Barriers to Recommended Gynecologic Care in an Urban United States HIV Clinic

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Abstract

Background: Despite an increased risk for cervical cytologic abnormalities, HIV-infected women frequently miss their gynecology appointments. We examined barriers to adherence with gynecologic care in an urban HIV clinic.

Methods: We conducted a cross-sectional survey of 200 women receiving gynecologic services in an urban HIV clinic, followed by focus groups. Primary outcomes included (1) missed gynecology appointments and (2) receipt of a Pap smear in the previous year. Independent variables included sociodemographic characteristics, child care responsibilities, substance use, depressive symptoms, social support, interpersonal violence, CD4 count, and HIV-1 RNA. We conducted multivariable logistic regression to examine associations between independent variables and outcomes. We then held two focus groups designed to gather opinions on and increase our understanding of the key findings from the survey.

Results: Of 200 women, 69% missed at least one gynecology appointment, and 22% had no Pap smear in the past year. In logistic regression, moderate (odds ratio [OR] 3.1, 95% confidence interval [CI] 1.4-6.7) and severe (OR 3.1, 95% CI 1.3-7.5) depressive symptoms and past-month substance use (OR 2.3, 95% CI 1.0-5.3) were associated with missing an appointment in the prior year. An education level of less than high school (OR 0.3, 95% CI 0.1-0.6) compared with high school diploma or greater was associated with not having a Pap smear in the previous year. When analyses were limited to women with a cervix ($n = 166$), moderate (OR 2.5, 95% CI 1.1-5.7) and severe (OR 2.5, 95% CI 1.0-6.3) depressive systems remained significantly associated with missing a gynecology appointment in the previous year and age >50 (OR 0.3, 95% CI 0.1-0.9), an HIV-1 RNA >50 (OR 0.4, 95% CI 0.2-0.9), and education level less than high school (OR 0.2, 95% CI 0.1-0.5) were associated with not having a Pap smear in the past 12 months. Qualitative analysis of the focus group data suggested that fear, inclement weather, and forgetting appointments may contribute to missed gynecology appointments.

Conclusion: Gynecologic healthcare is underused among HIV-infected women. We found that depressive symptoms, substance use, fear of the gynecologic examination, and simply forgetting about the appointment may be barriers to gynecologic care. Interventions targeting these barriers may improve use of gynecologic care among this population.

Introduction

WOMEN INFECTED WITH HIV are at increased risk for cervical, vulvar, vaginal, and anal intraepithelial lesions and other gynecologic problems.¹⁻³ Among HIV-infected women, there is a higher prevalence of squamous intraepithelial lesions (SIL) and^{1,2,4} cytologic atypia (such as atypical cells of undetermined significance [ASCUS]), which are more likely to be associated with dysplasia in HIV-infected women compared with HIV-uninfected women.^{1,5,6}

Despite widespread availability of Papanicolaou (Pap) smears, studies have reported that 18%–22% of HIV-infected women have not had a Pap smear in the previous year.⁷⁻⁹ Indeed, a 2006 Quality Improvement Review of HIV primary care services in Baltimore, Maryland, revealed that only 50% of HIV-positive women in Baltimore City had received a Pap smear in the previous year.¹⁰

We recently examined whether HIV-infected women were more likely to miss gynecology appointments compared with their primary care appointments. Using data from the Johns

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Hopkins HIV Clinic, where HIV primary care and gynecologic services are colocated, we determined that the rate of completed clinic visits was significantly lower for HIV gynecologic care (36%) than for HIV primary care (55%) in the same population of women ($p < 0.001$). Factors associated with missed HIV gynecology clinic visits included African American race/ethnicity, substance use, and more advanced immunosuppression.¹¹

Based on the low proportion of HIV-infected women receiving Pap smears in Baltimore City¹⁰ and the high proportion of missed gynecology appointments at our clinic site, we designed the current study to determine modifiable barriers to gynecology appointment adherence. We used quantitative and qualitative methods to further elucidate factors associated with (1) missed gynecology appointments and (2) receipt of a Pap smear in the previous year in an urban sample of HIV-infected women participating in clinical care.

Materials and Methods

Study design

We performed a cross-sectional survey, followed by focus groups of women attending the Johns Hopkins HIV Clinic, in Baltimore, Maryland.

