HHS Public Access

Author manuscript

Womens Health Issues. Author manuscript; available in PMC 2016 November 01.

Published in final edited form as:

Womens Health Issues. 2015 ; 25(6): 720–726. doi:10.1016/j.whi.2015.06.008.

Beliefs About Anal Cancer among HIV-Infected Women: Barriers and Motivators to Participation in Research

Tracy A. Battaglia,
Women's Health Unit, Section of General Internal Medicine Boston University School of Medicine and Boston Medical Center 801 Massachusetts Avenue, First Floor Boston, MA 02118 Tracy.Battaglia@bmc.org

Christine M. Gunn,
Women's Health Unit 801 Massachusetts Avenue, First Floor Boston, MA 02118

Molly E. McCoy,
Women's Health Unit 801 Massachusetts Avenue, First Floor Boston, MA 02118 Molly.McCoy@bmc.org

Helen H. Mu,
Department of Obstetrics and Gynecology, Boston University Medical Center 720 Harrison Avenue, Suite 1105 Boston, MA 02118 Helen.Mu@bmc.org

Amy S. Baranoski,
Division of Infectious Diseases and HIV Medicine, Drexel University College of Medicine 1427 Vine Street, 2nd Floor Philadelphia, PA 19102 Amy.Baranoski@DrexelMed.edu

Elizabeth Y. Chiao,
Department of Medicine, Baylor College of Medicine Houston Health Services Research and Development Center of Excellence, Michael E. DeBakey Veterans Affairs Medical Center Room N-1319, One Baylor Plaza Houston, TX 77030 echiao@bcm.edu

Lisa A. Kachnic, and
Department of Radiation Oncology, Boston University School of Medicine and Boston Medical Center 830 Harrison Avenue Moakley Building, Lower Level Boston, MA 02118 Lisa.Kachnic@bmc.org

Elizabeth A. Stier
Department of Obstetrics and Gynecology, Boston University Medical Center 720 Harrison Avenue, Suite 1105 Boston, MA 02118 Elizabeth.Stier@bmc.org

(Corresponding Author) Christine M. Gunn Phone: 617-638-8036 Christine.Gunn@bmc.org.

No authors have any financial conflicts of interest to disclose.

Introduction

In the United States the incidence rates of anal cancer have increased from 0.8 to 1.7 cases per 100,000 persons per year from 1976 to 2011, respectively (Shridhar, Shibata, Chan, & Thomas, 2015). Even with the widespread use of combination antiretroviral therapy, HIV infection is increasingly associated with a higher risk of anal cancer (Crum-Cianflone et al., 2009; D'Souza et al., 2008). While HIV-infected men who have sex with men are at highest risk, HIV-infected women have a significant burden of disease, with an anal cancer incidence rate of approximately 10-30/100,000 person-years (Silverberg et al., 2012). Compared to HIV-negative women, HIV-positive women are up to 6.8 times more likely to have an anal cancer diagnosis (Palefsky & Rubin, 2009). Given that African American and Hispanic women represent the majority of HIV-infected women in the United States at 62% and 17% respectively ("HIV/AIDS Statistics and Surveillance," 2013), minority populations are especially vulnerable.

Anal cancer screening with cytology (the "anal Pap test"), to identify treatable precancerous lesions (similar to cervical cancer screening) has been proposed in high risk populations, such as HIV-infected individuals. Patients with abnormal anal cytology are referred for a colposcopic evaluation of the anus called high resolution anoscopy (HRA) where directed biopsies may diagnose anal high-grade squamous intraepithelial lesions (AIN2-3) which are likely precursors to cancer (Jay et al., 1997). Once identified, these lesions are ablated or excised in hopes of preventing progression to anal cancer. However, the performance characteristics of anal cytology, HRA, and Human Papilloma Virus (HPV) testing as well as the prevalence and incidence of detection of precancerous lesions have been based on cohort studies of HIV-infected men who have sex with men who have undergone repeated concurrent anal cytology and HRA evaluations. The efficacy of these anal cancer screening tools in HIV-positive women is unknown as clinical practices around screening for anal cancer have been inconsistent among HIV-positive women, despite potential for early detection and removal of precancerous lesions (Heard et al., 2015; Wells, Holstad, Thomas, & Bruner, 2014).This is especially concerning given that studies have found 30-50% of HIV-infected women with abnormal anal cytology did not undergo the recommended follow-up HRA (Baranoski, Tandon, Weinberg, Huang, & Stier, 2012; Hessol et al., 2009). Studies of anal cancer screening with anal cytology and concurrent HRA with directed biopsies in HIV-infected women are now underway; these studies will provide the needed data to determine prevalence and incidence of precancerous anal lesions as well as the performance characteristics of anal cytology, anal HPV testing and HRA for HIV-infected women (Chiao & Stier, 2012; Heard et al., 2015; Palefsky & Berry, 2014).

