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Accuracy of Self-Reported Abnormal Pap Smears among Reproductive-Age African-American Women

Kristen R. Moore¹ and Donna D. Baird¹

¹Epidemiology Branch A3-05, National Institute of Environmental Health Sciences, Research Triangle Park, NC 27709, USA

Abstract

Background: Self-reported history of abnormal Pap smear is used in large public health surveys. However, literature on the accuracy of this reporting is limited. We sought to assess the validity of self-reported abnormal Pap history in a community-based sample of African-American women ages 24-37 in the Detroit, Michigan area, recruited from 2010 to 2012.

Methods: We compared self-reported data on 2-year history of abnormal Pap smear to medical Pap record data (the gold standard) obtained from eligible participants. Sensitivity and specificity were evaluated to summarize the accuracy of the self-reported data. We also explored the sensitivity by severity of abnormality.

Results: We identified 345 participants with 480 eligible Pap records. Thirty-five percent of abnormal Pap results were not identified by self-report (sensitivity/specificity: 65%/91%; kappa=0.54). The sensitivity of reporting an abnormal Pap tended to be higher for those with a more severe abnormality.

Conclusions: A large proportion of abnormal Pap smears were not identified by self-report in this sample of African-American women. Public health studies utilizing self-reported abnormal Pap information should be interpreted with caution.

Keywords

abnormal Pap smear; self-report; sensitivity; specificity

INTRODUCTION

Prior research examining the accuracy of self-reported recent Pap smear utilization found high sensitivity, but low specificity.¹ However, literature on the accuracy of self-reported abnormal Pap smear results is limited^{2–6}, especially among African-Americans.^{2,4,5} Self-reported history of abnormal Paps is used in large public health surveys such as the National Survey of Family Growth⁷ and studies of cervical cancer and other conditions where

Correspondence: Kristen R. Moore, PhD, Epidemiology Branch A3-05, National Institute of Environmental Health Sciences, Research Triangle Park, NC 27709 [PH: 984-287-3751; E-mail: kristen.moore@nih.gov].

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medical record retrieval is not feasible due to time and expense. Thus, it is important to better understand the validity of these data, especially among African-American women who have the greatest burden of cervical cancer in the US⁸ and may be less likely to provide accurate self-reported information^{9,10}. Previous studies including African-American women have only been among adolescents^{2,4} or cervical cancer cases.⁵

The aim of this study was to assess the validity of self-reported abnormal Pap history among African-American women of reproductive age (Pap smears are recommended starting at age 21 years)¹¹ in a community-based study. Self-reported history of abnormal Paps from questionnaire data was compared with medical Pap record data.

METHODS

We used data from the Study of Environment, Lifestyle, and Fibroids (SELF), a prospective study on fibroid growth and development among a community-based volunteer sample of 1,693 23-34 year-old African-American women in the Detroit, Michigan area.¹² Women were not eligible for SELF if they had previously been diagnosed with uterine fibroids; had a hysterectomy; had ever taken medication to treat lupus, Graves disease, Sjogren scleroderma, or multiple sclerosis; or ever had any type of cancer treated with radiation or chemotherapy. Starting in December 2010, recruitment materials were distributed throughout the Detroit area, primarily composed of targeted letters, a website, media announcements (local radio, televisions, newspaper, and magazine), flyers, brochures at health clinics, and booths at community events. The follow-up visit was approximately 20 months later, starting in 2012. Information on Pap smears was collected at follow-up using a self-administered questionnaire; the women were 24-37 years of age. Three Pap smear questions were included:

1. Have you had a Pap exam in the past two years? (yes, no)
2. How many Pap exams have you had in the past two years (1, 2, More than 2)
3. Have any results come back abnormal? (yes, no); Where did you have your most recent Pap exam? (Henry Ford Clinic, somewhere else, specify).

Medical Records

For this analysis, eligible Pap records were dated within 2 years before the date of the questionnaire and were among participants who had a signed consent form, had a questionnaire completed before 5/30/2014 (date of record retrieval), reported "Yes" to having had a Pap smear on their questionnaire, and reported the location of their most recent Pap as "HFHS" (see Figure 1). All eligible Pap records retrieved from our collaborating institution, Henry Ford Health System (HFHS) were included. Records reporting atypical squamous cells of undetermined significance (ASCUS), atypical squamous cells- cannot exclude HSIL (ASCH), low-grade squamous intraepithelial lesion (LSIL), or high-grade squamous intraepithelial lesion (HSIL) were considered abnormal. Records noting "negative for malignant cells" were considered normal. Participants gave written informed consent. The study was approved by the institutional review boards of the National Institute of Environmental Health Sciences and Henry Ford Health System.

Data Analysis

We first summarized the sociodemographic characteristics of the sample. Contingency tables were used to compare the self-reported and Pap record information (the gold standard). The following measures of agreement were evaluated to summarize the accuracy of the self-reported abnormal Pap data with respect to the abnormal Pap results in medical records: kappa¹³, sensitivity, positive predictive value (PPV), specificity, and negative predictive value (NPV). We also explored the sensitivity by severity of abnormality to determine if participants with more severe abnormalities had more accurate reporting. For participants with >1 abnormal Pap record and different types of abnormalities, we evaluated the highest-grade abnormality (HSIL>LSIL>ASCH>ASCUS).

