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Exploring the Perceptions of Anal Cancer Screening and Behaviors Among Gay and Bisexual Men Infected With HIV

Alexis M. Koskan, PhD, Natalie LeBlanc, MPH, and Isabella Rosa-Cunha, MD

University of Miami School of Nursing and Health Studies (AMK, NL), Sylvester Comprehensive Cancer Center (AMK), Coral Gables, Florida, and the Division of Infectious Diseases (IR-C), University of Miami School of Medicine, Miami, Florida

Abstract

Background—The incidence of anal cancer is on the rise among HIV-infected men who have sex with men (MSM). Given the increasing availability of screening, this study explored anal cancer screening awareness and behaviors among MSM infected with HIV.

Methods—In-depth interviews were conducted with 58 MSM infected with HIV.

Results—Other than 2 participants treated for anal cancer and 3 treated for precancerous anal lesions, the majority of participants had never heard of anal cancer. Men reported lack of awareness and recommendations from their health care professionals as the greatest barriers to screening. Upon learning about their risk for anal cancer and the availability of screening, the men were eager to discuss screening with their physicians. Participants provided numerous recommendations for future interventions, including training health care professionals to promote screening, disseminating information pertaining to anal cancer through social networks, and creating media campaigns to raise awareness about the need to screen for this type of cancer.

Conclusions—Future intervention work should focus on ensuring that health care professionals, particularly among HIV/primary care specialists, promote screening for anal dysplasia. It is critical that intervention methods use a community-based approach to raise awareness about the need to screen for anal cancer, especially among MSM infected with HIV.

Introduction

The incidence of squamous cell carcinoma of the anus, more commonly known as anal cancer, is on the rise. Persistent infection of high-risk strains of human papillomavirus (HPV) is the most common cause of anal cancer. Whereas the majority of individuals infected with HPV spontaneously clear the virus without ever showing symptoms, individuals with compromised immune systems, such as those infected with HIV, are at increased risk of persistent HPV infection. Two low-risk strains of HPV (types 6 and 11) cause condylomas, also known as genital warts, which, although they are non-cancerous, indicate HPV exposure and infection at the site where the warts develop. Persistent infection of the anal canal by high-risk strains of HPV (types 16 and 18) can lead to the development

of high-grade anal dysplasia, known as high-grade intraepithelial lesion (HSIL). If HSILs are left untreated, then these lesions are thought to develop into anal cancer. Men who have sex with men (MSM) and who are also infected with HIV are at greatest risk for developing HSIL and anal cancer.” This population is 52 times more likely to develop anal cancer as compared with the general, non-HIV-infected population, a disparity that can be potentially reduced through timely screening of and treatment for HSIL.”

Although no national screening guidelines for detecting anal dysplasia are available, the anal Papanicolaou (Pap) smear has been proposed as a tool for the initial screening of anal dysplasia in populations infected with HIV. The goal of screening is to identify patients with HSIL, which is a presumptive pre-cancerous lesion. If the patient has no symptoms and the anal Pap smear shows no abnormalities, then further screening can be offered annually. If the results from the anal Pap smear are abnormal, the patient is symptomatic, or both are present, then further evaluation can be performed with high-resolution anoscopy (HRA), also called colposcopy of the anal canal. Most HSILs are not visible to the bare eyes, so HRA allows the health care professional to perform a magnified examination and evaluation of the anal canal. A digital anorectal examination is also recommended at the time of screening. If HSIL is detected, then the lesion can be treated using different techniques, including trichloroacetic acid, a hyfrecator, and infrared coagulation.” Some disease may be too advanced to be treated with HRA and may require referral for colorectal surgery.

Although some HIV primary care clinics are beginning to integrate anal dysplasia screening into the routine examination, the screening rate for anal dysplasia is still lower than ideal, and the incidence of anal cancer continues to rise among MSM infected with HIV.” Thus, with the increased availability of screening, it is critical to explore the level of understanding among MSM infected with HIV about anal cancer and their need for screening. This research study explored the level of understanding, current behaviors, facilitators, and barriers to anal dysplasia screening, as well as the preferences of MSM infected with HIV for future health education efforts among this population.

Methods

Institutional Review Board approval was obtained to conduct in-depth interviews with MSM infected with HIV to explore their understanding, attitudes, and current behaviors related to anal dysplasia screening and prevention. The study team created an in-depth interview guide to explore participant perceptions related to HPV infection, anal cancer, screening for anal dysplasia, and preferences for future educational interventions. The interview consisted of open-ended questions and probes organized to enhance the flow of conversation and to elicit the clearest responses about HPV infection, anal cancer, screening for anal dysplasia, and preferences for upcoming educational interventions.

