HHS Public Access

Author manuscript

J Cancer Educ. Author manuscript; available in PMC 2016 June 01.

Published in final edited form as:

J Cancer Educ. 2015 June ; 30(2): 213–219. doi:10.1007/s13187-014-0688-9.

Cervical cancer prevention knowledge and abnormal Pap test experiences among women living with HIV/AIDS

Lisa T. Wigfall, PhD[1,2], **Shalanda A Bynum, PhD, MPH**[3], **Heather M. Brandt, PhD, CHES**[4,5], **Daniela B. Friedman, MSc, PhD**[4,5], **Sharon M. Bond, PhD, CNM**[6], **Gweneth B. Lazenby, MD, MSCR**[7], **Donna L. Richter, EdD, FAAHB**[4], **Saundra H. Glover, PhD, MBA**[1,2], and **James R. Hébert, ScD**[5,8]

[1]Department of Health Services Policy and Management, Arnold School of Public Health, University of South Carolina, 915 Greene Street, Columbia, SC 29208, USA

[2]Institute for Partnerships to Eliminate Health Disparities, Arnold School of Public Health, University of South Carolina, 220 Stoneridge Drive, Suite 103, Columbia, SC, 29210, USA

[3]Department of Preventive Medicine and Biometrics, F. Edward Hébert School of Medicine, Uniformed Services University of the Health Sciences, 4301 Jones Bridge Road, Bethesda, MD 20814, USA

[4]Department of Health Promotion, Education, and Behavior, Arnold School of Public Health, University of South Carolina, 915 Greene Street, Columbia, SC 29208, USA

[5]Statewide Cancer Prevention and Control Program, Arnold School of Public Health, University of South Carolina, 915 Greene Street, Columbia, SC 29208, USA

[6]College of Nursing, Medical University of South Carolina, 99 Jonathan Lucas Street, Charleston, SC 29425, USA

[7]Department of Obstetrics and Gynecology, College of Medicine, Medical University of South Carolina, 96 Jonathan Lucas Street, Charleston, SC 29425, USA

[8]Department of Epidemiology and Biostatistics, Arnold School of Public Health, University of South Carolina, 915 Greene Street, Columbia, SC 29208, USA

Abstract

Background—Cervical cancer prevention knowledge deficits persist among women living with HIV/AIDS (WLHA) despite increased risk of developing cervical dysplasia/cancer. We examined associations between WLHA's cervical cancer prevention knowledge and abnormal Pap test history.

Methods—We recruited 145 urban and rural WLHA from Ryan White-funded clinics and AIDS service organizations located in the southeastern United States between March 2011 and April 2012. For this analysis, women who reported a history of cervical cancer (n=3) or had a complete

Corresponding Author: Lisa T. Wigfall, PhD, 220 Stoneridge Drive, Suite 103, Columbia, SC 29210-8018, Phone: (803) 251-2298, Fax: (803) 251-6327, lisa.wigfall@sc.edu.

hysterectomy (n=14), and observations with missing data (n=22) were excluded. Stata/IC 13 was used to perform cross-tabulations and chi-squared tests.

Results—Our sample included 106 predominantly non-Hispanic Black (92%) WLHA. Mean age was 46.3±10.9 years. Half (50%) had ≤ high school education. One-third (37%) had low health literacy. The majority (83%) had a Pap test <1 year ago and 84% knew that WLHA should have a Pap test every year, once two tests are normal. Many (68%) have had an abnormal Pap test. Abnormal Pap test follow-up care knowledge varied. While 86% knew follow-up care could include a repeat Pap test, only 56% knew this could also include an HPV test. Significantly more women who had an abnormal Pap test knew follow-up care could include a biopsy (p=0.001).

Conclusions—For WLHA to make informed/shared decisions about their cervical health, they need to be knowledgeable about cervical cancer care options across the cancer control continuum. Providing WLHA with prevention knowledge beyond screening recommendations seems warranted given their increased risk of developing cervical dysplasia/neoplasia.

