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Perceptions of Barriers and Facilitators to Cervical Cancer Screening among Low-Income, HIV-Infected Women from an Integrated HIV Clinic

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Abstract

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Conflict of Interest
The authors have no conflict of interest to disclose.

Significantly elevated rates of cervical cancer and low rates of Papanicolaou (Pap) smear screening have been documented among HIV-infected women. However, little is known about women's perceptions of cervical cancer screening utilization. Hence, this study describes barriers and facilitators related to cervical cancer screening in a sample of HIV-infected women seeking care at an integrated HIV clinic in Houston, Texas. Using an inductive qualitative methodological approach, data were obtained from five focus group discussions with a total of 33, HIV-infected women. The majority of the study sample consisted of women who self-identified as Black (69.7%), and reported heterosexual contact as the mode of HIV acquisition (75.8%). Barriers to cervical cancer screening were described as pain and discomfort associated with receiving Pap smears and subsequent procedures; lack of awareness of cervical cancer as a preventable disease; limited transportation access; and systemic issues as it relates to scheduling gynecological appointments. Facilitators were described as awareness of HIV-infected women's increased risk of cervical cancer and strong provider-patient relationships. To address disparities in cervical cancer screening among low-income HIV-infected women, programs should capitalize on the identified facilitators and alleviate modifiable barriers using multi-level strategies.

Keywords

HIV-infected women; cervical cancer screening; barriers; facilitators; Pap smear screening

INTRODUCTION

Significantly elevated rates of cervical cancer have been documented among HIV-infected women generally four to five times higher than that of uninfected women (Ellerbrock et al., 2000; Moscicki et al., 1998; Wright et al., 1994). Current HIV treatment guidelines recommend biannual cervical cytology screening following women's initial HIV diagnosis. If both tests are normal, screening can be reduced to an annual schedule (Kaplan et al., 2009). Despite guidelines aimed to decrease the heavy burden of cervical cancer among HIV-infected women, Papanicolaou (Pap) screening is still underutilized by this population of women (Baranoski, Horsburgh, Cupples, Aschengrau, & Stier, 2011; Fletcher et al., 2013; Keiser et al., 2006; Logan, Khambaty, D'Souza, & Menezes, 2010; Oster, Sullivan, & Blair, 2009; Tello et al., 2010). However, a consensus is lacking on the most important barriers to cervical cancer screening utilization among HIV-infected women.

A growing body of literature suggests that a history of abnormal Pap testing, recent pregnancy and receiving gynecological care at the same location as HIV care are factors that increase a woman's likelihood of utilizing Pap smear screening services (Baranoski et al., 2011; Dal Maso et al.; Oster et al., 2009). Correlates of suboptimal screening have included severe depressive symptoms, substance use, intravenous drug use, lower education, African American race, CD4 count <200 cells/mm3, younger or older age, obesity, lower body weight, tobacco use, low health literacy, and receiving primary care from a private infectious disease physician (Baranoski et al., 2011; Bynum et al., 2013; Oster et al., 2009; Rahangdale, Sarnquist, Yavari, Blumenthal, & Israelski; SA et al., 2013; Tello et al., 2010; Tello et al., 2008). However, little is known about HIV-infected women's perceptions related to utilizing cervical cancer screening services. Such information could be crucial in designing much needed behavioral interventions to improve cervical cancer screening utilization. Hence, the purpose of this study was to qualitatively assess barriers and facilitators related to cervical cancer screening.

METHODS

Setting and study sample

Participants were recruited from Harris Health System at Thomas Street Health Center (TSHC) in Houston, Texas from August through November 2012. TSHC is a central clinic site for providing HIV/AIDS care to an indigent, HIV-infected population. As an integrated, freestanding clinic, TSHC offers both HIV primary care and specialty services including gynecologic care. To be eligible for this study, women were HIV-infected; 18 years or older; able to provide written informed consent; and able to speak English. Patients were not eligible to participate in the study if they reported a history of total or partial hysterectomy and/or were deemed ineligible by their clinic physician based on medical or psychiatric conditions.