Current evidence concerning the acceptability of anal cancer screening in HIV-infected persons has also focused on men who have sex with men (Reed, Reiter, Smith, Palefsky, & Brewer, 2010), with less attention given to women (Ferron et al., 2011; Miguez, Burbano-Levy, Rosenberg, & Malow, 2011). Since HIV-infected women have a high prevalence of depression and significant history of trauma and sexual violence (Kimerling et al., 1999; Machtinger, Wilson, Haberer, & Weiss, 2012; McIntosh & Rosselli, 2012), understanding acceptability of anal cancer screening and willingness to participate in needed research involving concurrent testing with HRA among this group is critical to designing patient-

centered screening programs. This is especially salient given the lower rates of participation in medical care among women who have experienced abuse and trauma following an HIV diagnosis (Maniglio, 2009). Those who experience trauma may demonstrate increased sensitivity to physiologic symptoms of anxiety and pain and be more likely to expect the worst compared to individuals without trauma or PTSD (Foa, Hembree, & Rothbaum, 2007). These are important considerations when engaging this vulnerable population in anal cancer screening strategies and warrant further examination. Ensuring the acceptability of concurrent anal cancer screening research among women needs to be evaluated in conjunction with clinical outcomes. To date there has been no examination of health beliefs about anal cancer screening research among a vulnerable population of HIV-infected women. Therefore, we assessed the barriers and motivators to participation in anal cancer screening research among urban HIV-infected women.

Material and Methods

We conducted a cross-sectional survey measuring attitudes and beliefs about anal cancer screening research to identify characteristics of women who indicate they would be willing to participate in these studies. HIV-infected adult, English-speaking women presenting for HIV-related care at two urban HIV practices in Texas and Massachusetts were eligible for this study. The two sites, who serve similar patient populations, jointly developed this survey as part of a collaboration through the AIDS Malignancy Consortium Behavioral Working Group. Eligible patients were approached before or after scheduled appointments and invited to participate. A convenience sample of 200 consecutive eligible women was recruited between March 2011 and June 2013. [Institution names blinded by *WHI* editors for peer review] Institutional Review Boards approved this study.

Survey Development and Study Measures

We constructed a survey based on the Health Belief Model (HBM) theoretical framework (Becker, 1974). Questions were adapted from prior studies examining similar topics to measure the HBM theoretical constructs. Knowledge about anal cancer was adapted from the National Cancer Institute and UNC Men's Health Survey (Reiter, Brewer, & Smith, 2010). Measures of perceived susceptibility (Byrd, Peterson, Chavez, & Heckert, 2004) and perceived harms and barriers (Johnson, Mues, Mayne, & Kiblawi, 2008) were adapted from studies conducted in similar populations. Beliefs about anal cancer, research, and screening were rated on a five-point Likert scale, with possible responses ranging from strongly disagree to strongly agree.

Psychosocial parameter measures included self-efficacy, depression, physical and sexual trauma, and Post-Traumatic Stress Disorder (PTSD). Self-efficacy was measured using a validated measurement adapted from the Communication and Attitudinal Self-Efficacy scale (Clayman et al., 2010). Depression was measured using a 2-item depression screening tool (Kroenke, Spitzer, & Williams, 2003), PTSD with a checklist (Blanchard, Jones, Buckley, & Forneris, 1996; Walker, Newman, Dobie, Ciechanowski, & Katon, 2002), and trauma with a 10-item questionnaire (McIntyre et al., 1999), all with demonstrated reliability and validity. Willingness to participate in anal cancer screening research was assessed using a 5-point

Likert scale with the question, “If you were invited to participate in a research study that included having **both** an anal Pap **and** high resolution anoscopy with possible biopsy, how likely are you to participate?”. We also inquired about factors that would facilitate participation in anal cancer screening research with six dichotomous items.

Data Collection

Interviews were conducted by trained research assistants in a private room after obtaining written informed consent. Surveys were conducted independent of the clinical team to ensure participant confidentiality and minimize response bias. Women were provided a brief educational overview of HPV and anal cancer prior to survey administration. Survey interviews lasted between 30 and 60 minutes. Participants were given an honorarium for participation.

Clinical data was abstracted from the electronic medical record to supplement survey responses. Abstracted items included history of cervical and anal cytology, smoking status, date of HIV diagnosis, HIV infection risk factors, most recent HIV viral load, as well as current and nadir CD4 T-cell counts.

Data Analysis

Descriptive statistics assessed the socio-demographic, clinical, and psychosocial characteristics of the study population. Likert responses for knowledge, attitudes, and beliefs were dichotomized into agree/disagree categories. Willingness to participate in anal cancer screening research was also analyzed as a binary outcome (likely/not likely). Neutral or not sure categories were grouped with the disagree responses. Participants may choose the midpoint option on a survey for several reasons: They perhaps have no opinion, or it may be the socially acceptable method of indicating they do not know (Sturgis, Roberts, & Smith, 2014). Thus, we concluded that these responses were more similar to the disagree category, and therefore reserved the agree/likely categories for those women most willing to participate in these behaviors, as it was the more conservative estimate of likelihood. Bivariate analyses using Chi-square and Fisher's Exact Tests examined associations between willingness to participate in research and socio-demographics, clinical characteristics, and health beliefs. Logistic regression modeled willingness to participate in research with significant bivariate associations included as independent variables. All tests were two-tailed with a statistical significance level set at p=0.05. Analysis was conducted using SAS version 9.1 (“SAS version 9.1.3,” 2002-2004).

