Anal Cancer Screening: Barriers and Facilitators Among Ethnically Diverse Gay, Bisexual, Transgender, and Other Men Who Have Sex With Men

Peter A. Newman, PhD
Centre for Applied Social Research, University of Toronto

Kathleen J. Roberts, PhD
Department of Sociology, University of California, Los Angeles

Emmanuel Masongsong, BS and D. J. Wiley, PhD, MPH
Division of Primary Care, School of Nursing, University of California, Los Angeles

Abstract
Knowledge and beliefs about anal cancer screening among gay and other men who have sex with men remains unclear, despite data that suggests significant risk for intra-anal HPV-related cancers. Nevertheless, community-based screening activities may be most effective when stake-holder perspectives are addressed. We conducted four focus groups among 16 male and 3 female health care advocates experienced in working with diverse gay and other men who have sex with men in Los Angeles. Barriers to anal cancer screening included lack of awareness, stigma, psychological and physical discomfort, the anus as hidden/private, primary concern with HIV, and men's lack of healthcare seeking. Facilitators were community screening sites, novel strategies such as home testing, health care system changes and targeted educational campaigns, which may increase anal cancer awareness and screening among ethnically diverse men who have sex with men.

Keywords
Anal cancer screening; gay men; MSM; ethnic minorities; qualitative methods; HPV; Pap test

INTRODUCTION
Increasing attention has been paid to anal cancer and preventive screening within communities of gay, bisexual, transgender (heretofore referred to as “gay men”), and other men who have sex with men (MSM; Gay and Lesbian Medical Association, 2001; Simple screening test, 2000; We the People, 1999), and, in particular, research groups throughout the world (Frisch et al., 1997, 1999; Kiviat et al., 1998; Melbye, Rabkin, Frisch, & Biggar, 1994; Palefsky & Holly, 2003). Human papillomaviruses (HPVs) have been divided into high-risk (hrHPV) and low-risk virus types, based on their historical association with...
cervical cancers (Bosch et al., 1995; Frisch et al., 1997; Munoz, 2000; Walboomers et al., 1999). For example, HPV types 6 and 11 are generally characterized as low-risk viruses because they are rarely associated with human cancers; however, HPV types 16 and 18 are associated with approximately 70% of cervical cancers worldwide and are classified as hrHPVs (Bosch et al., 1995; Munoz, 2000; Walboomers et al., 1999).

The vulnerability of both uterine cervical and anal tissues to HPV infection may be due to a common embryological pathway (Penington & Hutson, 2002). Epidemiological studies further suggest that anal and cervical cancers share etiological risk factors (Melbye & Sprogel, 1991; Scholefield et al., 1989) and that improved detection methods developed over 20 years show hrHPVs to be associated with cancers in other epithelial tissues, including oropharynx, penis, and vulva (zur Hausen, 2000). For example, registry data show that women diagnosed with anal cancer are four to five times more likely to have been diagnosed with HPV-related invasive cervical cancer (ICC) or cervical intraepithelial neoplasia (CIN) than otherwise similar women who are diagnosed with stomach cancer, a malignancy unrelated to HPVs (Melbye & Sprogel, 1991). Worldwide, almost all cervical cancers are causally associated with infection by hrHPV types, and data suggest the majority of anal cancers may be similarly associated with hrHPV infections (Bosch et al., 1995; Frisch et al., 1997; Munoz, 2000; Walboomers et al., 1999).