Participants, setting, and recruitment

We recruited 200 women attending the clinic between February 2008 and June 2008. The Johns Hopkins HIV Clinic offers both HIV primary and gynecologic care, colocated within the same site. Participants were recruited from the waiting room and through provider referral. Women were eligible if they were ≥ 18 years of age, English speaking, and received both HIV primary and gynecologic care at the Johns Hopkins HIV Clinic. A \$10.00 cash incentive was provided to all participants. Oral informed consent was obtained, and a copy of the consent was provided to all participants. Institutional Review Board Approval was obtained before the beginning of recruitment.

Survey

The survey comprised of 80 items, querying such demographic characteristics as race/ethnicity, education, and employment, gynecology visit and Pap smear adherence, reasons for missing gynecology appointments, drug and alcohol history, and several psychological constructs, including social support, depression, and interpersonal violence, as well as reasons for missing gynecology appointments. Items to be included in the survey were determined based on a review of the literature of gynecologic care in HIV-infected and all women, missed primary HIV care appointments or missed appointments in general, poor HIV medication adherence, and our previous findings.^{11–16}

Instruments and scales

We used several existent instruments with established reliability and validity: the MOS Social Support Survey,^{17–19} the Center for Epidemiologic Studies Short Depression Scale (CES-D 10),²⁰ and an expanded version of a previously validated partner violence scale,²¹ which also queried emotional abuse.

Social support. The MOS Social Support Survey is a 20-item survey that consists of an overall functional support index with subscales of emotional/informational support, tangible support, affectionate support, and positive social support. The survey begins with the general question: How often is each of the following kinds of support available to you if you need it? Possible answers include always, sometimes, and never. Examples of each of the subscales include: Someone to listen when you need to talk (emotional/informational support); Someone to give you money if you needed it (tangible support); Someone who shows you love and affection (affectionate support); Someone to have a good time with (positive social support). Social support was evaluated as both a continuous and a categorical variable. Based on previous studies using the MOS Social Support Survey, including a published study of HIV-positive women, the total score of the MOS Social Support Survey was converted to a 0–100 scale, with very low support defined as a score of $\leq 25\%$, low as 26%–50%, medium as 51%–75%, and high as $> 76\%$ on the overall functional support index.^{17–19}

Depressive symptoms. The CES-D 10 is a 10-item survey that asks how often respondents have felt a certain way during the past year, with responses on a scale from All of the time to Not at all, for example: I felt depressed. A CES-D score of 10–15 was considered moderate depressive symptoms and > 15 was considered severe depressive symptoms, as previous research has shown that scores > 10 correlate with a clinical diagnosis of depression.²⁰

Intimate partner violence (IPV). The Partner Violence Screen is a screening tool for IPV that asks: Have you been hit, kicked, punched, or otherwise hurt by someone you were in a relationship with in the past year? Do you feel safe from harm in your current relationship? Is there a person from a previous relationship who is making you feel unsafe now? We measured IPV using an expanded version of the Partner Violence Screen,²¹ which also queried emotional abuse, with any Yes response considered positive for IPV.

Medical record and registration data

We linked survey responses with registration, laboratory, and medical records data for each enrollee. All patient appointments are recorded in the registration database regardless of manner of arrangement. Automated registration data included HIV primary care and gynecology clinic visit attendance history. We abstracted demographic information (age), HIV-related medical data, such as CD4 count (cells/mm³), HIV-1 RNA (c/mL), and gynecologic data, including presence or absence of a cervix, a cervical or vaginal pool Pap smear within the past 365 days, a history of an abnormal Pap smear, and if there had been follow-up for the abnormal Pap smear, from the electronic medical record as well as laboratory records.

Outcome variables

Our primary outcome variables included (1) missed gynecology appointments over the past 1 year (yes/no), (2) receipt of a cervical or vaginal pool Pap smear within the past 1 year (yes/no), and (3) either a missed gynecology appointment or no Pap smear within the past year.

Independent variables

Our independent variables of interest were age, race, education, employment status, dependent children in the household, CD4 count (cells/mm³), HIV-1 RNA, substance use in the past month (cocaine, heroin, amphetamine, marijuana, binge alcohol use [>5 drinks/occasion]), social support, depressive symptoms, and IPV.