Focus group procedures

The research protocol was reviewed and approved by the Institutional Review Boards of The University of Texas MD Anderson Cancer Center and The University of Texas Health Science Center at Houston. Potential participants were informed of the study through physician referrals in addition to study flyers in waiting rooms. Prior to commencing the focus group discussions, each participant completed a written informed consent. Participants also completed a brief, self-administered socio-demographic questionnaire. All participants were compensated with a $20.00 gift card to a neighborhood grocery store.

Five focus groups were conducted with a total of 33 HIV-infected women in a private room at TSHC. Each focus group lasted approximately 1.5 hours. Focus group size ranged from two to ten participants. An investigator trained in conducting focus groups moderated all focus groups. Another investigator served as co-moderator with the primary responsibility of taking structured notes to capture verbal as well as non-verbal cues from participants to enhance the analysis. Finally, to protect the identities of the informants, women were asked to select pseudonyms and make use of them throughout the focus group discussion.

The focus group discussion was informed by the Health Belief Model which has been widely utilized to understand and predict cancer screening behaviors and practices among underserved women (Champion & Skinner, 2008). To engage participants and familiarize them with the focus group process, we initially asked women to describe what it means to be healthy, and how, if at all, their meaning of being healthy changed since being diagnosed with HIV. We additionally asked women specific contextual questions to capture their perceptions and understanding of cervical cancer, cervical cancer screening and practices, and abnormal Pap smears.

Analysis

All focus groups were digitally recorded, transcribed, and later analyzed separately by two coders utilizing NVivo 10 software. NVivo allows for hierarchical, or tree-like, coding and analysis of large amounts of text across multiple themes based on participant responses. Inductive content analysis was employed to analyze and interpret the qualitative data. Utilizing this analytic approach, we coded for emerging themes, patterns, and perceptions from the open-ended responses. Once data were independently analyzed by two research team members, emerging themes were discussed. All coding differences were resolved during the consensus process. Finally, demographic survey data were analyzed using SPSS 16.0 for Windows.

RESULTS

The majority of the study sample consisted of women who self-identified as Black/African American (69.7%) and reported heterosexual contact as the mode of HIV acquisition (75.8%). Participants' age ranged from 26–61 years with a median age of 51 years. Approximately, half of the participants reported being current smokers (51.5%), 21% were former smokers, and 27% never smoked. The majority (78.8%) of participants reported receiving a Pap smear in the past year, with 56% of participants reporting a history of abnormal Pap smears. A full description of socio-demographic characteristics of the study sample is presented in Table 2. Qualitative responses were categorized into perceived barriers and facilitators impacting cervical cancer screening utilization. Factors were also classified as intrapersonal, interpersonal or institutional.

Intrapersonal Barriers and Facilitators

Pain and discomfort associated with receiving Pap smears and subsequent procedures—Pain and discomfort associated with receiving Pap smears were frequently described by the majority of women as significant barriers to utilizing cervical cancer screening services. Women also expressed anxiety related to undergoing follow-up procedures such as colposcopies, biopsies and loop electrosurgical excision procedures (LEEP). Terms such as "clipping", "clamping", "scraping" and "pinching" were used by women to describe the part of the procedure that was most uncomfortable. A woman stated:

> "I still go for my Paps. I'm gonna continue to go. But I don't like the feelin' of the clamp."

Another participant noted the pain and discomfort she experienced with both Pap smears and biopsies.

> "And I told them last time they did it [Pap test] at Thomas Street, I'm not goin' through these biopsies no more, so we need to find a new method… It's painful; that's a painful procedure. I even hate Pap smears."

Awareness of HIV-infected women's increased risk of cervical cancer—The majority of women recognized that HIV infection increased their risk for many illnesses, including cervical cancer because of their compromised immune systems. Thus, they understood the importance of using available health services such as cervical cancer screening to improve their quality of life and increase survival. In addition, women perceived most of their health issues as HIV-related conditions.