HPVs are easily passed between sex partners through direct skin-to-skin contact. Some data suggest that condoms are not protective, which is likely due to the inability of condoms to cover all affected surfaces. Even so, epidemiological data suggest that these viruses must be “delivered” to the specific tissues that they infect. In women, HPV infections and related cervical cancers have long been associated with receptive vaginal intercourse; both are rarely associated with virginal women. Anal cancers that arise at or near the dentate line of the anus (intra-anal) are often misclassified or reported together with external perianal malignancies, which are etiologically different. In fact, epidemiological and molecular studies indicate that, like cervical cancers, intra-anal malignancies may be more clearly linked to infection by hrHPVs than are external perianal malignancies. Molecular studies show that hrHPVs promote and initiate cancer. For example, Frisch and colleagues reported that nearly 80% of intra-anal tumors tested positive for hrHPV DNA using Polymerase Chain Reaction (PCR); however, only about half of external perianal tumors showed similar findings (Frisch et al., 1997, 1999). Additionally, intra-anal malignancies in men were recovered from gay men exclusively whereas perianal tumors were recovered from heterosexual men. Nonetheless, even though cancers are rare, genital hrHPV infections are common in the general population. Since so many people are affected, developing innovative treatments may depend on demonstrating need through screening and early detection. Additionally, if anal lesions are similar to cervical lesions, early detection allows a greater opportunity for medical surveillance and, possibly, for less invasive treatment options before malignancies develop.

HPVs cause changes in cell nuclei that are readily detected using microscopy. The Pap test was developed nearly 100 years ago by George Papanicolaou to show the atypical nuclear characteristics of abnormal cells: nuclear darkening (hyperchromasia), enlargement, and atypical shapes, including “raisinoid” appearance, and abnormal numbers of chromosomes (Papanicolaou, 1928, 1954). Since 1930, the Pap test is credited with detecting treatable cervical cell abnormalities before cancer, thereby reducing the incidence of cervical malignancy by 70% (American Cancer Society, 2003; Christopherson & Scott, 1977; Kim et al., 1978). Pap testing can be used similarly to examine anal cell samples to diagnose mild abnormalities, sometimes called dysplasias or atypias, and malignant changes.
Currently, experts suggest that the rate of anal cancer diagnosed among immunocompetent gay men rivals the cervical cancer rate observed among women prior to the introduction of mass cytology screening strategies begun in the mid 1950s (Melbye, Rabkin, et al., 1994). HPV infections, associated dysplasias, and anal cancer occur at an even higher rate among HIV-infected gay men (Klencke & Palefsky, 2003; Melbye, Cote, Kessler, Gail, & Biggar, 1994; Palefsky et al., 1998). In women, a greater frequency of HPV-related cervical dysplasias has been reported since early in the HIV epidemic. Nonetheless, data and molecular studies support the notion that HPV infection is largely cleared by acquired human immune responses among immunocompetent individuals. HIV-infected individuals survived only about 10 years on average after primary infection, and, until recently, anal cancer remained quite rare among HIV-infected men and women. The advent of highly active antiretroviral therapy (HAART) for HIV infection has substantially improved the survival of HIV-infected men and women, although recent data suggest that intra-anal cancers are increasing among the HIV infected (Frisch, Biggar, & Goedert, 2000; Palefsky, 1998; Palefsky et al., 2002, 2005). Ironically, as patients are living longer with effective HIV treatment, enough time may pass for anal cancers to develop.

The purpose of this investigation was to explore barriers and facilitators to anal cancer screening among diverse gay communities. This study is part of broader efforts to understand HPV infection from a clinical and biological perspective in a (different) sample of HIV-infected men that underwent anal Pap testing, examination using high-resolution anoscopy (HRA) and medical biopsy, where indicated. We recognize that it is also imperative to understand the social context of the disease. Our own biological work has focused on HPV–host cell interactions on the molecular level, with the hope of characterizing a biomarker of HPV infection that will allow us to predict who is at highest risk for progressing to cancer (Wiley et al., 2005). Before planning long-term diagnostic and treatment strategies, it is imperative that we first address the issues of HPV awareness and willingness to participate in anal cancer screening; thus, it is timely to solicit perspectives of gay men and community health advocates regarding anal cancer screening.

**METHODS**

**Participants**

Four focus groups were conducted among 16 men and 3 women in community sites. Participants were recruited from a list of individuals who were known by project advisors and key informants to be community-based health advocates who worked with ethnically diverse gay and other MSM living in the greater Los Angeles area. We chose to recruit community advocates and service providers in order to canvass perspectives of relevance to diverse communities of gay and other MSM and from informants with knowledge of both the communities and the health care system. Many of these community advocates were themselves gay men and MSM of color who had particular knowledge from an insider perspective.