Analysis

We first performed descriptive analysis of reasons women gave for missed gynecology visits. We then performed bivariate comparisons between our outcomes (missed appointment and the receipt of a cervical or vaginal pool Pap smear in the previous year) and the independent variables of interest using chi-square test (for categorical predictors) or nonparametric Wilcoxon rank sum test (for continuous predictors) considering all women ($n=200$) and only women with a cervix ($n=166$). We then performed analyses of outcomes and independent variables of interest using logistic regression for both groups. All variables were examined, and the most parsimonious models were chosen; predictors that were demographically and clinically significant (such as age, race/ethnicity, CD4 count, viral load) were included regardless of statistical significance, and additional predictors were included if bivariate analyses revealed statistical significance ($p < 0.05$). All statistical analyses were conducted using STATA version 9.

Focus group methods

Focus groups participants. Three investigators (M.A.T., J.G., M.J.) held two focus group sessions; 12 women were invited to each session, and 4–8 attended. This number was based on our previous experience with focus groups and manageable group size for the space available. Women were eligible for the focus group if they were aged ≥ 18 and received HIV primary and gynecologic care at the Johns Hopkins HIV Clinic. Focus group participants were recruited from the group of women who had completed the questionnaire and answered Yes to the last question on the questionnaire: Would you like to be contacted about further research studies? and had provided a contact phone number. Recruitment to the focus groups aimed to select a range of ages and resulted in representation of women aged 20–60 years, including women who frequently miss appointments and women who have excellent compliance with appointments. We contacted these women and provided them with information about the focus group composition and format. If they agreed, we then sent them a packet of information, including the focus group time and meeting place. A \$15.00 cash incentive was provided to all participants.

Focus groups. Oral informed consent was obtained at the beginning of each focus group, and copies of the informed consent were provided to each participant. The focus group field guide included questions about why women might miss a gynecologic appointment, general attitudes about gynecologic care, and how women feel before and after visiting their primary care or women's healthcare providers. These questions were developed after reviewing survey results in order to further elucidate barriers to gynecologic care adherence. The focus group discussion was recorded for transcription by a standard Health Insurance Portability and Accountability Act (HIPAA)-approved medical transcription service.

Focus groups data analysis. The transcribed discussions were read and analyzed using a hermeneutic process, similar to the editing analysis technique described previously in healthcare research.²² Pertinent themes related to HIV, gynecology, and general clinic adherence attitudes and opinions were labeled and coded by two readers/coders trained in qualitative techniques (M.A.T., M.J.).

Results

The demographic, medical, and psychosocial characteristics of 200 female participants are reported overall and by primary outcome in Table 1. The average age of our subjects was 46, with 78% of women $>$ age 40 years. Eighty-five percent were African American, and 49% had less than a high school education. Of our primary outcomes, 138 (69%) had missed at least one gynecology appointment in the past year, and 44 (22%) had not had a Pap smear in the past year. Of women who missed a gynecology appointment, 82% also missed a primary care appointment; 53% of women completed more than half of their scheduled primary care appointments compared with 38% of women who completed more than half of their scheduled gynecology appointments. One hundred sixty-six women (83%) had a cervix, and of these, 37 (23%) had not had a Pap smear in the past year. The mean score on the MOS Social Support Survey was 71 (standard deviation [SD] 24), with 10% classified as very low, 21% as low, 37% as moderate, and 48% as high support. The mean CES-D score was 12 (SD 4); scores ranged from 3 to 30, with 24% of women screening positive for depressive symptoms (scores ≥ 10). Characteristics of the 166 women with a cervix did not differ significantly from those of the overall sample.

Predictors of gynecology appointment adherence and receipt of Pap smear

Predictors of gynecologic clinic adherence and receipt of cervical or vaginal pool Pap smear were examined for all women and for women with a cervix. Results for all women are presented in Table 2.

Analysis of total sample. In multivariable analysis, moderate (OR 3.1, 95% CI 1.4–6.7) and severe (OR 3.1, 95% CI 1.3–7.5) depressive symptoms (compared with none) and past-month substance use (OR 2.3, 95% CI 1.0–5.3) were associated with an increased odds of missing an appointment in the prior year. An education level of less than high school (OR 0.3, 95% CI 0.1–0.6) compared with high school diploma or greater was associated with not having a Pap smear in the previous year. When the outcomes of either a missed appointment or no Pap smear in the previous year were combined, moderate (OR 3.7, 95% CI 1.7–8.0) and severe (OR 4.4, 95% CI 1.7–11.1) depressive symptoms were associated with an increased odds of missing an appointment or not having a Pap smear.

