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# Pain predicts non-adherence to pap smear screening among middle-aged African American women

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#### Abstract

*Background.* Middle-aged African American women have the highest incidence and mortality of invasive cervical cancer in the United States and the lowest adherence to pap smear screening.

Methods. In 2001, we identified factors associated with non-adherence to screening recommendations using three focus group interviews and subsequently developed a questionnaire administered to 144 African American women aged 45 to 65 years.

Results. The perception that the Pap test was painful was associated with non-adherence to screening recommendations (OR = 4.78; 95%CI: 1.67–13.7). Difficulty to pay for the office visit coupled with perceived pain was associated with a nearly sixfold increase in risk of non-adherence (OR = 5.8; 95%CI: 2.8–15.5). Previously identified barriers to screening including lower education and socioeconomic status, poor access to care, knowledge of and exposure to known risk factors of invasive cervical cancer, cancer fatalism, and perceived racism were not independently associated with non-adherence.

Conclusions. These data suggest that, among middle-aged African American women, future interventions addressing pain during a Pap test will likely increase acceptability of and adherence to cervical cancer screening. Pain could be addressed either by providing information during the pap test and/or using smaller lubricated speculums.

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### Introduction

In the United States, an estimated 13,000 cases of invasive cervical cancer are diagnosed each year, with more than 4,100 deaths reported [1]. Despite overall declines in the last 20 years, invasive cervical cancer-related morbidity and mortality are higher in African American women when compared to Caucasian women, and this disparity increases with age [1,2]. Although Caucasians and African Americans have similar incidence rates at younger ages, Caucasian women experience a gradual decline in incidence after age

45, whereas cervical cancer incidence in African American women increases with age, peaking at 45 and again, after 80 years of age [3]. Similar patterns are evident for cervical cancer mortality, with the largest peak at 50–75 years [3]. Differences in risk factors such as cigarette smoking [4–7], higher gravidity [7,8], and differences in immune response to infection with oncogenic subtypes of human papillomavirus [9] have been proposed as reasons for higher incidence among African American women. Higher mortality among African American women has been attributed to a lower prevalence of screening resulting in delayed diagnosis and treatment.

Because screening for precursor lesions has been shown to decrease invasive cervical cancer in populations where screening prevalence is high and intervals between screens

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are regular [10,11], a combination of patient education [12–14], screening, and treatment for precursor lesions has become the mainstay of most cervical cancer control programs [15]. Adherence to screening recommendation among African Americans is similar to that of Whites overall; however, this utilization of Pap tests among African Americans is limited to younger women [3,16]. Among African American women older than 40 years, adherence to screening is low and corresponding invasive cervical cancer incidence and subsequent mortality are high [3].

Reasons for non-adherence to recommended screening have been an active topic of debate. Socioeconomic and demographic factors, including age, race, low income, inner-city residence, lack of health insurance coverage, and low educational status, have previously been shown to predict low adherence to Pap smear screening [12,13,17–30]. This suggests that non-adherence may be attributable in part to poor knowledge about the benefits of screening and poor access to care. The last two decades have seen an increase in mass education both in urban [12] and rural areas [14] and reductions in financial barriers with Pap tests covered by the majority of health insurance plans including Medicaid. Despite these reductions in financial and educational barriers, racial disparities in cervical cancer screening have persisted.

Recent studies have reported a moderate to strong association between non-adherence to recommended screening and patient obesity [31], or lack of physician recommendation to screen [25]. The mechanism underlying the relationship with obesity is unknown, although obese patients may be difficult to examine or physicians may be less likely to recommend screening among obese patients. It is also unclear whether disparities in cervical cancer screening have decreased due to physician awareness of the role of these barriers. To identify additional barriers, formative focus group interview discussions were conducted among middle-aged African American women. Based on these findings, a cross-sectional study to determine their association with non-adherence was designed. This report summarizes results of the cross-sectional study conducted among middle-aged African American women.

#### Methods

Identification of potential barriers using focus groups

An initial qualitative assessment of barriers to Pap smear screening in African American women was conducted via three focus groups comprising 6 to 10 participants per group. Participants, who were recruited by three Lay Health Advisors (LHAs), were women who had previously been identified for other community projects conducted among a church congregation, a university–community liaison group, and employees of North Carolina Central University. To be eligible, women had to be African American, aged 45 to 64

years, and living in Durham County, North Carolina. The focus group interview comprised five open-ended questions aimed at identifying barriers associated with non-adherence to screening for cervical cancer. Emerging themes were identified using qualitative analysis software, NUD\*IST v.4 (QSR International, Melbourne, Australia).

Results from the focus group interviews confirmed previously identified barriers to cervical cancer screening: poor access to health care, a failure to understand the benefits of screening, perceived racism by health care providers, and fatalism stemming from a perceived lack of social support networks in case of illness. Similar to a recent cross-section study [32], women also reported that physical discomfort or pain during a Pap test, particularly among those no longer sexually active, was an important barrier to screening. Findings from these focus group and from previous studies identified were used to design a standardized questionnaire for the cross-sectional study. Analyses reported here were aimed at determining the extent to which perceived pain was associated with non-adherence to cervical cancer screening in a convenience sample of middle-aged African American women.

## Accrual of participants for cross-sectional study

Inclusion criteria for the cross-sectional study were similar to those used for the focus group interviews. To be included, women had to be African American, aged 45 to 64 years, and live within the geographic area of Durham County. The same LHAs recruited participants from six congregations and five community subdivisions during a 6month period (September 2001-March 2002). Participants were recruited using flyers distributed at congregational or community-sponsored events, including Partners Against Crime meetings. Participants received US\$10 as compensation for their time. Women who had participated in focus group interviews were not eligible for the cross-sectional study. Participants were interviewed in person by a trained interviewer using the standardized questionnaire that was developed from focus group interviews. Data were entered and verified in EPIINFO version 6.4, (CDC, Atlanta, GA, USA) before conversion to SAS, v.8, (Cary, NC, USA) for statistical analyses. This study was approved by the Institutional Review Boards at North Carolina Central University and Duke University Medical Center.

#### Data collection

Adherence to Pap smear, the study outcome, was defined as a self-reported history of a Pap test within the 3 years preceding the interview. Pain or discomfort during Pap test, the main exposure, was a dichotomous (yes/no) response to the question 'It hurts to have a Pap smear'. Women were also asked to rank the severity of pain perceived on a 10-point scale. Potential covariates included the following factors identified in previous studies and during focus group inter-

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