Results

A total of 266 women were invited to participate and 200 eligible women completed the survey (75% response rate). Table 1 displays the demographic composition of the sample. The majority reported heterosexual contact as their risk factor for HIV infection. Almost half had nadir CD4 counts less than 200 cells/mm^3; with most having a recent viral load of ≤75 copies/mL, reflecting prevalent combination anti-retroviral therapy use. Ninety-eight percent had a prior cervical Pap test, 36% had a history of colposcopy, 24% had a prior anal Pap test, and 8% had a prior high resolution anoscopy (HRA) on record. Thirty-seven

percent screened positive for depression, 43% reported high trauma history and 36% screened positive for PTSD.

Table 1 also demonstrates that 65% of women sampled reported they were willing to participate in anal cancer screening research. Those who were likely to participate were older, reported intravenous drug use as their HIV risk factor, and had a history of prior HRA compared to those who reported they were unlikely to participate in research with anal Pap test and HRA (**Table 1**).

Table 2 displays participant knowledge, attitudes and beliefs about anal cancer and screening. While most participants agreed that HPV can cause anal cancer, 46% agreed that HIV increases the risk of anal cancer, and only 13% felt well informed about anal cancer. Less than half perceived themselves to be at personal risk for anal cancer. The most commonly reported barriers to anal Pap testing included fear of sexual assault flashbacks and pain associated with the test, although neither were significantly related to willingness to participate in research involving anal pap and HRA. Additional analyses (data not shown) indicated high trauma scores were associated with the belief that the anal pap test could cause sexual assault flashbacks (p=0.017, Fisher's exact test). Women identified altruism, gift card reimbursement and transportation as facilitators of participation in anal cancer screening research (**Table 3**).

When factors associated with willingness to participate with research were assessed using multivariate logistic regression, only two predictors, *lack of concern about pain* with the procedure and *history of HRA* were independently associated with willingness to enroll in an anal cancer screening research study (**Table 4**). Specifically, women concerned that the anal Pap test would be painful were 75.6% less likely to be willing to participate in research involving anal cancer screening (OR: 0.244; 95% CI: 0.11, 0.54). Conversely, those women who previously underwent a high resolution anoscopy had significantly increased odds of being willing to participate in anal cancer screening research (OR: 9.34; 95% CI: 1.70, 51.2).

Discussion

To our knowledge, this study is the first to examine health beliefs about anal cancer, screening, and research among a vulnerable population of HIV-infected women. We recruited a racially and ethnically-diverse population who reported high levels of prior physical or sexual trauma and PTSD. While only half perceived themselves to be at risk for anal cancer, almost all perceived a benefit to anal cancer screening using the anal Pap test. Most participants reported they were willing to participate in research involving anal Pap and HRA. Prior HRA experience and lack of concern about pain were the only factors that predicted willingness to participate in research in adjusted analyses.

PTSD and trauma have been shown to be associated with chronic pain (Pacella, Hruska, & Delahanty, 2013) and 36% of our sample had a positive PTSD screen and 43% had a high trauma score. Those who experience trauma may demonstrate increased sensitivity to physiologic symptoms of anxiety and pain and be more likely to expect the worst compared

to individuals without trauma or PTSD (Foa et al., 2007). These are important considerations when engaging this vulnerable population in anal cancer screening strategies and warrant further examination.

Knowledge and health beliefs relating to HPV and anal cancer did not appear to drive behavior in this sample. Instead, willingness to participate in research including anal Pap and HRA was associated with prior experience with HRA. Others have reported that women who have had a cervical Pap test were more likely to have another cervical Pap test which may be due to increased self-efficacy related to positive prior experiences (Fernandez et al., 2009). Future research should examine these links between prior health care experience and beliefs in predicting use of anal cancer screening tests.

Participants reported that altruism and monetary rewards facilitated participation in research. These findings are concordant with previous results among similar minority populations that suggest altruism is commonly reported as a reason for participation in AIDS-related research (Gwadz et al., 2006; Huang & Coker, 2008; Sengupta et al., 2000). Sengupta et al. found that altruism was the sole factor significantly associated with minorities being willing to participate in AIDS survey and educational research specifically (Sengupta et al., 2000). However, another study found that women at risk for HIV infection were more likely than men to provide other reasons for study participation beyond altruism, including financial incentives, health counseling, and free health care (Colfax et al., 2005). This is consistent with our findings suggesting that recruitment efforts should target multiple motivators. However, understanding the importance of altruism along with other incentives is key to improving representation of minority women in HIV-related research, as this group is currently under-represented in many types of trials (Huang & Coker, 2008), with large regional variation across the US (Heumann et al., 2015).