Subgroup analysis limited to women with a cervix. When analyses were limited to women with a cervix ($n=166$), moderate and severe depressive systems remained significantly associated with missing a gynecology appointment in the previous year and with our combined outcome of either a missed appointment or no Pap smear. Factors associated with

TABLE 1. DESCRIPTIVE RESULTS OF HIV-POSITIVE WOMEN RECEIVING GYNECOLOGIC CARE COLOCATED WITH HIV PRIMARY CARE (N=200)

Characteristic	Number (% of total in column)			
	(n = 200)	Missed appointment in past year (n = 138)	No Pap test past year (n = 44)	Missed or no Pap test (n = 144)
Age				
Mean (SD)	46 (9)	45 (8)	47 (8)	45 (8)
Range	23–78	23–67	28–64	23–67
Age ≤40	48 (24)	33 (24)	11 (25)	34 (24)
40–50	89 (45)	66 (48)	16 (36)	68 (47)
≥50	63 (31)	39 (28)	17 (39)	42 (29)
Race				
Caucasian	21 (11)	14 (10)	4 (9)	15 (10)
African American	169 (85)	119 (86)	39 (89)	124 (86)
Other ^a	8 (4)	5 (4)	1 (2)	5 (4)
Education				
<High school	98 (49)	72 (52)	32 (72)*	76 (53)
High school/GED+	102 (51)	66 (48)	12 (28)	68 (47)
Employment				
Full-time or part-time	41 (21)	23 (17)	4 (9)	25 (17)
Not working	139 (69)	99 (72)	36 (82)	103 (72)
Other (disability)	19 (10)	15 (11)	4 (9)	15 (11)
Caring for children				
No	90 (45)	64 (46)	19 (43)	68 (47)
Yes, 1+ child	109 (55)	74 (54)	25 (57)	76 (53)
CD4 (cells/mm ³) ^b				
≤200	39 (19)	29 (21)	11 (25)	30 (21)
HIV-1 RNA (c/mL) ^b				
Detectable >50 cells/mL	105 (52)	77 (56)	29 (66)	81 (56)
IPV ^c	52 (26)	41 (30)	10 (23)	41 (28)
Substance use ^d				
No	147 (74)	94 (68)	29 (66)	99 (69)
Yes	53 (26)	44 (32)	15 (34)	45 (31)
Depressive symptoms ^e				
None	49 (24)	25 (18)*	8 (18)	25 (17)*
Moderate	99 (50)	74 (54)	20 (46)	77 (54)
Severe	52 (26)	39 (28)	16 (36)	42 (29)
Social Support ^f				
Very low–low	31 (15)	23 (17)	8 (18)	23 (16)
Medium	73 (37)	51 (37)	15 (34)	52 (36)
High	96 (48)	64 (46)	21 (48)	69 (48)

* $p < 0.05$ by chi-square.

^aAmerican Indian/Alaska Native or Asian/Pacific Islander/Native Hawaiian.

^bMedical laboratory data, from dates closest to questionnaire date.

^cIPV measured using the Partner Violence Screen.²¹

^dSelf-reported any use in past month.

^eDepressive symptoms measured using the 10-item version of the Center for Epidemiologic Studies Short Depression Scale. (CES-D) using a score of 10–15 for moderate and >15 for severe depressive symptoms.⁸ Scores ranged from 3 to 30, with mean 12 (SD 4).

^fSocial support measured using the MOS Social Support Survey. The total score was converted to a 0–100 scale with very low support defined as ≤25%, low support as 26%–50%, medium as 51%–75%, and high >76%.^{6,7}

SD, standard deviation; IPV, intimate partner violence.

not having a Pap smear in the past year again included a less than high school education, age >50, and HIV RNA > 50.