The study team created recruitment fliers that included the topic of the research study, information about incentive for participation, a phone number for study screening and enrollment, and the following participant inclusion criteria: previously tested positive for HIV infection; self-identification as a gay or bisexual man; age 21 years or older; ability to fluently speak English; resident of Miami-Dade County; and willingness to provide

informed consent. The fliers were disseminated at a local health department meeting that focused on MSM health. At this meeting, representatives of MSM-serving, community-based organizations agreed to pass out study fliers to their clients. Many of the study participants were referred to the trial via snowball sampling when past participants recommended that friends call the study number and screen for eligibility.

Individuals interested in research participation were screened by phone, and interviews were scheduled with men who met the inclusion criteria. Participants recommended a date, time, and location for the interview. Table 1 contains demographic information about the study participants.

Conducting the Interviews

On the day of the in-depth interview, the interviewer reviewed the informed consent documents with participants and, upon obtaining consent, began the audio-recorded, in-depth interview. The interviewer used the in-depth interview guide to steer the conversation, varying the questions and probes based on participant responses and the direction of the conversation. Upon completing the interview, the research team member provided the participant with a monetary incentive (\$60) and conducted a short health education lesson about HPV infection, anal dysplasia screening, and anal cancer.

All digitally recorded interviews were transcribed by a local transcription company. The researchers created an initial codebook of a priori themes based on the in-depth interview guide to direct their qualitative content analysis. The team then coded a single, in-depth interview together to ensure that the information was similarly coded. Three additional transcripts were coded separately and the team then met to compare codes, resolve any coding discrepancies, and discuss the codebook. The researchers then coded an additional interview together to test the updated codebook. The team then split the remaining transcripts and separately hand-coded the interviews and organized all coded data on Atlas.ti software (ATLAS.ti, Berlin, Germany).

Results

A total of 60 participants were enrolled in the study. During the interview process, 2 participants did not meet inclusion criteria, so only 58 participant interviews were analyzed. The level of understanding and the perceptions of HPV infection and anal cancer among the participants varied based on whether or not they had been affected by HPV infection, anal dysplasia, or anal cancer.

Experiences

Of the 58 participants, 3 had been treated for HSIL and 2 were treated or were in treatment for anal cancer. Individuals treated for HSIL described how treatment was mildly uncomfortable. Table 2 details the responses from participants who were diagnosed and treated for HSIL or anal cancer. One participant recalled feeling itchiness around his anal canal and sought care to determine the cause of the itching. His HIV/AIDS specialist conducted an anal Pap smear followed by HRA, and the participant was diagnosed with and treated for HSIL.

Another participant had been diagnosed with HIV infection 3 months prior to the interview. He described the treatment he received during his hospital stay for multiple sores and warts (low-grade, benign growths) around his anal canal and on his upper thighs. He was currently receiving treatment for the warts, but the warts were responding poorly to treatment. He also reported having blood in his stool, so his health care team performed colonoscopy. Outcomes of the colonoscopy did not reveal polyps or risk for colorectal cancer, but his physicians were still unsure about the cause of the blood in his stool. To his knowledge, no one had ever screened him for anal cancer.

The participants diagnosed with anal cancer had also been diagnosed with AIDS. One participant receiving treatment for stage 3 anal cancer described how he was first diagnosed with HIV infection, pneumonia, and anal cancer. A coworker heard him coughing, wheezing, and breathing heavily at work and insisted that he go to the emergency department. At the hospital, a health care professional inquired about whether or not he had seen blood in his stool. The patient affirmed, noting that he believed the blood in his stool was from a hernia, so he bought medication to treat the hernia. Colonoscopy was then performed but no polyps were found. The health care professional subsequently conducted an anal Pap smear, obtained HRA, and performed biopsy of a tumor located on his anal canal, at which point he was diagnosed with stage 3 anal cancer. His treatment included multiple surgeries to remove cancerous tumors, chemotherapy, and radiation. After he began chemoradiation treatment, he was unable to work due to fatigue and sickness caused by the cancer treatment. He also explained that much of his skin between his waist and thighs had peeled and sloughed off, leaving raw, irritated skin near the 3 sites of his body where he had received chemotherapy injections.

Another participant was in his early 20s when he was diagnosed with anal cancer. He had tested positive for HIV infection a few years prior but did not immediately seek treatment. Within a few years, his HIV infection progressed to AIDS, and he periodically returned to the hospital to treat AIDS-related comorbidities. One day at work, a coworker who saw him limping forced him to go to the hospital. At the hospital, he was treated for anal warts. He returned home but was rushed to the hospital a few months later for rectal pain. On a subsequent visit, he was tested for anal dysplasia and diagnosed with anal cancer. His treatment included various trips to the hospital, each time resulting in aggressive tissue removal around the anal canal and antibiotics to treat infection. At 25 years of age, his anal canal collapsed, and he began using a colostomy bag. At the time of the interview, he was free of disease, but his overall quality of life had been diminished by treatments aimed at stopping the spread of cancer.