Although our study is the first to evaluate anal cancer screening and anal cancer research participation in women, there are limitations. Our findings may not be generalizable to the U.S. population of women living with HIV/AIDS because they were only recruited from two sites. Nonetheless, the demographic profile of the participants is similar to that of the HIV-infected population in the United States, which is predominantly Black and Hispanic (“HIV/AIDS Statistics and Surveillance,” 2013).

Implications for Practice and/or Policy

In order to increase participation of HIV-infected women in anal cancer screening research, it is vital to understand the perceptions of the target community and to develop culturally competent messages that address both barriers and motivators to anal cancer screening. Increasing knowledge and addressing concerns about pain may increase study enrollment as well as participation in clinical care. Post-procedure pain is a well-documented feature of the HRA procedure, and as we identified, concerns of pain may be a barrier to undergoing these procedures. Therefore, realistic expectations should be established by providers that stress the potential importance of these procedures. This is particularly salient as HIV-positive patients have been found to be likely to require repeat procedures due to recurrence of abnormalities over time (Chang, Berry, Jay, Palefsky, & Welton, 2002). In addition, guidelines for examining HIV-infected women who are more likely to have experienced

sexual trauma in the past recommend that physicians be frank about and pain and discomfort that might be experienced during procedures as a means of providing appropriate care to this population (Aaron, Criniti, Bonacquisti, & Geller, 2013; Coles & Jones, 2009).

One of the challenges faced by practices seeking to engage HIV-positive women in concurrent anal cancer screening research with HRA is the high rates of abuse and trauma among women living with HIV (Fergusson, Boden, & Horwood, 2008), which may prevent women from participating in care (Maniglio, 2009). Given the prevalence of past trauma and PTSD in this patient population, there is a need to provide trauma-informed care both in the research and clinical settings. HIV-infected women with a history of abuse have been shown to perceive a lack of control during medical encounters that results in decreased feelings of safety (Schachter, Radomsky, Stalker, & Teram, 2004). These feelings may be exacerbated when being asked to participate in research involving gynecological-like procedures that could invoke memories of trauma (Robohm & Buttenheim, 1997). This, along with our finding of an association between high trauma scores and the fear of sexual assault flashbacks, suggests clinics seeking to recruit women into anal cancer screening trials could benefit from developing a culture of trauma-informed care. There are several models of providing trauma informed care in HIV-infected populations. These emphasize that it is important to 1) understand there are ramifications in marginalizing the impact of trauma on a woman's life, 2) recognize that common practices may trigger reactions, and 3) provide trauma-informed services at all levels of interaction, from staff to clinicians (Aaron et al., 2013; Elliott, Bjelajac, Fallot, Markoff, & Reed, 2005; Jennings, 2004).

Possible approaches to increasing recruitment among women who do not have prior experience with this set of procedures is to use testimonials or narratives provided by HIV-infected women describing their thoughts and experiences with their first HRA. There are several interventions that have used narratives to change both behaviors and attitudes (Berkley-Patton, Goggin, Liston, Bradley-Ewing, & Neville, 2009; Houston et al., 2011). Role model stories have been successfully used as an HIV prevention strategy targeting minorities through culturally tailored narratives that model health risk reduction behaviors (Berkley-Patton et al., 2009). Further, peers have been shown to enhance the credibility of health messages among those who share the experience of living with HIV (Raja et al., 2008). The results of our research, along with patient focus groups, have informed the content of one such testimonial video targeting participation in anal cancer screening research among HIV-infected women. This tool is currently used by the AIDS Malignancy Consortium Behavioral Working Group to recruit to active clinical trials. Tailoring narratives to specific diseases, procedures, patient populations, or clinical trials may improve the ability to overcome embarrassment, complete research in a timely manner, and integrate findings into clinical practice. These tools may also help normalize behaviors among specific populations and build self-efficacy through modeling successful behavioral strategies, a process supported by social cognitive theory (Bandura, 2001).

The goals of these studies utilizing concurrent anal cytology and HRA for detection of anal lesions are to inform economic analyses and guidelines for preventing anal cancer in HIV-positive women. The cohort studies of HIV-positive MSM have provided a wealth of data on the prevalence and incidence of AIN2-3 lesions as well as estimates of the performance

characteristics of anal cytology for the detection of AIN2-3. Many providers caring for HIV-positive MSM are screening these patients for anal cancer precursors. However, the lack of information available for HIV-positive female cohorts has meant that providers are less likely to consider screening these patients. The data that will be obtained from the ongoing cohort studies with concurrent anal cytology and HRA will allow us to estimate the performance characteristics of the anal Pap and HPV tests in HIV-positive women. The information gained from these anal cancer screening studies in HIV-positive women will provide the necessary data to educate women and their providers about anal cancer risks and prevention as well as allow the development of anal cancer prevention guidelines.