Subgroup analysis limited to African American women. We also ran the models separately for African American women ($n = 169$) and found similar results. Moderate and severe depressive symptoms (OR 3.2, 95% CI 1.4–7.4) and substance use (OR 2.9, 95% CI 1.1–7.6) were associated with missing a gynecology appointment among all women, whereas lower education level (OR 0.4, 0.2–0.8 95% CI) was associated with not having a Pap smear in the previous year. Moderate (OR

3.9, 95% CI 1.7–9.3) and severe (OR 3.7, 95% CI 1.3–10.4) depression symptoms were also associated with the combined missed gynecology appointment and no Pap smear in the past year.

Reasons for missing gynecology appointment

Reasons that women chose for missing a gynecology appointment are shown in Table 3. The most common possible reasons for missing a gynecology visit were: Forgot about appointment (61%), Sick (52%), and Bad weather (42%).

TABLE 2. CRUDE AND ADJUSTED ODDS RATIOS OF FACTORS ASSOCIATED WITH MISSING A GYNECOLOGY APPOINTMENT AND RECEIPT OF PAP SMEAR IN PAST YEAR FOR ALL WOMEN RECEIVING HIV GYNECOLOGIC CARE COLOCATED WITH HIV PRIMARY CARE (N=200)

Independent variable	Missed gynecology appointment in past year OR (95%CI)		No Pap smear in past year OR (95%CI)		Missed appointment, no Pap smear OR (95%CI)	
	Crude odds	Adjusted odds	Crude odds	Adjusted odds	Crude odds	Adjusted odds
Age (years)						
<40	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)
40-50	1.3 (0.6-2.8)	1.4 (0.6-3.3)	0.7 (0.3-1.7)	0.7 (0.2-1.6)	1.3 (0.6-2.9)	1.6 (0.7-3.7)
>50	0.7 (0.3-1.6)	0.8 (0.3-1.8)	1.2 (0.5-3.0)	1.9 (0.7-5.3)	0.8 (0.4-1.9)	0.9 (0.4-2.1)
Race						
Other	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)
African American	0.7 (0.3-1.7)	0.7 (0.3-1.7)	0.6 (0.2-1.9)	0.8 (0.3-2.4)	0.7 (0.3-1.7)	0.7 (0.3-1.6)
Education						
<High school	1.0 (Ref)	—	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	—
High school/GED+	0.7 (0.4-1.2)	—	0.3 (0.1-0.6)*	0.3 (0.1-0.6)*	0.6 (0.3-1.1)	—
Employment						
Full-time or part-time	1.0 (Ref)	—	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	—
Not working	0.5 (0.3-1.1)	—	0.3 (0.1-0.9)*	0.4 (0.1-1.4)	0.5 (0.3-1.1)	—
Other (disability)	1.5 (0.5-4.9)	—	0.7 (0.2-2.5)	0.9 (0.3-3.2)	1.3 (0.4-4.2)	—
Caring for children						
No	1.0 (Ref)	—	1.0 (Ref)	—	1.0 (Ref)	—
Yes, 1+ child	0.8 (0.5-1.5)	—	1.1 (0.5-1.8)	—	0.7 (0.4-1.4)	—
CD4 count (<200 cells/mm ³)	1.4 (0.6-3.1)	1.2 (0.5-3.0)	1.5 (0.7-3.4)	1.2 (0.5-3.0)	1.4 (0.6-3.1)	1.2 (0.5-2.9)
HIV-1 RNA (>50 c/mL)	1.5 (0.8-2.8)	1.1 (0.6-2.3)	2.0 (1.0-4.1)	2.1 (0.9-4.9)	1.7 (0.9-3.2)	1.3 (0.7-2.8)
IPV	2.0 (0.9-4.1)	—	0.8 (0.4-1.8)	—	1.6 (0.8-3.5)	—
Substance use						
No	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	—	1.0 (Ref)	1.0 (Ref)
Yes	2.8 (1.3-6.1)*	2.3 (1.0-5.3)*	1.6 (0.8-3.3)	—	2.7 (1.2-6.2)*	2.2 (0.9-5.1)
Depressive symptoms						
None	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	—	1.0 (Ref)	1.0 (Ref)
Moderate	2.8 (1.4-5.8)*	3.1 (1.4-6.7)*	1.3 (0.5-3.2)	—	3.4 (1.6-7.0)*	3.7 (1.7-8.0)*
Severe	2.9 (1.2-6.7)*	3.1 (1.3-7.5)*	2.2 (0.9-6.0)	—	4.0 (1.7-9.8)*	4.4 (1.7-11.1)*
Social support						
Very low-low	1.0 (Ref)	—	1.0 (Ref)	—	1.0 (Ref)	—
Medium	0.8 (0.3-2.1)	—	0.7 (0.3-2.0)	—	0.9 (0.3-2.2)	—
High	0.7 (0.3-1.7)	—	0.8 (0.3-2.1)	—	0.9 (0.4-2.2)	—

* $p < 0.05$.

