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Assessing the Influence of Health Literacy on HIV-Positive Women's Cervical Cancer Prevention Knowledge and Behaviors

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Abstract

Women living with HIV (WLH) bear a disproportionate burden of cervical cancer and may face challenges understanding health information. The purpose of this study was to assess the influence of health literacy on WLH cervical cancer screening knowledge and behaviors. WLH were recruited from clinic- and community-based settings in the southeastern USA. The majority of women completing a questionnaire assessing factors related to cervical cancer were African American (90 %). About 38 % of women reported low health literacy. Compared to women with high health literacy, these women were more likely to report having had 2 Pap tests during the year after HIV diagnosis ($p=0.02$), and less likely to have had a Pap test <1 year previously ($p=0.05$). There was no difference in cervical cancer or human papillomavirus knowledge among those with low versus high health literacy. Results revealed mixed finding on the influence of health literacy on screening knowledge and behaviors.

Keywords

Health literacy; HIV-positive women; Cervical cancer

Introduction

Each year, approximately 12,000 women are diagnosed with cervical cancer in the USA [1]. Women living with HIV (WLH) bear the largest burden, accounting for 70 % of all cervical cancer cases [2]. The higher incidence of cervical cancer among WLH is related to persistent infection with high-risk (i.e., oncogenic) types of human papillomavirus (HPV) [3]. As such, routine cervical cancer screening and monitoring is central to curtailing the burden of cervical disease among this population. HIV treatment guidelines recommend that WLH have two Pap tests during the year after HIV diagnosis and annually thereafter [4]. Despite this evidence-based recommendation, the Centers for Disease Control and Prevention (CDC) found that 23 % of WLH do not receive annual Pap tests [5].

Several factors may impede a woman's ability to receive cervical cancer screening routinely. Research suggests that inadequate health literacy may be a contributing factor [6]. Approximately, 25–30 % of people living with HIV have inadequate health literacy [7, 8]. Inadequacies in health literacy have been linked to lower levels of cancer awareness, knowledge, screening utilization, and follow-up care [6, 9]. Literacy challenges may be exacerbated among WLH given the complexity and amount of health information they may encounter. These findings highlight the need to understand contextual factors such as health literacy in health decision making related to cervical cancer screening. Thus, the purpose of this study was to assess the influence of health literacy on cervical cancer prevention awareness, knowledge, and screening behaviors for WLH.

Methods

This study was part of a larger effort that explored HPV and cervical cancer prevention knowledge, attitudes, beliefs, and behaviors among WLH. In 2011, WLH were recruited from clinic- and community-based settings in the southeastern USA. Women were asked to complete a multi-item self-report questionnaire assessing factors related to cervical cancer prevention. A total of 145 women were recruited. Of these 145 women, 20 reported having a partial hysterectomy and 15 reported having a total hysterectomy. Based on cancer screening guidelines for WLH, those who have undergone a total hysterectomy, particularly if there is a history of cervical disease, should continue routine cervical cancer screening [4]. Keeping with recommendations for women without HIV, WLH who have had a partial hysterectomy should follow routine screening intervals. As such, women who reported having any type of

hysterectomy were included in the study. The study was approved by the University of South Carolina Institutional Review Board.

Measures

Health Literacy—The Single Item Literacy Screener (SILS) was adapted to assess health literacy in the current study [10]. The one question screener was developed by Morris et al. [10] to identify adults in need of help understanding printed health material. The SILS has been widely used across myriad of health topics. In the current study, women were asked, “How often do you need to have someone to help you understand information you get from your doctor, nurse, or other health care provider” (1=“never,” 2=“rarely,” 3=“sometimes,” 4=“often,” 5=“always”). Women were provided the full range of response options on the five-point Likert scale. In accordance with the SILS authors’ recommended cut point of 2 indicating difficulties in reading printed health material, women were grouped into two categories, “low health literacy” and “high health literacy” [10].