Conclusion

Understanding the barriers and motivators to participation in anal Pap and HRA are critical in defining the role of these new technologies as standard procedures for anal cancer prevention. Our findings indicate that even among a vulnerable population, HIV-infected women are amenable to participating in anal cancer screening research. While knowledge, beliefs, and psychosocial issues did not appear to be driving factors resulting in willingness to participate in research among this sample, several mutable factors were identified. Prior experience with study-related procedures and fear of pain indicate targets where behavioral interventions might prove useful. In addition, altruism and compensation were motivators for participation. These data suggest that to increase participation in anal Pap and HRA-related research for HIV-infected women, one single approach may not be adequate. Rather, we must harness patients' previous experiences and address psychosocial and financial concerns to overcome barriers to participation.

Acknowledgements

This work was supported by the National Institute of Health/National Cancer Institute under Grant U10 CA139519-02S; National Cancer Institute Center to Reduce Cancer Health Disparities under Grant NCI U01 CA116892-0551; Boston Medical Center Minority-Based Community Clinical Oncology Program under Grant NCI 1U-10CA129519-01A1; the AIDS Malignancy Consortium under Grant U01 CA121947; and the Houston Health Services Research and Development Center for Excellence under Grant FP90-020.

References

Aaron E, Criniti S, Bonacquisti A, Geller PA. Providing Sensitive Care for Adult HIV-Infected Women With a History of Childhood Sexual Abuse. Journal of the Association of Nurses in AIDS Care. 2013; 24(4):355–367. doi: 10.1016/j.jana.2013.03.004. [PubMed: 23790278]

Bandura A. Social cognitive theory: An agentic perspective. Annual Review of Psychology. 2001; 52:1–26. doi: 10.1146/annurev.psych.52.1.1.

Baranoski AS, Tandon R, Weinberg J, Huang FF, Stier EA. Risk factors for abnormal anal cytology over time in HIV-infected women. Am J Obstet Gynecol. 2012; 207(2):107, e101–108. doi: 10.1016/j.ajog.2012.03.030. [PubMed: 22520651]

Becker, M. Health Belief Model and Personal Health Behavior. Slack, Inc.; Thorofare, NJ: 1974.

Berkley-Patton J, Goggin K, Liston R, Bradley-Ewing A, Neville S. Adapting Effective Narrative-based HIV Prevention Interventions to Increase Minorities' Engagement in HIV/AIDS Services. Health communication. 2009; 24(3):199–209. doi: 10.1080/10410230902804091. [PubMed: 19415552]

Blanchard EB, Jones AJ, Buckley TC, Forneris CA. Psychometric properties of the PTSD checklist (PCL). Behaviour Research and Therapy. 1996; 34(8):669–673. doi: 10.1016/0005-7967(96)00033-2. [PubMed: 8870294]

Byrd TL, Peterson SK, Chavez R, Heckert A. Cervical cancer screening beliefs among young Hispanic women. Preventive Medicine. 2004; 38(2):192–197. doi: 10.1016/j.ypmed.2003.09.017. [PubMed: 14715211]

Chang GJ, Berry JM, Jay N, Palefsky JM, Welton ML. Surgical treatment of high-grade anal squamous intraepithelial lesions: a prospective study. Dis Colon Rectum. 2002; 45(4):453–458. [PubMed: 12006924]

Chiao E, Stier E. AMC #084: Screening HIV-Infected Women for Anal Cancer Precursors: AIDS Malignancy Clinical Trials Consortium. 2012

Clayman ML, Pandit AU, Bergeron AR, Cameron KA, Ross E, Wolf MS. Ask, Understand, Remember: A Brief Measure of Patient Communication Self-Efficacy Within Clinical Encounters. Journal of Health Communication. 2010; 15:72–79. doi: 10.1080/10810730.2010.500349. [PubMed: 20845194]

Coles J, Jones KT. “Universal Precautions”: Perinatal touch and examination after childhood sexual abuse. Birth. 2009; 36(3):230–236. [PubMed: 19747270]

Colfax G, Buchbinder S, Vamshidar G, Celum C, McKirnan D, Neidig J, Bartholow B. Motivations for participating in an HIV vaccine efficacy trial. Jaids-Journal of Acquired Immune Deficiency Syndromes. 2005; 39(3):359–364. doi: 10.1097/01.qai.0000152039.88422.ec.

Crum-Cianflone NF, Hullsiek KH, Marconi V, Weintrob A, Ganesan A, Barthel RV, Agan BK. Trends in the incidence of cancers among HIV-infected persons and the impact of antiretroviral therapy: authors' reply. Aids. 2009; 23(13):1791–1792. doi: 10.1097/QAD.0b013e32832cb296. [PubMed: 19684484]

D'Souza G, Cook RL, Ostrow D, Johnson-Hill LM, Wiley D, Silvestre T. Anal cancer screening behaviors and intentions in men who have sex with men. Journal of General Internal Medicine. 2008; 23(9):1452–1457. doi: 10.1007/s11606-008-0698-6. [PubMed: 18618198]

Elliott DE, Bjelajac P, Fallot RD, Markoff LS, Reed BG. Trauma-informed or trauma-denied: Principles and implementation of trauma-informed services for women. Journal of Community Psychology. 2005; 33(4):461–477. doi: 10.1002/jcop.20063.