Keywords

cervical cancer; HIV-positive women; cancer prevention and screening; women's health; cancer care continuum

Introduction

Kaposi's sarcoma, non-Hodgkin's lymphoma, and cervical cancer are among 26 acquired immune deficiency syndrome (AIDS)-defining clinical conditions [1]. The incidence rates of Kaposi's sarcoma and non-Hodgkin's lymphoma have decreased significantly since antiretroviral therapy was introduced in the mid-1990s [2]. In contrast, the incidence of cervical cancer has remained unchanged [3]. Most women with intact immune systems will clear human papillomavirus (HPV) infection. Among immunosuppressed women such as women living with HIV/AIDS (WLHA), potentially oncogenic HPV infection is less likely to be transient [4]. Increased cervical cancer risk among WLHA underscores the need for cervical cancer prevention and control efforts targeted at this vulnerable group.

Despite recommendations for increased surveillance and the disproportionate burden of cervical dysplasia/neoplasia, Pap testing is underutilized among WLHA [2,5-6]. These health system failures are exacerbated in older WLHA who are screened for cervical cancer even less frequently [6]. For sexually active WLHA ≥50 years old who are already disproportionately diagnosed with advanced HIV disease [7-8], adhering to screening guidelines and recommended follow-up care of abnormal Pap test results becomes increasingly important. In order to make informed health decisions about cervical cancer care, WLHA need to better understand what they can do to improve their cervical health outcomes to reduce cervical cancer health disparities between WLHA and HIV-negative women. Yet, cervical cancer prevention knowledge deficits persist among WLHA [9].

The purpose of this study was to examine WLHA's knowledge about cervical cancer screening guidelines for HIV-positive women by abnormal Pap test history. Because adults have reported increased adherence to other cancer screening recommendations among social network members who share health information, we will also examine cervical cancer

prevention knowledge by knowing other women with an abnormal Pap test history among our sample of WLHA [10].

Methods

This cross-sectional study consisted of a sample of 145 urban and rural-dwelling WLHA recruited from Ryan White-funded clinics and AIDS service organizations located in the southeastern United States. Cervical cancer prevention knowledge, attitudes, beliefs and behaviors were examined [11]. Participants who reported a history of cervical cancer (n=3) or had a total hysterectomy (removal of uterus and cervix) (n=14) were excluded. Observations with missing data (n=22) on any of our measures were also excluded.

Participants were asked (yes/no), Have you ever been told by a doctor, nurse or other health care provider that your Pap test result was not normal? Those with an abnormal Pap test result were asked (yes/no), Have any women that you know ever been told that their Pap test result was not normal?

Conceptual Model

The selection of outcomes of interest and covariates used to describe the social and vulnerability characteristics of participants have been informed by the Structural Influence Model of Communication Inequalities. This model posits that social and communication inequalities may contribute to health and health care disparities [12]. Our study design was also informed by the Behavioral Model for Vulnerable Populations commonly used in health services research to understand health behaviors and health services utilization among vulnerable populations such as persons living with HIV/AIDS [13].

Measures

Outcomes—We used two cervical cancer prevention knowledge items from the “HPV Knowledge Attitude and Behaviors” questionnaire used in the Women’s Interagency HIV Study (WIHS) [14]. The first item assessed knowledge about cervical cancer screening guidelines for WLHA, and the second item assessed knowledge about abnormal Pap test follow-up care.

Cervical cancer screening recommendations for WLHA: The guidelines that providers use to screen WLHA for cervical cancer are different from screening guidelines that are used to screen HIV-negative women [5]. For example, two Pap tests are recommended in the first year of diagnosis for WLHA [5]. If the results for both Pap tests are normal, annual screening is recommended thereafter [5]. HPV DNA testing is not recommended for screening WLHA for cervical cancer.