Level of Knowledge

Unless directly affected by the disease, most participants had never heard of anal cancer or the need to screen for this disease. Table 3 details the responses from participants never diagnosed with HSIL or anal cancer. Throughout the interview, they drew conclusions about the disease and how it affected the body. One participant joked, “I had no idea my butt could rot off.” However, some participants confused anal cancer with prostate cancer and, more often, colorectal cancer. For example, when asked about whether or not they had ever

received screening for anal cancer, participants discussed having completed a digital rectal examination, prostate-specific antigen testing, or, more commonly, colonoscopy. They also interchangeably used the terms “polyp,” “anal warts,” and “lesion.”

Those who had heard of HPV infection learned about the virus through advertisements for the HPV vaccine, but many believed that HPV affected women alone. Another participant sought medical attention after experiencing hoarseness that had lasted for more than 1 year. He was later diagnosed with condylomas, which are HPV-related noncancerous growths, on his vocal chords. Although he was aware that HPV infection caused these warts, he believed that HPV infection only caused cervical cancer as opposed to other types of cancers.

Screening for Anal Dysplasia

Most participants had never received screening for anal dysplasia. Participants who received primary care from 1 specific federally qualified health clinic and 1 private hospital reported having received screening for anal dysplasia. Although the majority of the participants screened could not articulate the name of the screening test (anal Pap smear), they could confirm whether they had been screened upon hearing the procedures of the test. Men who had received an anal Pap smear reported that the procedure was not overly invasive or painful. A few men described how the test was mildly uncomfortable.

Facilitators and Barriers—According to the participants, the 2 greatest factors that influenced screening for anal dysplasia screening were awareness about anal dysplasia screening and recommendations from a health care professional to obtain screening. The participants described how the current interview alone would prompt them to ask their HIV/AIDS specialist to screen or refer them for screening at their next health care visit.

Similarly, the participants reported that the greatest barrier to anal dysplasia screening was lack of awareness about anal cancer and the need to screen. Participants repeated their intentions to screen and prevent diseases, especially if prompted by a health care professional (more often their physicians). One participant shared an emotional story about a former partner who survived anal cancer. After describing his partner’s medical treatment, he questioned why he had never screened for that same cancer. Further, he explained how no one had ever spoken with him about the need to screen for anal dysplasia.

One participant reported being unwilling to screen for anal dysplasia. He had stopped taking his antiretroviral therapy, believing that his HIV infection could be controlled without medication, and his health had rapidly declined. His rationale for not wanting to screen for anal dysplasia was based on his need to focus on controlling his HIV infection before testing and potentially detecting another health concern.

When the participants were asked about what they believed may stop other men with HIV infection from screening for anal dysplasia, they reported fear of cancer as being a barrier. Fear of knowing about cancer and having to confront the diagnosis also served as a barrier to screening. Another participant described embarrassment of anal dysplasia screening as a potential barrier. Although few participants described potential barriers for screening, all of

them wanted to learn more about anal cancer and recommended various methods for interpersonal and community health education.

Preferences for Methods of Health Education

When asked about the best ways to increase awareness among men infected with HIV regarding the need to screen for anal dysplasia, participants most often recommended interpersonal health education methods to increase anal cancer awareness. Many participants described how the current interview followed by the one-on-one discussion about HPV infection and anal cancer was the best way to teach men infected with HIV about anal dysplasia screening. Participants also recommended working with HIV/AIDS specialists and case managers to ensure they discuss anal cancer with their patients and recommend screening. Some recommended creating and disseminating a screening checklist to use during their primary care visits. This would empower the participant with the information necessary to have informed conversations with their physicians related to the screenings they need.

Participants also recommended training local leaders and health care advocates to disseminate information about anal dysplasia screening through their peer networks. Health care professionals could train peer health educators, community champions, or other community members to rapidly spread anal dysplasia screening messages to social networks. This method could also reach individuals not currently receiving HIV primary care.

Another recommendation included the creation of print media such as educational brochures, running health education messages in newspapers and magazines for HIV-infected populations, and using posters to increase community awareness about anal cancer. Specifically, participants recommended leaving educational brochures in HIV primary care clinic waiting and examination rooms for patients to read. Many participants also recommended posting similar informational fliers at bus stops and on buses to reach individuals who may rely on public transportation and who are currently not seeking HIV primary care.