Measures were computed for the entire sample and for a sensitivity analysis on a subsample of records that were considered “clean”. To obtain the clean sample (N=188), we excluded participants whose self-reported number of Pap smears in the 2 years before the date of reporting was not equivalent to the number of Pap records retrieved (n=151, 44%). These participants could have had an abnormal Pap at a location other than HFHS, resulting in missing records. Also, because excessive inflammation can obscure Pap results, we excluded participants who only had records with “limited satisfactory for evaluation due to excessive inflammation” (n=6, 2%). Thus, we excluded 157 participants total. For all analyses, Pap record data where specimens were not satisfactory for evaluation were coded as missing.

RESULTS

In total, 345 participants were eligible with 480 total Pap records (2 of 480 were coded as missing). At follow-up, the median age of participants was 31 years and most completed at least some college (90%). Thirty-seven percent (n=125) of participants had more than one eligible Pap record in the 2 years before the date of reporting. Seventeen percent (n=57) of eligible participants had at least one abnormal Pap, and 18% (n=62) self-reported an abnormal Pap on their questionnaire.

Agreement by kappa was 54%. The sensitivity of 65% indicates that 35% of abnormal Pap results were not identified by self-report (Table 1). Specificity was higher (91%), indicating that most women whose medical records indicated normal Pap results reported correctly. The NPV of 93% indicates that 7% of those reporting normal Pap results actually had an abnormal result. The sensitivity of reporting an abnormal Pap tended to be higher for those with a more severe abnormality (71%, 95% confidence interval (CI): 0.53, 0.89 for LSIL/HSIL vs. 61%, 95% CI: 0.44, 0.77 for ASCUS/ASCH). The results for the clean sample were very similar to those for the full sample (Table).

DISCUSSION

In our community-based sample of African-American women of reproductive age, we found that self-reported data missed approximately a third of the women with an abnormal Pap result in their medical records. However, women with more severe results were more likely to accurately report an abnormal Pap, but 29% were still missed.

Literature on self-report accuracy of abnormal Pap in African-American women is limited to adolescents ^{2,4} and cervical cancer cases. ⁵ The study among African-American women with cervical cancer found extremely poor (slight) agreement ($\kappa=0.08$; sensitivity =55% [computed from data in publication]) for abnormal Pap within 3 years of their diagnosis excluding the year of diagnosis. ⁵ A study of 477 young African-American women (mean age 18 years) from a hospital-based urban clinic showed better agreement ($\kappa=0.66$) with a sensitivity of 79% and specificity of 89% ⁴, most likely due to the short recall period (the median interval since previous Pap was 43 days). Another study among adolescent girls (12-15 years; 76% African-American) from an urban clinic in the US found only fair agreement between report of abnormal Pap and documented dysplasia (no sensitivity reported; $\kappa=0.40$). ²

Our study has limitations. Study participants are from a single locale, potentially limiting generalizability. The questionnaire only asked about Pap history for the past 2 years; however, using this short interval should minimize recall bias. Participants were only asked about their most recent Pap location; thus, people who reported an abnormal Pap, but none was found in their record, could have had an abnormal Pap at a location other than HFHS, but the clean sample minimized this concern.

The analysis also had strengths. We investigated the validity of self-report of abnormal Pap with medical Pap record data in a large community-based sample of reproductive-age African-American women, a high-risk ethnic group. In addition, we conducted a sensitivity analysis with a clean subsample of participants who had the same number of Pap records as self-reported Pap smears, thus minimizing possible bias from missing records.

PUBLIC HEALTH IMPLICATIONS

Overall, we found that a large proportion of abnormal Paps were not identified by self-report among this community-based sample of reproductive-age African-American women. However, there was somewhat better reporting as severity of cervical abnormality increased. Public health studies that utilize self-reported abnormal Pap information should be interpreted with caution.

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Figure 1.
Flow Chart of Eligible Participants from the Study of Environment, Lifestyle and Fibroids (SELF), Detroit, MI Metropolitan Area
HFHS, Henry Ford Health System

Table 1.

Comparison of Abnormal Pap Results Based on Self-Report and Pap Record Data in both the Full and Clean Sample among 24-37 Year-Old, African-American Women in the Study of Environment, Lifestyle and Fibroids (SELF), Detroit, MI Metropolitan Area

Abnormality in Medical Record			
Self-Reported Abnormality	Yes	No	Total
Full Sample			
Yes	37	25	62
No	20	263	283
Total	57	288	345 Participants
Clean Sample			
Yes	19	8	27
No	10	151	161
Total	29	159	188 Participants

Kappa	Sensitivity	Specificity	PPV	NPV
	(95% CI)	(95% CI)	(95% CI)	(95% CI)
Full 0.54 95% CI (0.43, 0.66)	37/57=65%	263/288=91%	37/62=60%	263/283=93%
	(0.53, 0.77)	(0.88-0.95)	(0.47-0.72)	(0.90-0.96)
	19/29=66%	151/159=95%	19/27=70%	151/161=94%
Clean ^a 0.62 95% CI (0.46, 0.78)	(0.48, 0.83)	(0.92, 0.98)	(0.53, 0.88)	(0.90, 0.98)

CI, confidence interval; NPV, negative predictive value; PPV, positive predictive value

^aExcluded data from participants whose self-reported number of Pap smears was not equivalent to the number of Pap records retrieved and who only had records with excessive inflammation