We used a single item to assess WLHA knowledge of Pap test recommendations for HIV-positive women. We asked, How often should a Pap test be done for a woman with HIV? Response were: every year, once two tests are normal (correct response); every 3 years; every 4-5 years; when a woman has a discharge; don’t know.

Abnormal Pap test follow-up care: True/false questions were used to assess WLHA's knowledge about abnormal Pap test follow-up care. We asked, *After an abnormal Pap test, follow-up may include:* another Pap test; an HPV test; a colposcopy; a biopsy; a hysterectomy; a blood test; nothing. Response options were true, false or don't know. All of the questions with the exception of two distractors (i.e., a blood test, nothing). Don't know was treated as an incorrect response.

We assessed colposcopy awareness prior to assessing abnormal Pap test follow-up care knowledge by asking participants (yes/no), Have you ever heard of a health test called a colposcopy? The response for the abnormal Pap test follow-up care question about colposcopy was recoded as "don't know" for participants who had never heard of a colposcopy.

Cervical Cancer Screening—We adapted a question used on the Health Information National Trends Survey [15] to assess Pap test use. We asked participants, *When did you have your most recent Pap test?* Response options were: less than 1 year ago; 1-3 years ago; 3-5 years ago; more than 5 years ago; never; don't know / not sure; refused. Those who responded "less than 1 year ago" were recoded as being "adherent" to cervical cancer screening recommendations for HIV-positive women [5]. All other responses were recoded as "non-adherent".

Health Literacy—The Single Item Literacy Screener (SILS) was used to assess health literacy [16]. We asked participants, How often do you need to have someone to help you understand information you get from your doctor, nurse, or other health care provider?" Response options were: never, rarely, sometimes, often, or always. The SILS authors [16] recommended a cut point of two to recode into a dichotomous measure of health literacy. Never or rarely was recoded as "high health literacy," and sometimes, often, or always were recoded as "low health literacy."

Social and Vulnerability Characteristics—We assessed education (less than high school, high school/GED, some college, college or more); household income (less than $10K, $10-25K, $25K); age in years (18-34; 35-49; 50-64, 65+); race/ethnicity (non-Hispanic African-American or black; non-Hispanic white; non-Hispanic other; Latina).

We assessed unsafe sex practices using a single item from the Behavioral Risk Factor Surveillance System survey [17]. We asked participants if they have: had unprotected vaginal, oral or anal sex; been treated for one or more sexually transmitted diseases; given or received money or drugs in exchange for sex; been forced to have sex with someone against your will in the past year. Response options were: yes, no, don't know/not sure or refused. Sexual orientation was also reported as heterosexual or lesbian/gay/bisexual/transgender (LGBT).

Other social and vulnerability characteristics included place of residence (own/rent versus sheltered/unsheltered homeless), and smoking status (current, former, nonsmoker).

Data Analysis

Chi-square tests were used to examine group differences in cervical cancer screening behaviors, cervical cancer prevention knowledge, health literacy, as well as social and vulnerability characteristics between participants with an abnormal Pap test history versus those who reported that they have never been told that their Pap test was abnormal. We also used chi-square tests to examine these differences between participants who knew other women who have had an abnormal Pap test versus those who did not know other women who have had an abnormal Pap test. Stata/IC 13 was used to perform all data analyses. An alpha level of 0.05 was used to assign statistical significance. These results are described below and reported in Table 1.

Results

Sample Characteristics

Of the 106 participants in our sample, 92% were non-Hispanic Black. Ages ranged from 20-68 years and the mean age was 46.3±10.9. Half (50%) had a high school diploma/GED or did not complete high school. One-third (37%) had low health literacy. About one-fifth of our sample engaged in risky sexual behaviors in the past year (21%). About one-fourth did not own or rent their own home (29%) which included sheltered (n=26) and unsheltered (n=4) homeless. Less than half of participants were current smokers (44%). Only a few identified as being LGBT (6%).