All participants were aged 18 years or above at the time of recruitment and individually provided written informed consent. The study protocol and consent form were reviewed and approved by UCLA’s Human Subjects Institutional Review Board. All participants were remunerated $50 for engaging in a 90-minute focus group.

**Data Collection**

Focus group data were collected using a semistructured open-ended focus group interview guide (Morgan, 1998). After a brief introduction to the focus group, open-ended questions explored general knowledge, perceptions, and beliefs that gay men have about anal cancer.
screening and risk for HPV infection and related malignancies. Next, a brief presentation was made about HPV and HPV screening, along with a presentation of the screening instruments by one of the investigators, a registered nurse and epidemiologist. After the presentation, further discussion was elicited, including questions that arose around the instrumentation and suggestions for facilitating HPV screening among ethnically diverse gay men. To enhance the credibility of the data, respondent validation (“member checking”) was utilized by having the facilitator periodically check in with participants to ensure that their statements were interpreted correctly, and through brief follow-up interviews with two informants who had agreed to be recontacted (Chamaz, 1997).

Data Analysis

Focus groups were audiotaped and transcribed verbatim. All transcripts were uploaded into Ethnograph, a software program for qualitative data analysis. Multiple readings of the transcripts were performed by three independent investigators to identify major themes. Next, a line-by-line review of the transcripts was performed and first-level codes—descriptors of important categories in the data—were noted in the margins. All codes were then entered into Ethnograph, tagged to associated segments of text. Text corresponding to each of the first-level codes was then printed and reviewed by three independent investigators, and subcodes were established using a constant comparative method to divide the first-level codes into smaller categories (Chamaz, 1997). Data source triangulation (comparing data across groups) and researcher triangulation (three investigators independently read and coded the same transcripts) were used to enhance the trustworthiness of the findings (Lincoln & Guba, 1985). The results correspond to the categories that emerged in the analysis, and all quotations are drawn from the focus group participants.

RESULTS

Barriers

Barriers to HPV and anal cancer screening emerged in six categories: (a) lack of awareness of HPV, (b) stigma associated with anal Pap testing, (c) psychological discomfort associated with anal Pap testing, (d) the anus as hidden or private, (e) HIV as an overriding concern, and (f) general reluctance among men to seek health care. Distinct issues arose within each of these categories as well as interrelationships among the barriers.

Lack of Awareness of HPV—Focus group participants suggested that many men who have a history of receptive anal intercourse do not realize that it is important to be screened for HPV and anal cancer. Male focus group participants were split on the issue of media coverage with regard to anal cancer and Pap testing. Some male and all female participants perceived that there is little information about this topic in the media, since “you never see commercials or something.” Some male participants said they had read about anal cancer and screening in written media easily available in gay-identified communities. Additionally, participants suggested that HPV awareness might also vary with different racial and ethnic groups. A man said, “When you talk about HPV in a cancerous form, this is something that is not even known in the Black and brown communities.”

Part of this lack of awareness may also be related to age; focus group subjects thought that younger men would be much less aware of the need for a Pap test than older men. One participant said, “I think most men aren’t really aware. I mean, maybe after they reach 50 and their doctors say, ‘You’ve gotta do this.’” Participants suggested that as men get older, they might be more likely to undergo medical screenings, such as prostate exams. Young men, in contrast, are “not thinking of their anus, or any sexually transmitted disease.”
Health care professionals may themselves have misperceptions about the importance of anal cancer screening among patients with a history of receptive anal intercourse. In addition, participants expressed that clinicians have limited time to interact with patients in most settings and that they must prioritize what they consider to be most crucial. This prioritizing, along with misperceptions of risk, may place anal Pap test screening as more or less crucial depending upon the patient, their sociodemographic characteristics, and the comfort the provider feels in discussing and performing Pap tests.