Cervical Cancer Screening and Knowledge—Cervical cancer screening and knowledge items were adapted from previous work of the authors and the Behavioral Risk Factor Surveillance System [11, 12]. Pap test awareness was captured by one item, “Before this interview, have you ever heard of a Pap test (or a Pap smear)?” (yes/no). Two items were used to assess cervical cancer screening: (1) “When did you have your most recent Pap test?” (<1 year ago/ 1 year ago) and (2) “How many Pap tests did you have during the first year after being diagnosed HIV-positive? (2/< 2/Don’t Know)”. Five items assessed cervical cancer knowledge (e.g., HIV-positive women should have a Pap test more often than HIV-negative women) (see Table 1). Correct responses were given a score of 1 and incorrect and “don’t know” responses a score of 0 to create a maximum 5-point cervical cancer knowledge score.

HPV Awareness, Knowledge, and Vaccination—HPV items have been used in previous work of the authors and were adapted for use in the current study [11]. One item assessed HPV awareness, “Have you ever heard of HPV?” (yes/no). To determine awareness of the HPV test, women were asked, “Before this interview, have you ever heard of an HPV test?” (yes/no). One item assessed HPV vaccine awareness, “Before this interview, have you ever heard of the HPV shot or cervical cancer vaccine?”(yes/no). A single item assessed HPV vaccine utilization, “Have you ever had the HPV shot or cervical cancer vaccine?” (yes/no). Four items were used to assess HPV knowledge (e.g., Infection with certain types of HPV can cause cervical cancer) (see Table 1). Correct responses were given a score of 1 and incorrect and “don’t know” responses a score of 0 to create a maximum 4-point HPV knowledge score.

Data Analysis

Descriptive statistics summarized sociodemographic characteristics. Chi-square tests were used to explore differences in Pap test awareness and utilization, HPV awareness, and HPV vaccine awareness between women with low health literacy versus high health literacy. Independent sample *t* tests explored differences in cervical cancer and HPV knowledge. All analyses were conducted using SPSS 20.0 (Chicago, IL). Statistical tests were two-tailed with an alpha level of 0.05.

Results

Sociodemographics Characteristics

The majority of women were African American (90 %; *n*=131). The mean age was 46.15±10.65 years; range 20–68. Fourteen percent (*n*=20) reported having a college degree,

31 % ($n=45$) some college education/technical school, 32 % ($n=47$) a high school diploma/GED, and 21 % ($n=31$) reported having no high school diploma/GED. In total, 38 % ($n=55$) reported low health literacy.

Cervical Cancer Screening and Knowledge

All women reported ever hearing of the Pap test. Thirty-six percent ($n=52$) reported having at least two Pap tests during the first year after HIV diagnosis. A larger proportion of women with low health literacy compared to high health literacy reported having at least two Pap test during their first year (49 vs. 30 %): $\chi^2=8.19$, $p=0.02$. About 81 % ($n=118$) reported having a Pap test less than 1 year ago. Fewer women with low health literacy comparatively reported having a Pap test less than 1 year ago (75 vs. 86 %): $\chi^2=3.94$, $p=0.05$. There was no significant difference in cervical cancer knowledge between women with low and high health literacy.

HPV Awareness and Knowledge

Overall, 66 % ($n=96$) of women reported hearing of HPV; 46 % ($n=67$) heard of the HPV test; 36 % ($n=52$) heard of the HPV vaccine; and 4 % ($n=6$) reported receiving at least one HPV vaccine dose. A significantly smaller proportion of women with low health literacy compared to high health literacy reported ever hearing of HPV (52 vs. 76 %): $\chi^2=8.53$, $p<0.01$. Fewer women with low health literacy than high health literacy reported ever hearing of the HPV vaccine (28 vs. 68 %), $\chi^2=12.42$, $p<0.01$. There was no significant difference in HPV test awareness or HPV knowledge between low and high literacy women.

Discussion

This formative study provides insight into the health literacy challenges that WLH may face in making preventive health decisions. Currently, women comprise 25 % of the population living with HIV. As this number continues to grow, cervical cancer will remain a source of morbidity and mortality in absence of intervention.

The major findings of our study indicate that women who reported low health literacy are more likely to comply with at least some screening recommendation (i.e., to have 2 Pap tests in the year after HIV diagnosis). However, these women were also less likely to meet the annual screening recommendation after their first year. These mixed findings warrant further investigation to elucidate the influence of health literacy on WLH cervical cancer screening behaviors. Verifying these results and understanding their cause has important implications for identifying targeted screening promotion efforts for WLH at different health literacy levels and those who will be more receptive to cervical cancer screening programs in the future.