Cervical Cancer Prevention Knowledge and Behaviors

Screening recommendations—About half (48%) of participants had their most recent Pap test done at an HIV clinic. The majority (84%) had a Pap test <1 year ago and 85% knew that HIV-positive women should have a Pap test every year, once two tests are normal. <ADD> (Table 1) Group differences in knowledge of cervical cancer screening recommendations were not statistically significant by abnormal Pap test history (p=0.630). (Table 1) Fewer than half (42%) of the 74 participants in our subsample who had an abnormal Pap test knew a friend or family member who also had an abnormal Pap test (n=31). (Table 1) The proportion of participants from this group (97%) who knew what the cervical cancer screening recommendations were for HIV-positive women was significantly higher compared with participants (79%) who did not know other women who have had an abnormal Pap test (p=0.028). (Table 2)

Abnormal Pap test follow-up care—Even though more than half (72%) of the 103 participants had an abnormal Pap test, abnormal follow-up care knowledge varied. While 85% knew this could include a repeat Pap test, only 54% knew this also could include an HPV test. Significantly more participants who had an abnormal Pap test correctly knew that this could include a colposcopy (p=0.055) or a biopsy (p<0.001) compared with participants who have not had an abnormal Pap test. A marginally significant higher proportion of women who had an abnormal Pap knew that abnormal follow-up would not include doing nothing (p=0.093) or a blood test (p=0.058) compared with participants who have not had an abnormal Pap test. These were only marginally statistically significant differences between our abnormal Pap test versus no abnormal Pap test groups. There were no significant group

differences in abnormal Pap test knowledge between the groups in our subsample of participants who had an abnormal Pap test and either knew or did not know other women who have had an abnormal Pap test. These findings are reported in Table 1 and Table 2.

Discussion

Because cervical cancer is one of only a few cancers that are preventable through screening, cervical incidence rates represent missed opportunities to either prevent oncogenic HPV infection or detect precancerous cells. Likewise, cervical cancer mortality rates represent missed opportunities to treat cervical intraepithelial neoplasia, a precancerous condition, at early stages before lesions progress to frank cancer. As a result, non-Hispanic Black women are disproportionately diagnosed with cervical cancer and are diagnosed with cervical cancer at more advanced stages. [18] These health system failures that occur along the cancer care continuum become an increasing concern among older WLHA who are also largely non-Hispanic Black and disproportionately diagnosed with advanced HIV disease.

Early detection of precancerous conditions through screening and timely abnormal follow-up care is essential to prevent and control cervical cancer among WLHA. A necessary intermediate step is to raise awareness and increase knowledge about cervical cancer screening and abnormal follow-up care among WLHA. In terms of both the proportion of correct responses as well as the variation in higher and lower knowledge about abnormal Pap test follow-up care, participants in our study were similar regarding their knowledge about cervical cancer screening recommendations for HIV-positive and follow-up care of abnormal Pap test results. While participants who had an abnormal Pap test were more knowledgeable about some things that might be done as part of abnormal Pap test follow-up care, the majority of participants thought incorrectly that this might include not doing anything. Our mixed findings suggest that there is definitely more work to be done to overcome cognitive barriers that WLHA may encounter across the cancer care continuum [19].

While some researchers have reported that health information sharing between friends and family members may indeed have a positive effect on cancer prevention beliefs and screening behaviors, these studies have included adults of higher socioeconomic position than many WLHA [10]. A significantly higher proportion of participants who had members in their social networks who had an abnormal Pap test history report knowing that HIV-positive women should have an annual Pap tests after their initial year of diagnosis. We thought that this finding was noteworthy in that it further underscores the fact that we need to better understand how effective interpersonal health communication strategies can be used to reduce cancer and other health disparities among WLHA.

