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A Community–Academic Partnership to Increase Pap Testing in Appalachian Kentucky

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Abstract

Introduction—Appalachian Kentucky is recognized for elevated rates of cervical cancer, which exerts an undue burden in this medically underserved region. The purpose of this study was to examine the impact of an academic–community partnership, specifically a regional health department and a CDC Prevention Research Center, in conducting outreach aimed at improving Pap testing rates and examining barriers among under-screened women in Appalachian Kentucky. Differences between women with abnormal and negative results were also examined.

Methods—The Prevention Research Center provided technical assistance to the district health department that, in turn, hosted “Women’s Health Day” events at county health departments, providing incentives to women who had never had a Pap test or those who had not received one in at least 3 years to receive guideline-recommended screening.

Results—From 2011 to 2014, 317 women were screened for cervical cancer; data were analyzed in 2014. The mean age was 42.1 (SD=13.6) years. More than half (54.5%) of the sample reported high school as their highest level of education, and 57.7% had an annual household income of < $25,000. The most commonly reported barriers to Pap testing were cost (28.4%) and lack of a perceived need for screening (25.6%). Approximately one in five (21.7%) women received abnormal Pap results.

Conclusions—As a result of this community–academic public health partnership and its shared resources, Appalachian Kentucky women received needed cervical cancer screening and appropriate follow-up for abnormal results, thereby increasing this population’s compliance with guideline-recommended screening.

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Introduction

Screening women for precancerous changes of the cervix via Pap testing has made cervical cancer one of the most preventable cancers in the U.S.[1,2] Cervical cancer incidence and mortality rates continue to decrease annually in the U.S., yet an estimated 12,900 new cases and 4,100 related deaths will occur in 2015.[3,4] The enduring burden of cervical cancer in the U.S. may be a result of the lack of adherence to recommended screenings, as screening rates have remained below national goals.[5,6] For instance, low-income, medically underserved populations have consistently been under-screened for cervical cancer, including women in Appalachia.[7,8] Appalachian women receive cervical cancer screenings less frequently than their non-Appalachian counterparts,[8–10] which has been linked to screening barriers, including geographic isolation, cost, lack of insurance, and limited access to medical care.[8,11–16]

Lower screening rates in Appalachia is disconcerting given the elevated cervical cancer incidence and mortality in this region;[11,13,16,17] these cancer disparities are further amplified in Kentucky.[16–18] Kentucky Cancer Registry data indicate that Appalachian-designated counties reported higher cervical cancer incidence rates (9.5 per 100,000) than the rest of the state (8.4) from 2007 to 2011.[19] Moreover, cervical cancer screening rates in Appalachian Kentucky are also lower than in other parts of Appalachia.[10] Previous studies in Appalachian Kentucky found that more than 30% of women reported to be rarely (i.e., have not been screened within the past 5 years) or never screened for cervical cancer;[9,20] in comparison, roughly 10% of U.S. women report to be rarely or never screened.[21]

To assist underserved women at risk for developing cervical cancer, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides funding to local and state health departments for the implementation of screening programs. These programs aim to remove screening barriers, such as cost and access to care, by providing Pap testing and follow-up care at little to no cost.[22] Despite the availability of such programs, many underserved women are not utilizing them; from 2010 to 2012, less than 7% of NBCCEDP-eligible women took part in the program.[23] Low participation rates highlight the need for enhanced promotional efforts to reach program-eligible women, including the identification and characterization of women at risk for abnormal results.

To identify additional screening barriers and enhance awareness of existing screening programs for underserved women, efforts have increasingly focused on the development of academic–community partnerships.[24] Partnerships enhance the ability of communities to meet screening needs with collective resources and increased capacity;[25] they also serve as a mechanism for community-engaged research, which integrates evidence-based health promotion practices with extensive community knowledge.[26] Ultimately, findings can be used to implement sustainable solutions that meet a community's distinctive needs.[27,28] Such partnerships have been used in cervical cancer screening research in Appalachia focusing on faith-based organizations, utilization of lay health navigators, and adherence to follow-up services.[12,14,15,29] The purpose of this study was twofold:

1. to examine the impact of an academic–community partnership, specifically a regional health department and a CDC Prevention Research Center (PRC), in

conducting outreach aimed at improving cervical cancer screening rates and examining barriers among under-screened women in a rural Appalachian area; and

2. to determine whether differences existed between women with an abnormal result and those with a negative result, as differences could potentially guide targeted efforts directed at women likely to have early-stage cervical cancer.