Fergusson D, Boden J, Horwood L. Exposure to childhood sexual and physical abuse and adjustment in early adulthood. Child abuse and neglect. 2008; 32(6):607–619. [PubMed: 18565580]

Fernandez ME, Diamond PM, Rakowski W, Gonzales A, Tortolero-Luna G, Williams J, Morales-Campos DY. Development and Validation of a Cervical Cancer Screening Self-Efficacy Scale for Low-income Mexican American Women. Cancer Epidemiology Biomarkers & Prevention. 2009; 18(3):866–875. doi: 10.1158/1055-9965.epi-07-2950.

Ferron P, Young S, Doyle F, Symes S, Powell A, Diaz-Mendez N, Rosa-Cunha I. A Case Illustration About the Importance of Integrating Women's Anal Health in an HIV Primary Care Clinic. Janac-Journal of the Association of Nurses in Aids Care. 2011; 22(6):489–493. doi: 10.1016/j.jana.2011.08.005.

Foa, E.; Hembree, E.; Rothbaum, B. Prolonged Exposure Therapy for PTSD: Emotional Processing of Traumatic Experiences, Therapist Guide. Oxford University Press; New York, NY: 2007.

Gwadz MV, Leonard NR, Nakagawa A, Cylar K, Finkelstein M, Herzog N, Mildvan D. Gender differences in attitudes toward AIDS clinical trials among urban HIV-infected individuals from racial and ethnic minority backgrounds. AIDS Care. 2006; 18(7):786–794. doi: 10.1080/09540120500428952. [PubMed: 16971289]

Heard I, Etienney I, Potard V, Poizot-Martin I, Moore C, Lesage A-C, Darragh TM. High Prevalence of Anal Human Papillomavirus– Associated Cancer Precursors in a Contemporary Cohort of Asymptomatic HIV-Infected Women. Clinical Infectious Diseases. 2015 doi: 10.1093/cid/civ049.

Hessol N, Holly EA, Efrid J, Minkoff H, Schowalter K, Darragh T, Palefsky J. Anal intraepithelial neoplasia in a multisite study of HIV-infected and high-risk HIV-uninfected women. AIDS Behav. 2009; 23(1):59–70.

Heumann C, Cohn SE, Krishnan S, Castillo-Mancilla JR, Cespedes M, Floris-Moore M, Smith KY. Regional Variation in HIV Clinical Trials Participation in the United States. Southern Medical Journal. 2015; 108(2):107–116. doi: 10.14423/SMJ.0000000000000234. [PubMed: 25688896]

[March 9, 2015] HIV/AIDS Statistics and Surveillance. Feb 23. 2013 2015, from http://www.cdc.gov/hiv/pdf/g-l/cdc-hiv-genepislideseries-2013.pdf

Houston TK, Allison JJ, Sussman M, Horn W, Holt CL, Trobaugh J. Culturally appropriate storytelling to improve blood pressure: a randomized trial. Annals of Internal Medicine. 2011; 154:77–84. [PubMed: 21242364]

Huang, H.-h.; Coker, AD. Examining Issues Affecting African American Participation in Research Studies. Journal of Black Studies. 2008 doi: 10.1177/0021934708317749.

Jay N, Berry JM, Hogeboom CJ, Holly EA, Darragh TM, Palefsky JM. Colposcopic appearance of anal squamous intraepithelial lesions - Relationship to histopathology. Diseases of the Colon & Rectum. 1997; 40(8):919–928. doi: 10.1007/bf02051199. [PubMed: 9269808]

Jennings A. Models for Developing Trauma-Informed Behavioral Health Systems and TraumaSpecific Services. 2004

Johnson CE, Mues KE, Mayne SL, Kiblawi AN. Cervical Cancer Screening Among Immigrants and Ethnic Minorities: A Systematic Review Using the Health Belief Model. Journal of Lower Genital Tract Disease. 2008; 12(3):232–241. doi: 10.1097/LGT.0b013e31815d8d88. [PubMed: 18596467]

Kimerling R, Calhoun KS, Forehand R, Armistead L, Morse E, Morse P, Clark L. Traumatic stress in HIV-infected women. AIDS Educ Prev. 1999; 11(4):321–330. [PubMed: 10494356]

Kroenke K, Spitzer RL, Williams JBW. The Patient Health Questionnaire-2 - Validity of a two-item depression screener. Medical Care. 2003; 41(11):1284–1292. doi: 10.1097/01.mlr.0000093487.78664.3c. [PubMed: 14583691]

Machtinger EL, Wilson TC, Haberer JE, Weiss DS. Psychological trauma and PTSD in HIV-positive women: a meta-analysis. AIDS Behav. 2012; 16(8):2091–2100. doi: 10.1007/s10461-011-0127-4. [PubMed: 22249954]

Maniglio R. The impact of child sexual abuse on health: A systematic review of reviews. Clinical Psychology Review. 2009; 29(7):631–642.