Study Limitations

Although we did observe some statistically significant group differences in our outcomes of interest, the likelihood of Type II errors limiting our ability to observe other statistically significant relationships is high given our small sample size. Thus, it is unfortunate that this pilot study is not powered to detect other differences if they exist. Other study design limitations include the fact that data are obtained self-reported and hence subject to recall

bias. One example of this was participants' limited recall of complete or partial hysterectomy. Limitations pertain to other measures. While we know that some health information exchange took place about abnormal Pap tests between participants and their friends or family members, we do not know much more than that. For example, was this sharing of health information bidirectional or unidirectional, and if the latter, from and to whom are unanswered questions? It also was difficult to assess Pap test adherence for participants diagnosed <1 year ago. Additionally, we do not know if the most recent Pap test reported was a screening or repeat Pap test. Thus, we have operationalized adherence as having had a Pap test within the past year, in accordance with screening guidelines for HIV-positive women diagnosed more than a year ago [5].

We recognize that study findings may not be generalizable to either a general female population or WLHA residing in geographical areas outside of the southeastern United States. However, the two cervical cancer prevention knowledge items that we used for this study have been used by other researchers with WLHA and HIV-negative women residing in large metropolitan areas (i.e., Bronx, NY; Brooklyn, NY; Chicago, IL; Los Angeles, CA; San Francisco, CA; Washington, DC) [14].

Conclusions

Reducing cervical cancer incidence and mortality are among our nation's health goals. To this end, a stated goal of *Healthy People 2020* is that 93% of females 21-65 years old adhere to recommended screening guidelines. [20] With only 84% of participants adhering to Pap test guidelines for WLHA [5], our findings underscore the need for cancer prevention and control efforts aimed at promoting timely screening among WLHA. However, in order for WLHA to make informed/shared health decisions, they need to be knowledgeable of their treatment options across the cervical cancer care continuum. This becomes increasingly important as our nation continues to shift from a medical care model to a preventive care model. Given WLHA's high risk for developing cervical dysplasia/cancer, providing them with prevention knowledge beyond screening recommendations is warranted. Future research is needed to better understand how to reduce health system failures that occur along the cervical cancer care continuum that contributed to these disparities among WLHA. We believe that raising awareness about increased cervical cancer risk as well as the benefits of timely adherence to abnormal Pap test recommendations are necessary first steps to reducing cervical cancer disparities among HIV-positive women. To this end, cancer prevention and control efforts should aim to increase cervical cancer prevention education knowledge among HIV-positive women given their increased risk for developing cervical disease and cancer.

Acknowledgements

This research study was supported by the National Cancer Institute (NCI) of the National Institutes of Health (NIH) under an Administrative Supplements for Community-Engaged Research on HIV/AIDS-Related Cancers Among Underserved Populations (U01-CA114601-05S4/PI: Hébert/Project Leader:Wigfall), NCI Mentored Research Scientist Development Award to Promote Diversity (K01CA175239/PI:Wigfall), and an Established Investigator Award in Cancer Prevention and Control (K05 CA136975/PI:Hébert). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NCI, NIH, Uniformed Services University of the Health Sciences or the Department of Defense.

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Table 1

Cervical cancer prevention knowledge/screening behaviors and social determinants of health among HIV-positive women by abnormal Pap test history

	Total N=103	ABN Pap Test n=74	No ABN Pap Test n=29	P-value
Cervical Cancer Prevention Knowledge				
How often should a Pap test be done for a woman with HIV?				
Every year, once two tests are normal	85%	86%	83%	0.63
Abnormal Pap test follow-up care may include:				
Another Pap test (**True**)	85%	86%	83%	0.63
HPV test (**True**)	54%	57%	48%	0.44
Colposcopy[a] (**True**)	66%	72%	52%	0.06
Biopsy (**True**)	73%	82%	48%	<0.01
Hysterectomy (**True**)	30%	34%	21%	0.19
Blood test (**False**)	18%	23%	7%	0.06
Nothing (**False**)	77%	81%	66%	0.09
Cervical Cancer Screening Behaviors				
Adherent (<1 year ago)	84%	85%	79%	0.47
Health Literacy				
Low	36%	32%	45%	0.24
Social & Vulnerability Characteristics				
Socioeconomic Position:				
Education				0.05
<High school	17%	14%	24%	
High school/GED	33%	28%	45%	
Some college	38%	46%	17%	
College+	13%	12%	14%	
Income				0.45 (f)
<10	59%	55%	69%	
10-25	24%	28%	14%	
25+	6%	5%	7%	
Not reported	11%	11%	10%	
Sociodemographics:				
Age (years)				0.18
18-34	13%	14%	10%	
35-49	47%	51%	34%	
50+	41%	35%	55%	
Race				0.31
Non-Hispanic Black	92%	91%	97%	