Overall, participants were eager to receive any recommendation possible to improve their health and were therefore eager to learn more about anal dysplasia screening. They noted that increasing awareness about anal cancer is critical to ensuring the health of patients infected with HIV. Saturating their physical and social environments would enhance general awareness and also acceptance for anal dysplasia screening. They also needed clear descriptions of the different screening tests and information about how often to screen.

Discussion

Similar to prior research, most of the MSM infected with HIV participating in this study did not know about HPV infection and its connection to anal cancer. Among those who were aware of HPV infection, most knew only about the connection between HPV infection and cervical cancer in women. These findings highlight the need to correct this perception and

inform communities that HPV infection is a universal health issue and can cause various cancers that affect both men and women.

Roughly one-half of the study participants regularly received regular care at HIV primary care clinics that perform anal Pap smears as part of a routine annual examination. Among those who did not screen for anal dysplasia, their reported barriers were lack of awareness about anal dysplasia, HSIL, and anal cancer, as well as lack of health care professional recommendations to screen. Although some participants mentioned that the anal Pap smear was slightly uncomfortable, most did not report this as a barrier to screening.

The few participants who reported hesitancy to screen noted that embarrassment about screening procedures may stop them from screening. Similar to home-based, self-sampling for precancerous colorectal polyps, individuals could use anal dysplasia self-screening kits to avoid the embarrassment of having a health care professional conduct the screening. However, most MSM infected with HIV described their willingness to screen for anal dysplasia. Among those who had never been screened, they said they were willing to undergo screening once they learned more about the procedure for the anal Pap smear.

Patients with anal symptoms may not be receiving appropriate screening, diagnostic testing, or both for anal dysplasia and cancer. One participant had symptoms concerning for anal cancer, but, rather than undergoing a digital rectal examination or anoscopy, he had undergone colonoscopy for colorectal cancer. Although this participant had not been diagnosed with HPV infection or anal cancer, his symptoms — particularly the presence of genital warts and sores — led us to believe that he could have benefited from a detailed anal examination, including a digital anorectal examination, HRA, or both. This participant's experience may point to underscreening for anal dysplasia and cancer or even misuse of colonoscopy. However, more information about the patient's health status is needed to support this conclusion. No studies, to our knowledge, have reported the incorrect use of colonoscopy after detecting and treating genital warts and lesions.

Future Research

Future research should explore the processes, policies, barriers, and facilitators of HIV primary care clinics to screen for anal dysplasia as part of the routine examination of HIV-infected populations. Further, given our participants' emphasis on a physician recommendation as the greatest influence on screening, future studies should explore awareness and the behaviors related to screening for anal dysplasia among HIV/AIDS specialists and primary care physicians, because this information could help identify what is needed to ensure this screening is offered as a part of standard care among patients infected with HIV.

Participants wanted to learn more about anal cancer, and they wanted this information to come from both health care professionals and the local media, highlighting the need for health education about anal dysplasia screening at the community level. Future intervention research studies should utilize community-based, multilevel interventional designs that target doctor–patient, clinical, and community health education to enhance anal dysplasia screening among HIV-infected populations.

Study Limitations

Our data come from a convenience sample of men infected with HIV recruited from HIV primary care clinics who were adherent to their antiretroviral therapy. Thus, generalizations to other HIV-infected individuals should be made with caution. Another limitation is that Spanish-language interviews were not conducted. However, these interviews will be conducted in the near future.

Conclusions

Anal cancer is a disease that can potentially be prevented with timely anal dysplasia screening that should be promoted using a 3-prong approach. To improve anal dysplasia prevention, gay and bisexual men infected with HIV must be empowered to prevent cancer by being knowledgeable about anal dysplasia screening and be aware of how to access that screening. More training is needed for health care professionals, particularly among HIV/AIDS specialists, to perform this test or refer patients to other clinics that conduct the test. National guidelines are needed to promote anal dysplasia screening among HIV-infected populations to standardize this procedure as part of HIV primary care. Such guidelines will increase the visibility of this disease among patients and health care professionals, possibly leading to increased early detection and treatment of precancerous lesions.

This study also indicates the need to use various modes of communication (eg, in-clinic print media, community-wide health education, doctor–patient communication) to inform HIV-infected populations about HPV infection and the possible benefits of screening for anal dysplasia. Such public health communication is warranted to increase screening efforts for anal dysplasia and, thus, reduce the incidence of this potentially preventable cancer.