One participant stated:

> "We have higher risk with lung cancer…I mean, with everything, not just cervical cancer."

Similarly, another participant expressed:

> "Well, it's, uh, hard to fight off infections when you're HIV-positive, so that may cause you to be more at risk [for cervical cancer] than a person that's not HIV-positive."

Lack of awareness of cervical cancer as preventable disease—Although most participants were aware that HIV-infected women are at higher risk for developing cervical cancer, in general, they did not believe that cervical cancer could be prevented. Pap smears were described as tools solely to diagnose cervical cancer as opposed to a method of detecting precancerous cervical cells. Furthermore, many women strongly believed that cancer, including cervical cancer, was unavoidable due to family history. As one woman noted:

> "Cancer is hereditary. My great-grandmother had breast cancer. My sister had cervical cancer. My daddy he just found out that he has lung cancer."

Since most women did not understand the mechanisms linking cervical cancer to HIV status, they were generally unaware of and unable to identify individual risk factors such as tobacco use, HPV infection, and multiple sexual partners associated with cervical cancer. One participant conceptualized cervical cancer-associated risks in this way:

> "Cancer is not like HIV to me because we did things to put ourselves at risk for HIV. I shot dope and I used a syringe so we put ourselves at risk for HIV, but I don't think you can put yourself at risk for cancer. I think cancer is just somethin' that may come like family, you know."

Another participant similarly noted:

> "From looking at the TV, listening to the TV, it's [cervical cancer] just somethin' that come on us. It don't have to be from cigarettes or from sex. You know, just somethin' that come automatically."

Interpersonal Facilitator

Strong provider-patient relationships—The majority of women described strong relationships with health care providers as a facilitating factor to utilizing cervical cancer screening services at TSHC. For many, TSHC health care providers were their primary source of medical knowledge. Additionally, they described TSHC providers as delivering specialized care to an HIV-infected population in a non-discriminating, non-judgmental, and caring manner.

> "She [my health care provider] is real good. I mean, she's so thorough, she break it down [cervical cancer information] to you like you're two years old. So if you don't understand it's cause you don't wanna understand."

> "They [health care providers] don't judge you. They don't."

Institutional Barriers

Limited transportation access—Transportation was one of the most pervasive barriers to attending cervical cancer screening appointments, especially for women with longer commutes to the clinic. Many women relied on the medical transportation assistance system, but described it as unreliable and ultimately a deterrent to attending appointments at TSHC. Women expressed a great deal of frustration in describing instances when medical transportation arrived at their homes extremely late; arrived at their homes or clinic for pick-up, but left without notifying them; or failed to even show up. Many women who utilized public transportation were dissatisfied with the significant of travel time to get to and from the clinic.

> "It takes me thirty minutes to get to the bus stop on foot."

> "They'll leave you [medical transportation] 'cause I was left here [at clinic] one day, and I called and gave 'em a piece of my mind, too."

Extensive wait time—The majority of women were dissatisfied with waits of several hours or more to be seen by health care providers, particularly if they had multiple appointments. Some women even preferred to return to the clinic another day to attend additional appointments rather than waiting all day for several appointments.

> "Yeah, the waiting periods to see the doctor, you know, everybody gets appointments and, you know, you got a whole lobby full of people and you're here all day."

Systemic issues related to scheduling gynecological appointments—Some women mistakenly thought that they could only see a gynecologist if they had a referral from their HIV health care provider. In addition, women expressed challenges with actually scheduling and keeping cervical cancer screening appointments because they occurred so infrequently.

> "Like with me, I go every year, and they say, "Okay, well they say call in six months to make an appointment." And then when you make an appointment for six months later, it's forgetting that you have an appointment because you have a whole year in between appointments."