	Total N=103	**ABN Pap Test n=74**	**No ABN Pap Test n=29**	**P-value**
Other (includes n=3 Latinas)*	8%	9%	3%	
Vulnerable Domain:				
Health Behaviors				
Unsafe sex (n=102)	21%	22%	17%	0.60
Current smoker (n=102/103)	44%	45%	41%	0.56
Health Need				
Post-menopausal (n=103)	41%	35%	55%	0.06
Predisposing/Enabling Factors				
LGBT	6%	7%	3%	0.52
Sheltered/unsheltered homelessness	26%	26%	27%	0.93

Bold text=correct responses; ABN=abnormal; LGBT=lesbian/gay/bisexual/transgender; (f)=Fisher's exact test

Table 2

Cervical cancer prevention knowledge/screening behaviors and social determinants of health among HIV-positive women by social network member(s) abnormal Pap test history

	Total N=74	Friends/Family With ABN Pap Test n=31	No Friends/Family with ABN Pap Test n=43	P-value
Cervical Cancer Prevention Knowledge				
How often should a Pap test be done for a woman with HIV?				
Every year, once two tests are normal	86%	97%	79%	0.03
Abnormal Pap test follow-up care may include:				
Another Pap test (**True**)	86%	94%	81%	0.13
HPV test (**True**)	57%	58%	56%	0.85
Colposcopy[a] (**True**)	72%	71%	72%	0.92
Biopsy (**True**)	82%	84%	81%	0.78
Hysterectomy (**True**)	34%	35%	33%	0.79
Blood test (**False**)	23%	29%	19%	0.29
Nothing (**False**)	81%	84%	79%	0.60
Cervical Cancer Screening Behaviors				
Adherent (<1 year ago)	85%	90%	81%	0.29
Health Literacy				
Low	32%	23%	40%	0.12
Social & Vulnerability Characteristics				
Socioeconomic Position:				
Education				0.39
<High school	14%	10%	16%	
High school/GED	28%	29%	28%	
Some college	46%	42%	49%	
College+	12%	19%	7%	
Income				0.61 (f)
<10	55%	52%	58%	
10-25	28%	29%	28%	
25+	5%	3%	7%	
Not reported	11%	16%	7%	
Sociodemographics:				
Age (years)				0.62
18-34	14%	16%	12%	
35-49	51%	55%	49%	
50+	35%	29%	40%	
Race				0.45
Non-Hispanic Black	91%	94%	88%	

	Total N=74	Friends/Family With ABN Pap Test n=31	No Friends/Family with ABN Pap Test n=43	P-value
Other (includes n=3 Latinas)*	9%	6%	12%	
Vulnerable Domain:				
Health Behaviors				
Unsafe sex (n=73)	22%	26%	19%	0.49
Current smoker (n=73)	45%	52%	41%	0.30
Health Need				
Post-menopausal (n=74)	35%	29%	40%	0.35
Predisposing/Enabling Factors				
LGBT (n=74)	7%	10%	5%	0.64
Sheltered/unsheltered homelessness (n=73)	26%	23%	29%	0.56

Bold text=correct responses; ABN=abnormal; LGBT=lesbian/gay/bisexual/transgender; (f)=Fisher's exact test