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Table 1

Participant Demographics

Characteristic	No. of Participants (N = 58)
Age, y	
21–30	7
31–36	7
37–40	3
41–45	10
46–50	8
51–55	8
56–60	9
61–65	4
66	2
Race	
White, non-Hispanic	12
African American	23
White Hispanic	23
Country of Origin	
United States	45
Cuba	9
Nicaragua	1
Honduras	1
Mexico	1
Jamaica	1
Level of Education	
Graduate degree	4
Bachelor degree	12
Associate degree	2
Some college	17
High school/general educational development diploma	19
Some high school	3
Employment	
Self-employed	2
Employed for wages	23
Unemployed and looking for work	8
Unable to work (disability)	21
Retired	4
Annual Income, \$	
< 20,000	36

Characteristic	No. of Participants (N = 58)
20,000–40,000	12
> 40,000–70,000	9
> 70,000	1

Table 2

Experiences Among Participants When Diagnosed and Treated for HSIL, Anal Cancer, or Both

Theme	Subtheme	Participant Comment
Received treatment for HSIL (n = 3)	Positive experience	“So, I think I came into the clinic a total of 3 times for treatment, and each time they cauterized something, so it was a little uncomfortable, but it was all done on an ambulatory basis. Afterward I walked out, went home, took the rest of the afternoon off from work.”
	Painful experience	“They removed everything [lesions] in the rectum. I stayed in the hospital a total of 3 or 4 days because I lost a lot of blood during the surgery. That was a very bad experience because it was very painful.”
Experience with anal cancer (n = 2)	Self-misdiagnosis	“I misdiagnosed it myself because I considered it to be a hernia. So I was using hernia medicine thinking that’s what it was, and it wasn’t.”
	Symptoms	“I was limping real hard because I couldn’t really walk. It hurt. I couldn’t even sit. I couldn’t close my legs. I had to shuffle.”
	Cancer treatment	“And when you go to the bathroom you feel like you’re peeing fire. It just hurts all of the time. And this went on; I couldn’t sleep at night. All my skin came off my body, and all of it was just raw.”

HSIL = high-grade intraepithelial lesion.

Table 3

Experiences Among Participants Without Symptoms or a Diagnosis of Anal Dysplasia, HSIL, or Anal Cancer

Theme	Subtheme	Participant Comment
Awareness of anal cancer	Lack of awareness	“And the anal cancer. I’ve never heard — it’s never really heard of. Not in that — other than, again, like I say, prostate cancer or something like that. I don’t even know what it is. I haven’t really heard anybody talk about it in my support groups. We talk about different things, but that has never come up.”
Facilitators to screening for anal dysplasia	Media Physician recommendations	“If I knew there was a likelihood of getting it ... You know, nobody got colonoscopies before Katie Couric talked about it on the <i>Today Show</i> . So you do hear it [the need to screen for colon cancer] through the media. If there was something similar in the news or media [about anal cancer], or if my doctor strongly recommended I get screened for anal cancer.”
	Willingness to screen	“So, when I go back to my doctor, I will ask him to do it [screen for anal cancer] again since it has been a couple of years now and because I had this interview with you. I am really going to do that, and I am probably going to recommend it [screening] to a few friends I know.”
Barriers to screening for anal cancer	Lack of physician recommendations	“Yes, he basically said you should talk to your doctor and get screened. But, I’ve never had my doctor talk to me about it, and I’ve never brought it up. I don’t know that I’ve ever seen any media articles or anything about getting screened for anal cancer.”
	Fear of cancer	“It’s confirming [the anal cancer diagnosis]. It’s a psychological thing. I do find this more with the people that I meet. I don’t tell everybody about my virus, but only those that need to know because there are those that are struggling with the same things — but it’s just the fear of actually knowing it.”
	Embarrassment of testing for anal dysplasia	“Just the embarrassment of knowing someone is going to put something up your butt... Most people are not going to let a stranger do that, even if it is your doctor.”
Health education preferences	Health care professional	“In my opinion, the doctors should recommend to do it [screen for anal cancer], and they should also work together with the case manager and peer educators to explain to people they have to do it.”
	Media	“Anything you put out there [in the media], advertisement or news or anything, is better than coming from a doctor. Not everybody wants to go to a doctor. Not everybody goes to a doctor.”
	Print media	“There are HIV posters on the bus stops; I see them all the time. I think a poster campaign in the areas where gay men are going. But in the back of whatever the magazine is — I mean, people do look at those, and they do read them.”
		“You should put posters or flyers on buses. You know how they have a lot of flyers inside the bus, and the buses actually have on the outside, and maybe some billboards along the highways or something, I mean — maybe even have some people near health clinics pass out pamphlets or something.”

HSIL = high-grade intraepithelial lesion.