Qualitative analysis of focus group data

Qualitative analysis of the focus group data showed recurrent themes; Table 4 shows specific participant comments. These included fears of discomfort during the examination or

of unmasking a problem, forgetting appointments, and inclement weather.

Discussion

In our study of HIV gynecology clinic visit and Pap smear adherence, 68% of all women had missed a gynecology appointment in the previous year, and 22% of women had not had a Pap smear in the past year. From our previous study of the same clinic population, where HIV gynecology and primary care services are colocated, we knew that the rate of completed clinic visits was significantly lower for HIV gynecology (36%) than for HIV primary care (55%) ($p < 0.001$). This study used mixed methods to elucidate reasons for missed HIV gynecology visits and recommended Pap screening. In this study, we found that factors associated with suboptimal gynecologic care included less than a high school education, substance use, depressive symptoms, older age, and detectable viral load. In addition, our focus groups revealed four major barriers to care: forgetting the appointment, inclement weather, discomfort/pain during the examination, and fear of a bad diagnosis. Our results are consistent with those of other studies examining gynecologic care among

TABLE 3. REASONS WOMEN GIVE FOR MISSING GYNECOLOGY APPOINTMENT

	Number (% of 200)
Forgot about appointment	121 (61)
Sick	104 (52)
Bad weather	83 (42)
Could not get to clinic	61 (31)
Afraid of bad news	27 (14)
Had to take care of someone	12 (6)
No child care	8 (4)
Afraid of pelvic examination	8 (4)
Don't like the clinic	8 (4)
Feel violated by pelvic examination	6 (3)
Don't like the doctor	3 (1.5)

Responses from <2 women (<1% of sample) omitted.

TABLE 4. FOCUS GROUP GENERATED REASONS FOR MISSING GYNECOLOGIC EXAMINATIONS

Fear of discomfort

"...there are some women who are ferociously afraid. They really have a phobia about the forceps..."
 "...when I went for that one examination, I felt it was extremely painful, and even though she was trying to be sensitive, but I thought that she was being a little too masculine when she was down there, and a little bit more, you know what I'm saying?... To me, that was like a violation. That's how I felt about the experience. And every time I have it now, it's becoming more and more painful."

Fear of diagnosis

"You have people that are afraid of finding out something bad is going on with them. You know, they'd rather not know."
 "I had a great fear because I had some things going on, but the doctor was saying for me to ask questions, she listened to them for me, and she answered as much as she could and the examination was fine. Me with my fears and the problem that I was having, it was a difficult thing, but in the end she explained to me about the problems I was going through... I'm fearful when I go, but I like it when I have a good doctor."

Forgetting appointments

"I forget. That's the way my memory sometimes is, sometimes I forget."
 "For me, I just don't remember. I just put on there, I don't remember, you know what I mean? I'm not trying to guess, you know what I mean? I might try to remember my last appointment."

Weather

"Just coming across town, you know, and the heat is hot, and you don't feel like being out there in that sun, you know?"
 "The weather maybe. Ice more than heat, you know, cold weather. Because I don't like to move on ice, and my cane, it don't like ice either."