In the current study, health literacy influenced whether women heard of HPV with low literacy women being less aware. However, among this sample of women, health literacy had no influence on what women knew about cervical cancer or HPV. This finding may suggest that health literacy has a greater influence on actual behaviors (i.e., cervical cancer screening) and awareness rather than knowledge. The avenue through which health literacy operates to influence knowledge and behaviors is complex. Additional research to understand the complexities of health literacy among WLH is warranted.

Logan et al. found that only 25 % of women had the recommended two Pap tests during the year after being diagnosed with HIV [13]. A slightly higher proportion was found in the current study with 36 % meeting the recommendation. An even larger proportion (81%) of women reported adhering to the recommended annual Pap test. These findings are promising, but remain less than optimal given that WLH progress more rapidly to invasive

cervical cancer, and have a lower rate of treatment success and survival compared to women without HIV [14, 15]. Additional efforts to promote recommended cervical cancer screening utilization are central to the survival of WLH as prevention and control (i.e., early intervention) are most critical for this population who bear excess burden of cervical disease.

There are limitations that should be considered when interpreting the results of this study. First, we were unable to objectively assess cervical cancer screening behaviors through medical chart review. As such, all data were self-reported which may have introduced recall and reporting error. Lastly, the CDC recommends continued cervical cancer screening for women who have undergone a hysterectomy particularly if there is a history of invasive cervical disease [4]. Screening for women with a history of benign disease who have undergone a hysterectomy is not recommended [4]. Because we were unable to objectively assess if women underwent a hysterectomy because of invasive cervical disease or benign disease, we included all women who reported having a hysterectomy in the analyses.

Conclusions

Study results revealed mixed findings regarding the influence of health literacy on cervical cancer prevention behaviors and knowledge. Nonetheless, overall findings suggest that WLH could benefit from increased health literacy efforts. Specifically, these efforts should focus on improving utilization of cervical cancer screening and increasing knowledge of cervical cancer and HPV. Moreover, while not a focus of this study, determining the role of health care providers in recommending and promoting cervical cancer screening is an equally important effort. Health care providers remain the most trusted source of health information for patients, and their delivery of culturally and linguistically appropriate health messages are important for utilization of cancer care services such as the Pap test. The presentation of cervical cancer screening messages to WLH may be particularly important given the myriad of health issues requiring care among this vulnerable group.

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References

1. Siegel R, Naishadham D, Jemal A. Cancer statistics, 2012. *CA Cancer J Clin.* 2012; 62(1):10–29. [PubMed: 22237781]
2. Shiels MS, Pfeiffer RM, Hall HI, Li J, Goedert JJ, Morton LM, Hartge P, Engels EA. Proportions of Kaposi sarcoma, selected non-Hodgkin lymphomas, and cervical cancer in the United States occurring in persons with AIDS, 1980–2007. *JAMA.* 2011; 305(14):1450–1459. [PubMed: 21486978]
3. Sun XW, Kuhn L, Ellerbrock TV, Chiasson MA, Bush TJ, Wright TC Jr. Human papillomavirus infection in women infected with the human immunodeficiency virus. *N Engl J Med.* 1997; 337(19):1343–1349. [PubMed: 9358128]
4. Kaplan JE, Benson C, Holmes KH, Brooks JT, Pau A, Masur H. Guidelines for prevention and treatment of opportunistic infections in HIV-infected adults and adolescents: recommendations from CDC, the National Institutes of Health, and the HIV Medicine Association of the Infectious Diseases Society of America. *MMWR Recomm Rep.* 2009; 58(RR-4):1–207. quiz CE201–204.