McIntosh RC, Rosselli M. Stress and coping in women living with HIV: a meta-analytic review. AIDS Behav. 2012; 16(8):2144–2159. doi: 10.1007/s10461-012-0166-5. [PubMed: 22434282]

McIntyre LM, Butterfield MI, Nanda K, Parsey K, Stechuchak KM, McChesney AW, Bastian LA. Validation of a trauma questionnaire in veteran women. Journal of General Internal Medicine. 1999; 14(3):186–189. doi: 10.1046/j.1525-1497.1999.00311.x. [PubMed: 10203625]

Miguez MJ, Burbano-Levy X, Rosenberg R, Malow R. The Importance of HIV Status and Gender When Designing Prevention Strategies for Anal Cancer. Janac-Journal of the Association of Nurses in Aids Care. 2011; 22(6):454–464. doi: 10.1016/j.jana.2011.08.015.

Pacella M, Hruska B, Delahanty D. The physical health consequences of PTSD and PTSD symptoms: a meta-analytic review. Journal of anxiety disorders. 2013; 27(1):33–46. [PubMed: 23247200]

Palefsky, JM.; Berry, JM. ANCHOR Study: Anal Cancer/HSIL Outcomes Research Study. National Cancer Institute (AMC Protocol A01); 2014. p. 126

Palefsky JM, Rubin M. The epidemiology of anal human papillomavirus and related neoplasia. Obstet Gynecol Clin North Am. 2009; 36(1):187–200. doi: 10.1016/j.ogc.2009.02.003. [PubMed: 19344856]

Raja S, Teti M, Knauz R, Echenique M, Capistrant B, Rubinstein S, Glick N. Implementing peer-based interventions in clinic-based settings: Lessons from a multi-site HIV prevention with positives initiative. Journal of HIV/AIDS & Social Services. 2008; 7:7–26.

Reed AC, Reiter PL, Smith JS, Palefsky JM, Brewer NT. Gay and Bisexual Men's Willingness to Receive Anal Papanicolaou Testing. American Journal of Public Health. 2010; 100(6):1123–1129. doi: 10.2105/ajph.2009.176446. [PubMed: 20395576]

Reiter PL, Brewer NT, Smith JS. Human papillomavirus knowledge and vaccine acceptability among a national sample of heterosexual men. Sexually Transmitted Infections. 2010; 86(3):241–246. doi: 10.1136/sti.2009.039065. [PubMed: 19951936]

Robohm J, Buttenheim M. The gynecological care experirence of adult suvivors of childhood sexual abuse: A preliminary investigation. Women & Health. 1997; 24(3):59–75. [PubMed: 9046553]

SAS version 9.1.3. (2002-2004). SAS Institute Inc.; Cary, NC:

Schachter C, Radomsky N, Stalker C, Teram E. Women survivors of child sexual abuse: How can health professionals promote healing? Canadian Family Physician. 2004; 50:405–412. [PubMed: 15318678]

Sengupta S, Strauss RP, DeVellis R, Quinn SC, DeVellis B, Ware WB. Factors Affecting African-American Participation in AIDS Research. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2000; 24(3):275–284. [PubMed: 10969353]

Shridhar R, Shibata D, Chan E, Thomas CR. Anal cancer: Current standards in care and recent changes in practice. CA Cancer J Clin. 2015 doi: 10.3322/caac.21259.

Silverberg MJ, Lau B, Justice AC, Engels E, Gill MJ, Goedert JJ, Dubrow R. Risk of Anal Cancer in HIV-Infected and HIV-Uninfected Individuals in North America. Clinical Infectious Diseases. 2012; 54(7):1026–1034. doi: 10.1093/cid/cir1012. [PubMed: 22291097]

Sturgis P, Roberts C, Smith P. Middle Alternatives Revisited: How the neither/nor Response Acts as a Way of Saying “I Don't Know”? Sociological Methods & Research. 2014; 43(1):15–38. doi: 10.1177/0049124112452527.

Walker EA, Newman E, Dobie DJ, Ciechanowski P, Katon W. Validation of the PTSD checklist in an HMO sample of women. General Hospital Psychiatry. 2002; 24(6):375–380. doi: 10.1016/s0163-8343(02)00203-7. [PubMed: 12490338]

Wells JS, Holstad MM, Thomas T, Bruner DW. An integrative review of guidelines for anal cancer screening in HIV-infected persons. AIDS Patient Care STDS. 2014; 28(7):350–357. doi: 10.1089/apc.2013.0358. [PubMed: 24936878]

Table 1

Socio-demographic and Clinical Characteristics by Willingness to Participate in Research