Methods

Academic–Community Partnership

In 2010, the University of Kentucky (UK)—with funding from the CDC PRC program—formed the Rural Cancer Prevention Center (RCPC), which aims to address cancer disparities in a medically underserved, high-poverty area in Appalachian Kentucky. To inform actions within the community, the RCPC recruited local constituents for its Community Advisory Board (CAB), which consists of Kentucky River District Health Department (KRDHD) staff, cancer survivors, lay citizens, and representatives from local schools, faith-based organizations, and civic groups.

In 2011, a CAB member suggested that KRDHD host “Women’s Health Day” (WHD) events at each of its seven clinics. During these events, women who were due for a guideline-recommended cervical cancer screening would be offered free Pap testing, as previous evaluations revealed that many women in the area were guideline discordant (D Neace, KRDHD, personal communication, 2014). The events would also be used to promote and enroll women into the NBCCEDP-funded Kentucky Women’s Cancer Screening Program (KWCSP). CAB members were supportive of the proposal, and a collaborative agreement between the RCPC and KRDHD was established. The health department managed project implementation, survey development, participant recruitment, KWCSP promotion and enrollment, and data collection. Given the lower socioeconomic characteristics of the catchment area’s population,[30] most of the WHD participants were eligible for free screening and follow-up services via the cancer screening program. Therefore, the majority of WHD-related costs were covered by program funding; the health department covered screening and follow-up services for women ineligible for KWCSP. The RCPC was responsible for assisting with promotional activities, data analysis, results dissemination, and participant incentives. The study protocol was approved by the UK and Kentucky Cabinet for Health and Family Services IRB.

Participant Recruitment

Prior to WHD, health department staff promoted the event during patient visits, advertisements were placed in local newspapers, and announcements were made on local radio stations. The health department hosted 29 of these events from October 2011 to May 2014. To participate in the project, women had to be aged 18–65 years, eligible to receive health department services, and self-report not ever receiving a Pap test (classified as never screened) or within the past 3 years (classified as rarely screened). Women were not eligible to participate if they were currently pregnant, had a hysterectomy, or were previously diagnosed with cervical cancer.

The WHD events began prior to the 2012 U.S. Preventive Services Task Force (USPSTF) cervical cancer screening guideline revisions.[31] Accordingly, KRDHD followed 2003 USPSTF guidelines, which recommended screening within 3 years of sexual debut or at age 21 years, whichever came first, and routine screening at least every 3 years.[32] KRDHD decided to follow the 2003 recommendations for the duration of the events to maintain continuity of the project. Thus, women aged 18–20 years were eligible for participation, and women outside of recommended guidelines (i.e., had not been screened within the past 3 years) were classified as rarely screened.

Women's Health Day Activities

At these events, health department staff provided education on women's health issues and screenings, including diabetes and mammography; staff also identified attendees who were overdue for a Pap test and verbally recruited eligible women for the project. Those agreeing to participate were given an IRB-approved cover letter explaining the purpose of the project and an eight-question survey to complete. The survey assessed sociodemographics, primary barrier(s) to screening, and motivation(s) for requesting a Pap test. After completing the survey, women received a $20 gift card for their time and were given the opportunity to receive a Pap test from health department nurse practitioners at no cost.

Patient Navigation and Follow-up Care

Pap test results and information on screening recommendations were mailed to each participant. Letters detailing abnormal results requested that women call the health department within 4 working days to schedule a follow-up appointment; non-responders were subsequently sent a certified letter. Health department staff conducted home visits for non-responders if their results indicated advanced dysplasia or precancerous or cancerous cells. Women requiring follow-up care were offered navigation, including assistance with scheduling diagnostic testing appointments and enrollment in the cancer screening program, if needed. The health department provided all navigation; follow-up care was provided by health department–contracted gynecologic providers.

Statistical Analysis

Data analyses consisted of basic frequencies for the eight-item survey, Pap testing results, and reported follow-up care for those with abnormal results. To determine whether differences existed between women with an abnormal result and those with a negative result, bivariate analyses were conducted. This analysis included basic sociodemographic characteristics, reported barriers to Pap testing, and self-reported motives for Pap testing at WHD. All analyses were conducted in 2014 using SPSS, version 22.0.

Results

During WHD events, 317 women who self-reported to be rarely or never screened for cervical cancer participated in the project. As presented in Table 1, the majority of women were aged 26–55 years (64.1%), with a mean age of 42.1 (SD=13.6) years. Project participants, in comparison to U.S. Census estimates (2009–2013) for women in the

catchment area, reported higher education levels (84% vs 75.7%, high school degree or higher) and lower household incomes (57.7% vs 42.2%, income of ≤$25,000).[30]

As shown in Table 2, the most commonly reported Pap testing barriers were cost (28.4%); lack of perceived need for screening (25.6%); and lack of transportation (11.0%). Other reported barriers related to fear of test results (9.1%); lack of time or not taking the time to engage in screening (8.8%); and dislike of the screening process, which some women perceived to cause pain, discomfort, fear, or embarrassment (5.7%). In addition, almost 8% of participants reported other screening barriers (e.g., preference for a female healthcare provider, lack of parental support); three-quarters of women indicated one primary barrier to screening (75.4%).