DISCUSSION

As AIDS-related mortality decreases in women who have access to highly active antiretroviral therapy (Bonnet et al., 2004; Palella et al., 2006), cervical cancer among HIV-infected women has become more salient as a preventable cause of death. In addition to disparities in the development and progression of cervical disease among HIV-infected women, sub-optimal screening rates have been documented in this population (Baranoski et al., 2011; Fletcher et al., 2013; Keiser et al., 2006; Keller et al., 2012; Logan et al., 2010; Oster et al., 2009; Tello et al., 2010). Consistent with previous studies, we found that pain and discomfort associated with receiving Pap smears and subsequent procedures were significant barriers to women obtaining Pap smears and appropriate follow-up for abnormal results (Hoyo et al., 2005; Taylor et al., 2004). Self-reports of pain during these tests are particularly intense for non-white women of low socioeconomic status (Basen-Engquist et al., 2007), a group that is more likely to have poor adherence to cervical cancer screening and follow-up recommendations (Hewitt, Devesa, & Breen, 2004; Michielutte, Diseker, Young, & May, 1985; Peterson, Han, & Freund, 2003). As a result, strategies which aim to alleviate both physical and psychological pain should be explored (Ackerson, 2010, 2012).

Despite pain reported by this population, women were aware that they are more susceptible to developing diseases and illnesses such as cervical cancer due to their weakened immune system. Interestingly, women did not perceive cervical cancer as a disease that they could prevent through their own behaviors. The explanation is two-fold: Women’s strongest risk behavior frame of reference surrounded HIV infection. Specifically, participants discussed acquiring HIV through high-risk behaviors which included intravenous drug use, unprotected sex, and multiple sexual partners. On the contrary, cervical cancer was perceived as a non-preventable hereditary illness like breast cancer. As a result, the majority of women identified Pap test screening, not as a method of detecting cervical changes early, but as a tool to diagnosis cervical cancer. This compelling finding has not been described elsewhere and has implications for framing cervical cancer screening prevention messages and educational strategies for HIV-infected women. Strategies should emphasize that cervical cancer is preventable; cervical cancer is slow growing and as a result Pap tests are instrumental in detecting cell changes early before cancer develops; and individual level risk behaviors such as tobacco use and unprotected sexual contact can increase one’s chances of developing cervical cancer. Women should ultimately be empowered to engage in actions that might serve to prevent the development of cervical cancer.

Our study participants described positive relationships with health care providers at TSHC as facilitating their use of cervical cancer screening. Strong provider-patient relationships are critical to linking and retaining patients in care especially for patients with concomitant medical and social needs (Aziz & Smith, 2011; Kempf et al., 2010). Further, for HIV-infected individuals who are stigmatized by friends, family members, and/or community members, a favorable and supportive relationship with health care providers may be both socially and medically advantageous.

Besides intrapersonal and interpersonal barriers and facilitators, this study revealed institutional level barriers which included limited transportation access, extensive wait times, and systemic issues as it relates to scheduling gynecological appointments. Consistent with previous studies with HIV-infected populations (Kempf et al., 2010; Sagrestano, Clay, Finerman, Gooch, & Rapino, 2013; Tello et al., 2010) many women described limited transportation access as a pervasive barrier to accessing cervical cancer screening. Because lack of transportation contributes to poor utilization of health care services and ultimately leads to poor health outcomes, addressing the impact of transportation vulnerability with HIV-infected populations is most critical.

A “one-stop medical shop” allows patients to access various medical and social services within a single facility. However, because of the low ratio of health care providers to patients, patients with multiple appointments may experience long clinic waits which minimizes the advantages. Our study participants preferred to return on multiple days in order to avoid excessive wait times. Kempf and colleagues contend that extensive time spent at the clinic “interferes with child care, work schedules, and transportation opportunities (Kempf et al., 2010).” Hence study findings suggest that health care staff should work with patients to address their scheduling needs to improve adherence to medical appointments.