5. Oster AM, Sullivan PS, Blair JM. Prevalence of cervical cancer screening of HIV-infected women in the United States. *J Acquir Immune Defic Syndr*. 2009; 51(4):430–436. [PubMed: 19474756]
6. Lindau ST, Basu A, Leitsch SA. Health literacy as a predictor of follow-up after an abnormal Pap smear: a prospective study. *J Gen Intern Med*. 2006; 21(8):829–834. [PubMed: 16881942]
7. Hicks G, Barragan M, Franco-Paredes C, Williams MV, del Rio C. Health literacy is a predictor of HIV/AIDS knowledge. *Fam Med*. 2006; 38(10):717–723. [PubMed: 17075745]
8. Drainoni ML, Rajabiun S, Rumpitz M, Welles SL, Relf M, Rebholz C, Holmes L, et al. Health literacy of HIV-positive individuals enrolled in an outreach intervention: results of a cross-site analysis. *J Health Commun*. 2008; 13(3):287–302. [PubMed: 18569359]
9. Arnold CL, Rademaker A, Bailey SC, Esparza JM, Reynolds C, Liu D, Platt D, Davis TC. Literacy barriers to colorectal cancer screening in community clinics. *J Health Commun*. 2012; 17(Suppl 3): 252–264. [PubMed: 23030574]
10. Morris NS, MacLean CD, Chew LD, Littenberg B. The Single Item Literacy Screener: evaluation of a brief instrument to identify limited reading ability. *BMC Fam Pract*. 2006; 7:21. [PubMed: 16563164]
11. Bynum SA, Wright MS, Brandt HM, Burgis JT, Bacon JL. Knowledge, beliefs, and attitudes related to human papillomavirus infection and vaccination, pap tests, and cervical intraepithelial neoplasia among adolescent girls and young women. *J S C Med Assoc*. 2009; 105(7):267–272. [PubMed: 20108716]
12. Bynum SA, Brandt HM, Friedman DB, Annang L, Tanner A. Knowledge, beliefs, and behaviors: examining human papillomavirus-related gender differences among African American college students. *J Am Coll Health*. 2011; 59(4):296–302. [PubMed: 21308590]
13. Logan JL, Khambaty MQ, D'Souza KM, Menezes LJ. Cervical cancer screening among HIV-infected women in a health department setting. *AIDS Patient Care STDS*. 2010; 24(8):471–475. [PubMed: 20653483]
14. Maiman M, Fruchter RG, Guy L, Cuthill S, Levine P, Serur E. Human immunodeficiency virus infection and invasive cervical carcinoma. *Cancer*. 1993; 71(2):402–406. [PubMed: 8093678]
15. Danso D, Lyons F, Bradbeer C. Cervical screening and management of cervical intraepithelial neoplasia in HIV-positive women. *Int J STD AIDS*. 2006; 17(9):579–584. quiz 585–577. [PubMed: 16942648]

Table 1

Cervical cancer and HPV knowledge correct responses of women living HIV

	Correct Response	Low health literacy <i>n</i> =55	High health literacy <i>n</i> =90	Total <i>N</i> =145
Cervical Cancer Knowledge Items				
A Pap test checks to see if you have any cancer cells around your cervix.	True	48 (87 %)	84 (93 %)	132 (91 %)
HIV-positive women should have a Pap test more often than HIV-negative women.	True	42 (76 %)	54 (60 %)	96 (66 %)
Women who are done having children do not need to keep having Pap tests.	False	47 (86 %)	85 (94 %)	132 (91 %)
Cervical cancer is easier to prevent if abnormal cells are found early.	True	47 (86 %)	80 (89 %)	127 (88 %)
Infection with HIV increases a woman's chances of getting cervical cancer.	True	28 (51 %)	42 (47 %)	70 (48 %)
Mean ^a	—	3.85±0.97	3.86±1.05	3.86±1.02
HPV Knowledge Items				
HPV can be passed by skin-to-skin contact in the genital area during sex.	True	13 (24 %)	28 (31 %)	41 (28 %)
Women who get infected with certain types of HPV have a greater chance of getting cervical cancer.	True	18 (33 %)	58 (64 %)	76 (52 %)
Infection with certain types of HPV can cause cervical cancer.	True	17 (31 %)	53 (59 %)	70 (48 %)
Using condoms during sexual intercourse can lower a person's chances of getting infected with HPV.	True	18 (33 %)	49 (54 %)	67 (46 %)
Mean ^b	—	2.37±1.45	2.82±1.01	2.68±1.17

^aMean scores for cervical cancer knowledge items are out of a maximum five points^bMean scores for HPV knowledge items are out of a maximum four points