The most commonly reported motives for Pap testing at WHD were referrals from a healthcare provider or health department (25.6%); experiencing problems or symptoms (17.0%); and the perceived need to have a Pap test (11.7%). Women also reported that having a family member or friend with a previous cancer experience (9.8%) and receiving a gift card (8.5%) motivated their participation; almost all women reported one primary motive for participating in screening (90.9%).

Nearly 80% of women received a negative result (i.e., negative for intraepithelial lesion or malignancy). However, as presented in Table 3, 68 women (21.7%) received an abnormal test result. The most frequent abnormal results were atypical squamous cells of undetermined significance (22 women, 7.0%) and low-grade squamous intraepithelial lesions (21 women, 6.7%); one woman tested positive for squamous cell carcinoma. Health department Pap testing logs indicated that 16 women with abnormal results received some form of navigation or follow-up care, consisting of colposcopy or gynecologist referrals (five women); colposcopy (ten women): or loop electrosurgical excision procedure (one woman). Bivariate analyses determined no significant differences between Pap test result groups (i.e., negative or positive) in regard to demographics, with the exception of age (p=0.001). Women aged 18–25 years were more likely to receive positive test results than women aged 45–65 years; women aged 26–45 years also were more likely to receive a positive test result than women aged 56–65 years. Cost was found to be the only significant screening barrier (p=0.034); those with negative results were more likely to report cost as a primary barrier. No reported motivators reached statistical significance.

Discussion

The WHD events allowed rarely or never-screened women to receive much-needed Pap testing services. Notably, more than 20% of participants had an abnormal Pap test result, with one woman being diagnosed with cervical cancer. The significant findings regarding age and screening results mirror previous findings, as abnormal results tend to be more common among younger women owing to the higher prevalence of human papillomavirus.[33,34] Although younger women are more likely to have abnormal results, women older than 30 years are more likely to develop cervical cancer.[35] Women older than 30 years should continue to be targeted because of their increased risk for invasive disease. Nearly 25% of women with abnormal screening results received navigation to follow-up

care. Lack of appropriate follow-up care after an abnormal screening has been previously documented among women enrolled in public programs (e.g., Medicaid, NBCCEDP), with follow-up rates ranging from 10.1% to 31.5% in a recent study involving Medicaid enrollees.[34,36] Women's eligibility for such programs frequently changes and may lead women to receive follow-up care elsewhere, thus not allowing for accurate documentation of services.[34] Some women may also choose to forego follow-up services even if navigation is offered. Moreover, those with less serious test results may only need more-frequent screenings rather than further navigation.[35] In this case, follow-up information may not have been explicitly documented. Of note, many of the women with more-serious abnormalities were among those successfully navigated for additional care.

Many of the Pap testing barriers reported by WHD participants (e.g., cost, lack of perceived need for screening, lack of transportation) reinforced previous findings regarding screening barriers in Appalachia.[9,20,37,38] Screening costs were found to be a significant barrier for women in the project, despite their testing outcome. With more than half reporting an annual household income of less than $25,000, this finding reflects previous results suggesting that costs remain a primary barrier for rural women.[8,9] Interestingly, women with negative Pap test results were significantly more likely to report cost as a primary barrier to screening; further investigation of this unique finding is warranted.

Of particular importance is the lack of perceived need for screening among this population. Decreased risk perceptions may contribute to the belief that cervical cancer screening is only needed when physical symptoms occur, which is a common misperception among rural and Appalachian women.[20,38–40] However, this belief is also found in other populations; in a recent systematic review, nearly 12% of included studies reported results involving the belief that screening is only needed in the presence of physical symptoms.[41] One of the primary motives for Pap testing in this project was the occurrence of problems or symptoms; this suggests that further education about cervical cancer, specifically established risk factors and symptoms, may be warranted.[38,40,42]

As previously noted, women in the project reported lower household incomes, yet higher education levels compared with Census data for the catchment area. Higher education levels have been found to be correlated with participation in Pap testing across varying populations.[43] Despite higher educational attainment, women in the project may have been guideline discordant prior to WHD because of reported screening barriers, such as cost and lack of perceived susceptibility. WHD events may have helped women overcome these barriers by providing accurate information on cervical cancer risk, free onsite Pap testing services, and participation incentives. Among this sample of guideline-discordant women, three fourths reported only one primary barrier to screening, suggesting that minimal but strategic effort may be needed to remove these barriers. Increased promotion of existing screening programs through targeted partnerships and special events are viable strategies to encourage participation in cervical cancer screenings.[25,44] Special events, such as WHD, provide health-related education to attendees and facilitate the removal of screening barriers.[45] WHD events also serve as a sustainable model for increasing the reach of existing screening programs by promoting awareness and uptake of cervical cancer screening with

very few associated costs. Beyond incentive funds, existing staff and KWCSP funding were redistributed to cover event costs.

