64.2	68.3	69.3
No	35.8	31.7	30.7
Smoking status (n=542) ***			
Never	68.6	48.0	47.6
Former	19.0	24.2	10.7
Current	12.4	27.8	41.7

* P<0.05:

** P<0.01:

*** P<0.001

Table 2

Final Multivariable Binary Logistic Regression Model With “Much Lower/About the Same” vs “Much/Somewhat Higher” as the Reference Category for the Outcomes (n=502)

Variables With Significant Associations	Much/Somewhat Higher
Knowledge ***	
Poor to fair (–14 to 4)	1.0
Good (5 to 6)	2.54 (1.21–5.33)
Very good (7 to 8)	3.32 (1.63–6.77)
Excellent (9 to 14)	1.03 (0.48–2.23)
Worry about Cervical Cancer ***	
Not at all	1.0
Some	2.41 (1.43–4.06)
A lot	5.97 (2.60–13.7)
Personal History of STI ***	
No	1.0
Yes	2.38 (1.38–4.09)
History of Abnormal Pap **	
No	1.0
Yes	1.71 (1.02–2.85)
Smoking Status **	
Never	1.00
Former	0.47 (0.22–0.99)
Current	1.27 (0.75–2.15)

**
P<0.05

***
P<0.01