Systemic issues related to scheduling and remembering future gynecological appointments were institutional barriers to cervical cancer screening use. Women desire a system which would alleviate the burden, on their end, of scheduling and remembering cervical cancer screening appointments. According to women, they are provided a reminder card with the due date of the next Pap smear. This is ineffective because pap tests are infrequent events and the cards are often misplaced. Women stated that they commonly forget to schedule or attend an appointment. In addition, many women believed that they needed to obtain a referral from their HIV health care provider before they could schedule a Pap smear appointment. Because some women may rely heavily on their primary HIV providers’ recommendations and referrals for Pap screening, clear and accurate communication between HIV primary providers, gynecologists, patients, and scheduling staff is essential to improving Pap smear scheduling.

This study has limitations, including the small sample size and inclusion of HIV-infected women seeking HIV care at a comprehensive health clinic. As a result, findings may not be relevant to HIV-infected women who are not seeking HIV/AIDS care. It should also be acknowledged that the compensation provided to study participants may have resulted in response bias. Further, this study included both cervical cancer screeners and non-screeners in the past year. Despite limitations, this study represents an important step in informing future survey development and assessment given a lack of validated instruments for this population.

CONCLUSION

Study findings support the need to employ a holistic approach to HIV/AIDS care which includes cancer preventive services. Existing HIV clinics which specialize in delivering comprehensive services can function as models for other HIV care centers by working to strategically integrate cancer preventive services into their current practices. Thus, a key area of research exploration includes assessing HIV primary health care providers’ perceptions and current practices as it relates to recommending cervical cancer screening to HIV-infected women. Understanding health care providers’ perceptions of barriers and facilitators to delivering integrated HIV and cancer services has not yet been elucidated.

In light of disparities in cervical cancer and screening rates, the current study examined barriers and facilitators to cervical cancer screening utilization among HIV-infected women. To address disparities in cervical cancer screening among low-income HIV-infected women, programs should capitalize on the identified facilitators and alleviate modifiable barriers using multi-level strategies.

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Table 1

Sample focus group questions

Sample Question	**Content/Construct**
What does cervical cancer mean to you?	Cervical cancer perceptions
If your doctor said that you had an “abnormal Pap smear,” what would that mean to you?	Cervical cancer perceptions
Do you think you are at risk of developing cervical cancer?	Perceived susceptibility
What are your thoughts about being able to prevent cervical cancer with Pap test/smear screening?	Perceived benefits
What are some things that make it harder for you to schedule or keep appointments for routine Pap smears?	Perceived barriers
What are some things that might make it easier for you to schedule or keep appointments for routine Pap smears?	Perceived facilitators/ cues to action

Table 2

Socio-demographic characteristics of the sample (N=33)

Characteristic	**Number (%)**
Median age in years (SD)	51.0 (8.78)
Median years living with HIV (SD)[1]	10.0 (7.12)
Race/ethnicity	
African American/Black	23 (69.7)
White	4 (12.1)
Hispanic	6 (18.2)
Level of education	
Less than high school	7 (21.2)
High school diploma/GED	16 (48.5)
Technical/vocational degree	5 (15.2)
Some college or 2-year degree	5 (15.2)
HIV transmission	
Heterosexual contact	25 (75.8)
Injection drug use	5 (15.2)
Other	3 (9.1)
Health insurance	
Medicare and/or Medicaid	20 (60.6)
No insurance	13 (39.4)
Relationship status	
Single	29 (87.9)
Married	4 (12.1)
Religion	
Christian	29 (87.9)
Muslim	2 (6.1)
Other	2 (6.1)
Job Status[1]	
Not working due to health	22 (71.0)
Not working for other reasons	5 (16.1)
Unable to find work	4 (12.9)
Annual Income[1]	
<$10,000	30 (93.8)
≥$10,000	2 (6.2)
Smoking Status	
Current smoker	17 (51.5)
Former smoker	7 (21.2)
Never smoked	9 (27.2)
Pap smear in the last 1-year	26 (78.8)
History of abnormal Pap[1]	18 (56.3)

[1] Missing data for some participants