HIV-positive women.^{23,24} The prospective Swiss HIV Cohort Study (SHCS)⁷ examined factors associated with frequency of gynecologic follow-up in a cohort of 2186 HIV-positive women over 3 years; they found that 82% of those women reported having a Pap smear at some point in the 3 years, although 7.2% of women had not seen a gynecologist at all. In a more recent study of 2548 women infected with HIV in the United States, 1992 (78%) had a Pap smear in the previous year.⁹

We found that women with a lower education level were less likely to have had a cervical or vaginal pool Pap smear in the previous year. This association was strongly significant in all women and in women with a cervix. Our results are consistent with several studies of cervical cancer screening among ethnic minority women in the United States, where lower level of education and not understanding the need for a Pap smear were associated with not having had a cervical Pap smear within the past 12 months.^{25,26} In a study of 148 HIV-uninfected women with invasive cervical cancer, lack of knowledge about cervical cancer risk, fatalistic attitude (having cancer is just bad luck), and denial (did not want to know cancer diagnosis) were all associated with never having been screened by Pap smear.²⁷ This literature and our findings suggest that basic education about the purpose and benefits of regular Pap smears for cervical cancer screening may improve adherence with screening.

In addition, our qualitative analysis of focus group data suggests that fear of or discomfort from the examination and fear of diagnosis may contribute to missed appointments and inadequate use of care. This was also found in a recent qualitative study of 35 low-income HIV-positive African American women who had not had cervical cancer screening in 5 years or more, in which psychological/emotional barriers were the most commonly reported barriers to care: specifically, fear of diagnosis, fear of pain or discomfort during the examination, low self-esteem, and denial were major reported barriers to care.²⁸ The authors conclude that efforts to improve access to and use of healthcare services for these women should address their psychological and emotional needs.²⁸

Andrasik et al.²⁸ also found that a conflicting need, most commonly an active drug addiction, was a major reported barrier to care for those women. Our quantitative results showed that substance use is a barrier to having a cervical or vaginal pool Pap smear in the past year. This finding is consistent with a recent study of HIV-infected women in the Swiss Cohort Study,⁷ as predictors for fewer reported gynecologic examinations and Pap smears included current intravenous drug use and lower CD4 counts.

We also found that moderate and severe depressive symptoms are strongly associated with missing gynecology visits. Depression is common among people infected with HIV^{29,30} and has been associated with HIV appointment³¹ and medication nonadherence.³²⁻³⁶ Screening for and treating depression may improve gynecology clinic appointment attendance.

Given our findings, providers should also be cognizant of psychosocial and emotional barriers, such as depression, women's fears, denial, low self-esteem, and competing needs, such as addiction, that may contribute to lower appointment adherence. Outreach programs incorporating education, explanation, and peer support may be effective methods for addressing these psychosocial and emotional barriers, thus improving adherence. A recent qualitative study of people living with AIDS in the United States examined the role of outreach programs in engaging and retaining patients in medical care; they found that almost all patients cycle in and out of care, and outreach programs of various kinds were able to reconnect patients to consistent care through education (dispelling myths and improving HIV knowledge), reducing barriers to care (arranging transport, helping with insurance paperwork, accessing drug and alcohol treatment programs), and providing support (connecting patients to support networks).³⁷

In our study, the most common reason given for missing a gynecology appointment was simply forgetting. In the recent qualitative study,³⁷ patients reported that phone calls and other reminder systems improved appointment and medication adherence. In addition, in a review of the literature on

barriers to adherence for follow-up care for abnormal Pap smears, communication interventions, such as telephone reminders, counseling, and educational sessions, increased follow-up across several studies.³⁸

In addition to addressing patient barriers to gynecology appointment adherence, structural or clinic system changes, such as consolidating or bundling HIV primary care with gynecology care (such as cervical cancer and sexually transmitted disease screening at the same visit), would likely improve Pap smear and gynecology appointment adherence. In one study of self-reported factors associated with cervical cancer screening among HIV-positive women, women who reported having a gynecologist and a primary care provider at the same clinic site were almost twice as likely to report having had a Pap smear in the previous 12 months.³⁹ Having gynecology and primary care appointments scheduled for the same day may result in even greater adherence.

Our study has potential limitations. It was conducted at a single institution and consisted of a sample of women from an urban HIV care clinic; thus, results may not be generalizable to some settings. In addition, the quantitative component was cross-sectional; thus, causal inferences cannot be made. Given that the survey was self-report, there may have been some social desirability bias.

In conclusion, suboptimal adherence to routine gynecology care among HIV-infected women remains prevalent. Interventions targeting modifiable barriers to care, such as substance use, depressive symptoms, patient fears, and forgetting appointments, may improve participation in gynecology care and patient outcomes.

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Disclosure Statement

The authors have no conflicts of interest to report.

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