



Original article

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



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A B S T R A C T

Background: Infection with the human immunodeficiency virus (HIV) remains associated with a greater risk of anal cancer, despite widespread use of combination antiretroviral therapy. Evidence concerning the acceptability of anal cancer screening gives little attention to women. Because HIV-infected women have a high prevalence of depression and history of sexual trauma, understanding acceptability among this group is critical.

Purpose: We sought to assess barriers and motivators to participation in anal cancer screening research among a racial/ethnically diverse HIV-infected female population.

Methods: We conducted a survey based on the Health Belief Model to identify characteristics of women willing to participate in anal cancer screening research ($n = 200$). Bivariate analyses examined associations between willingness to participate and sociodemographics, clinical characteristics, and health beliefs. Logistic regression modeled willingness to participate in research.

Main Findings: Of the women who participated, 37% screened positive for depression, 43% reported a high trauma history, and 36% screened positive for posttraumatic stress disorder. Overall, 65% reported willingness to participate in research. Those likely to participate were older, reported intravenous drug use as their HIV risk factor, and had a history of prior high-resolution anoscopy (HRA) compared with those unwilling to participate. The most commonly reported barrier to anal Pap testing was fear of pain. In adjusted analyses, a lack of fear of pain and prior experience with HRA significantly predicted willingness to participate.

Conclusions: Findings suggest that, to increase participation in anal Pap and HRA-related research for HIV-infected women, a single approach may not be adequate. Rather, we must harness patients' previous experiences and address psychosocial and financial concerns to overcome barriers to participation.

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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 (Shridhar, Shibata, Chan, & Thomas, 2015). Even with the widespread use of combination antiretroviral therapy,

infection with the human immunodeficiency virus (HIV) is increasingly associated with a higher risk of anal cancer (Crum-Cianflone et al., 2009; D'Souza et al., 2008). Although 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 with 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

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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](#)). Because 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 the 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 after being diagnosed with HIV ([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 with individuals without trauma or posttraumatic stress disorder (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, which 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. The local institutional review boards approved this study.

Survey Development and Study Measures

We constructed a survey based on the Health Belief Model theoretical framework ([Becker, 1974](#)). Questions were adapted from prior studies examining similar topics to measure the Health Belief Model theoretical constructs. Knowledge about anal cancer was adapted from the National Cancer Institute and University of North Carolina 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 5-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 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 sociodemographic, 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, because it was the more conservative estimate of likelihood. Bivariate analyses using χ^2 and Fisher's exact tests examined associations between willingness to participate in research and sociodemographics, 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 $p = .05$. 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 of less than 200 cells/mm³, with most having a recent viral load of 75 copies/mL or less, reflecting prevalent combination antiretroviral 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 HRA on record. Thirty-seven percent screened positive for depression, 43% reported high trauma history, and 36% screened positive for PTSD.

Table 1 also shows 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 with 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. Although 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. Fewer than one-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 related significantly to willingness to participate in research involving anal pap and HRA. Additional analyses (data not shown) indicated high trauma scores were associated with

Table 1

Sociodemographic and Clinical Characteristics by Willingness to Participate in Research

Characteristic	Willingness to Participate in Research With Anal PAP + HRA			p Value
	Total N (%)	Likely (%)	Unlikely (%)	
	200	65.0	35.0	
Age (y)				.03*
<40	51 (26)	21.5	32.9	
40–49	73 (37)	33.9	41.4	
≥50	76 (38)	44.6	25.7	
Race				.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	.73
Educational attainment				.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				.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	.08
HIV exposure route				.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				.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				.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	.30
History of colposcopy (yes)	71 (36)	32.0	45.6	.06
History of anal pap test (yes)	48 (24)	26.9	18.6	.19
History of high-resolution anoscopy	16 (8)	10.8	2.9	.05*
Positive depression screening	73 (37)	39.3	31.4	.27
High trauma screening	85 (43)	40.0	47.1	.33
Positive PTSD screening	72 (36)	33.9	40.0	.39

Abbreviations: HIV, human immunodeficiency virus; HRA, high-resolution anoscopy; IVDU, intravenous drug use; PTSD, posttraumatic stress disorder.

* $p < .05$.

the belief that the anal pap test could cause sexual assault flashbacks ($p = .017$; 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 associated independently with a 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 (odds ratio [OR], 0.244; 95% CI: 0.11–0.54). Conversely, those women who previously underwent a HRA had significantly increased

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	.58
HIV increases chances of anal cancer.	91	49.2	38.6	.15
I am well-informed about anal cancer.	26	13.1	12.9	.96
Perceived susceptibility				
I am at risk for anal cancer.	90	47.7	40.0	.30
Perceived benefit				
Anal Pap test can find abnormalities before it's cancer.	198	98.5	100.0	.54
Anal Pap test is important to know I'm healthy.	193	97.7	94.3	.21
If abnormal cells are found early it's easily cured.	195	96.2	100.0	.16
Barriers				
Medical instruments used in anal Pap test may harm me e.g. cause bleeding, infection, cancer.	19	7.7	12.9	.23
I don't trust hospital/staff giving anal Pap.	7	2.3	5.7	.21
Anal Pap can cause sexual assault flashbacks.	46	23.9	21.4	.70
The anal Pap test is painful.	46	16.2	35.7	<.01*
Too embarrassing to have an anal Pap test.	35	14.6	22.9	.14
I don't have family or community support.	40	23.9	12.9	.06
It is too expensive to have an anal Pap test.	21	9.2	12.9	.42
Scheduling issues/understaffed/overbooking.	18	6.9	12.9	.16
Don't want to know anal Pap test results or if I have a disease.	13	4.6	10.0	.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	.32

Abbreviation: HPV, human papilloma virus.

* $p < .05$.

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. Although only one-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

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	<.01*
Getting a gift card for each visit	148	83.9	55.7	<.01*
Being provided with transportation to and from visit	140	80.6	51.4	<.01*
Having a female doctor do the study	122	64.6	54.3	.25
Having the option of sedation for the procedure	146	77.5	65.7	.09
Having a friend/family member present	89	49.2	35.7	.07

* $p < .05$.

Table 4
Logistic Regression for Willingness to Participate in Research With HRA

	Odds Ratio (95% CI)
Age, y (reference: <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)*

Abbreviation: HRA, high-resolution anoscopy.

Overall model: Likelihood ratio $\chi^2 = 26.08$, DF = 9, $p = .002$; c-statistic = 0.713.

* $p < .05$.

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 with 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 seem 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 owing 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, 2010; Sengupta et al., 2000). Sengupta et al. (2000) found that altruism was the sole factor significantly associated with minorities being willing to participate in AIDS survey and educational research specifically. 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 underrepresented in many types of trials (Huang & Coker, 2010), with large regional variation across the United States (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

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. Postprocedure pain is a well-documented feature of the HRA procedure and, as we identified, concerns about 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 because HIV-positive patients have been found to be likely to require repeat procedures owing 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, which 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 that 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 to 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 men who have sex with men 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 men who have sex with men 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. Although knowledge, beliefs, and psychosocial issues did not seem 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, a single approach may not be adequate. Rather, we must harness patients' previous experiences and address psychosocial and financial concerns to overcome barriers to participation.

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