Notably, many participants were established health department patients and had a medical home in which to receive recommended screenings, yet they were guideline discordant. Although an increase in baseline screening rates cannot be determined, findings suggest that women participated in screenings that they were otherwise not engaging in; women may have remained guideline discordant without the removal of screening barriers provided by the WHD events. Thus, rural Appalachian women who are guideline discordant may need targeted inventions, such as special events, in order to encourage participation in routine cervical cancer screenings. According to the Community Preventive Services Task Force, there are still research gaps regarding effective cervical cancer screening intervention strategies.[46] Although special events have been commonly used to promote cancer screening, there remains insufficient evidence to determine their true impact on screening rates.[45] The study findings contribute to the existing literature by providing additional evidence that targeted interventions, such as special events, can encourage guideline-discordant women to participate in cervical cancer screenings.

Limitations

Owing to the cross-sectional nature of the survey, no causal inference can be established between barriers and motives. Because this study used a convenience sample, project findings may not be generalizable to women residing in other parts of rural Appalachia. Selection bias may also be present, as women who participated in the project may differ from rarely and never-screened women who did not participate. The participation rate could not be determined because neither data regarding the number of women eligible for participation nor the number of women who refused to participate were collected. Pap testing history was self-reported; thus, reported years since last Pap test may be inaccurate.

Conclusions

As advocated by Mays and Scutchfield,[47] coordinated, well-defined partnerships are needed to improve public health outcomes. The academic–community partnership between KRDHD and RCPC is an example of a successful public health collaboration that led to increased promotion of an existing screening program and uptake of Pap testing services among rarely and never-screened women in Appalachian Kentucky. Such collaborations will be needed in the future to continue addressing cancer disparities in Appalachia and beyond.

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Table 1

Participant Characteristics (N=317)

Characteristic	***n* (%)**
Age (years)	
18–25	51 (16.1)
26–45	120 (37.9)
46–55	83 (26.2)
56–65	63 (19.9)
Education (*n*=308)	
<High school	49 (15.9)
High school graduate or GED	168 (54.5)
≥Some college	91 (29.5)
Income (*n*=310)	
<$25,000	179 (57.7)
$25,000–$50,000	72 (23.2)
>$50,000	59 (19.0)
Number of people in household (*n*=316)	
1–3	219 (69.3)
≥4	97 (30.7)

Table 2

Reported Barriers and Motives for Pap Testing (N=317)

Barriers and motives	***n*** **(%)**
Primary barrier(s) to Pap testing[a]	
Could not afford it	90 (28.4)
No transportation	35 (11.0)
Didn't feel I needed it	81 (25.6)
Husband would not let me	2 (0.6)
Afraid to hear the results	29 (9.1)
Did not have the time/take the time	28 (8.8)
Do not like it (i.e., painful, uncomfortable, afraid, embarrassing)	18 (5.7)
Other	24 (7.6)
Primary motivation(s) for requesting Pap test[a]	
Referred by healthcare provider/health department	81 (25.6)
Received information from the RCPC	18 (5.7)
Change in marital status	12 (3.8)
Having problems (symptoms)	54 (17.0)
Family member or friend with cancer experience	31 (9.8)
Ad in newspaper	5 (1.6)
Time for Pap test/knew I needed to get it done	37 (11.7)
Birth control	20 (6.3)
Family/friend encouraged me	17 (5.4)
Gift card/Door prize	27 (8.5)
Other	33 (10.4)

[a]Multiple responses provided; percentages may add up to ≥100% RCPC, Rural Cancer Prevention Center.

Table 3

Participant Pap Test Results (*n*=314)

Result	***n* (%)**
Negative	246 (78.3)
Abnormal	68 (21.7)
Atypical glandular cells	4 (1.3)
Atypical squamous cells of uncertain significance (ACS-US)	22 (7.0)
Atypical squamous cells, cannot exclude high-grade squamous intraepithelial lesion (ASC-H)	10 (3.2)
Low-grade squamous intraepithelial lesions (LSIL: CIN I, HPV)	21 (6.7)
High-grade squamous intraepithelial lesions (HSIL: CIN II, CIN III, CIS)	10 (3.2)
Squamous cell carcinoma	1 (0.3)