	WILLINGNESS TO PARTICIPATE IN RESEARCH WITH ANAL PAP + HRA			
	Total N (%)	LIKELY (%)	UNLIKELY (%)	p-value
	200	65.0	35.0	
Age				**0.03***
<40 yrs	51 (26)	21.5	32.9	
40-49 yrs	73 (37)	33.9	41.4	
50+ yrs	76 (38)	44.6	25.7	
Race				0.24
White	22 (11)	10.8	11.4	
Black	153 (77)	73.8	81.4	
Hispanic	25 (13)	15.4	7.1	
U.S. Born	169 (85)	83.9	85.7	0.73
Educational Attainment				0.88
<High School	70 (35)	36.4	32.9	
High School	74 (37)	36.4	38.6	
College+	55 (28)	27.1	28.6	
Insurance				0.99
Private	30 (15)	15.8	14.9	
Public	129 (65)	66.1	67.2	
Uninsured	35 (18)	18.1	17.9	
Married (yes)	22 (11)	13.9	5.7	0.08
HIV Exposure Route				**0.02***
IVDU	37 (19)	22.3	11.4	
Sex	149 (75)	73.9	75.7	
Other/Unknown	14 (7)	3.9	12.9	
Nadir CD4 count				0.33
<200	94 (47)	43.9	52.9	
200-349	17 (9)	10.0	5.7	
350-500	70 (35)	34.6	35.7	
>500	19 (10)	11.5	5.7	
Most Recent Viral Load				0.44
<76	126 (63)	66.2	57.1	
76-10,000	38 (19)	17.7	21.4	
10,000+	36 (18)	16.1	21.4	
History of Cervical Pap Test (yes)	196 (98)	96.9	100.0	0.30
History of Colposcopy (yes)	71 (36)	32.0	45.6	0.06
History of Anal Pap Test (yes)	48 (24)	26.9	18.6	0.19

	WILLINGNESS TO PARTICIPATE IN RESEARCH WITH ANAL PAP + HRA			
	Total N (%)	**LIKELY (%)**	**UNLIKELY (%)**	**p-value**
	200	**65.0**	**35.0**	
History of High Resolution Anoscopy	16 (8)	10.8	2.9	**0.05***
Positive Depression Screening	73 (37)	39.3	31.4	0.27
High Trauma Screening	85 (43)	40.0	47.1	0.33
Positive PTSD Screening	72 (36)	33.9	40.0	0.39

* $p < 0.05$

Table 2

Health Beliefs about Anal Cancer Screening by Willingness to Participate in Research

	Health Belief Variable	Total (N)	Likely (%)	Unlikely (%)	p-value
Knowledge	HPV can cause anal cancer	111	56.9	52.9	0.58
	HIV increases chances of anal cancer	91	49.2	38.6	0.15
	I am well informed about anal cancer	26	13.1	12.9	0.96
Perceived Susceptibility	I am at risk for anal cancer	90	47.7	40.0	0.30
Perceived Benefit	Anal Pap test can find abnormalities before it's cancer	198	98.5	100.0	0.54
	Anal Pap test is important to know I'm healthy	193	97.7	94.3	0.21
	If abnormal cells are found early it's easily cured	195	96.2	100.0	0.16
Barriers	Medical instruments used in anal Pap test may harm me e.g. cause bleeding, infection, cancer	19	7.7	12.9	0.23
	I don't trust hospital/staff giving anal Pap	7	2.3	5.7	0.21
	Anal Pap can cause sexual assault flashbacks	46	23.9	21.4	0.70
	The anal Pap test is painful	46	16.2	35.7	**<0.01***
	Too embarrassing to have an anal Pap test	35	14.6	22.9	0.14
	I don't have family or community support	40	23.9	12.9	0.06
	It is too expensive to have an anal Pap test	21	9.2	12.9	0.42
	Scheduling issues/under-staffed/overbooking	18	6.9	12.9	0.16
	Don't want to know anal Pap test results or if I have a disease	13	4.6	10.0	0.14
	No point in getting an anal Pap if I am going to die of anal cancer or other causes	15	6.2	10.0	0.32

Table 3

Factors that Increase Willingness to Participate in Research

Facilitating Factor	Total (N)	Likely (%)	Unlikely (%)	p-value
Knowing this study will help other women	182	95.4	82.9	**<0.01***
Getting a gift card for each visit	148	83.9	55.7	**<0.01***
Being provided with transportation to and from visit	140	80.6	51.4	**<0.01***
Having a female doctor do the study	122	64.6	54.3	0.25
Having the option of sedation for the procedure	146	77.5	65.7	0.09
Having a friend/family member present	89	49.2	35.7	0.07

Table 4

Logistic Regression for Willingness to Participate in Research with HRA

	Odds Ratio (95% CI)
Age (reference: less than 40)	
40-49	0.866 (0.39, 1.92)
50+	1.944 (0.85, 4.46)
Race (reference: white)	
Black	0.997 (0.36, 2.75)
Hispanic	3.241 (0.77, 13.69)
Insurance (reference: private)	
Public	0.640 (0.25, 1.65)
Uninsured	0.839 (0.24, 2.89)
Site (reference: TX)	
	0.961 (0.47, 1.97)
Pain (reference: pain not a barrier)	
	0.244 (0.11, 0.54)*
HRA (reference: no history of HRA)	
	9.338 (1.70, 51.18)*
Overall model: Likelihood ratio χ^2=26.08, DF=9, P=0.002 c-statistic=0.713	

* p<0.05