While participants seemed to recognize the importance of providers’ introducing the idea of an anal Pap test to their patients, many emphasized that health care professionals avoid checking men’s anuses. One participant reasoned that “it’s an area … that most physicians are not necessarily real comfortable with.” Another participant said, “Physicians hate, hate to check your anus!” Respondents also thought that health care professionals may be less willing and able to focus on HPV in racial and ethnic communities: “This is not a subject that most of the health care professionals are talking about. They might do it in the White gay area, but in the Black and brown community they are trying to deal with just HIV.”

**Stigma**—Stigma associated with anal Pap screening emerged as a concern across all focus groups. There was expressed concern that anal cancer screening alone identifies men as first, engaging in receptive anal intercourse, and second, as being gay. Participants stated that the health risks associated with unprotected receptive anal intercourse are well described, have been evident since early in the HIV epidemic, and are openly discussed in the gay community. Thus, for gay-identified men, unprotected receptive anal intercourse is not socially acceptable within the community due to its implication in spreading HIV infection, syphilis, and other diseases. One participant illustrated the hesitance in disclosing anoreceptive intercourse as the fear of being labeled as submissive or less masculine:

> There’s this stigma that they believe that being a “bottom” is … passive or … is being dominated. And I guess [they] feel … discriminated … I mean, take the power away from them as being a male and, sometimes it’s very difficult to disclose that issue.

Stigmatization was also identified specifically within the context of relating to a medical provider. For example, respondents understood that some discussion of risk status would determine the necessity of anal cancer screening, as routine screening would not be offered to men who have never engaged in receptive anal intercourse. Thus, respondents noted that even gay-identified men may remain hesitant to explicitly discuss anal sex with their clinicians: “Even gay men are not generally going to the doctor and say, ‘Yes, I have anal sex, I want you to check me for HPV.’ ”

Second, for men who are not openly gay, requesting anal cancer screening inadvertently discloses them as having had sex with other men. It is probably unrealistic to depend on at-risk individuals to acknowledge stigmatizing behaviors, or on clinicians to inquire about them routinely. As participants suggested, at-risk men will avoid testing and the embarrassment of the moment, “especially someone who is not ‘out.’” Finally, screening within communities also requires additional sensitivity about the social milieu, as one participant who predominantly serves African Americans stated:

> In our community we are dealing with a lot of people with very little or no income. You have to use a public health facility to get any treatment. Just the stigma of walking into a public health clinic and having anal screening, and maybe seeing a home-boy there, frequently that will prevent our population from seeking the medical attention that they need.

*J Gay Lesbian Soc Serv. Author manuscript; available in PMC 2010 December 15.*
**Psychological and Anticipated Physical Discomfort**—Participants reported that anal Pap tests might be uncomfortable both psychologically and physically. Emasculation was described as a substantial cause for apprehension in all men, including those who are gay and engage in anal sex: “It is a very submissive situation when you talk about the anus, so it's not a manly thing, even being gay.” Participants agreed that many men would refuse to undergo a procedure that might be considered humiliating, when “You see this little bitty thing … your head says, ‘I am not as much of a man. … Someone is doing this to me.’” Another participant emphasized the influence of psychological distress: “I don't think that is people's fear, that something is going in, that it will be hurtful … it is the emasculation and perhaps the smell and the cleanliness.” Of course, some men might also be anxious about anal Pap testing based on their degree of anal hygiene, since “they gotta worry about if they’ve douche or not because they're embarrassed.” Participants also mentioned that a patient could become uncomfortable if a gay clinician performed the anal Pap test. As one participant illustrated, “Think about it, if you happen to have a gay physician who's very popular, and has a large gay clientele, they [gay men] may or may not want him to be the one checking their anus.” This comment suggests that anal Pap testing could potentially bring up feelings, perhaps sexual in nature, that are uncomfortable for patients while screening is being conducted. Additionally, there is uneasiness when a clinician performs testing that is considered deeply private. Inadvertent violation of confidentiality by health care providers who are also active social partners in relatively small, local gay communities may deter some men from seeking screening.

There was also great perception of physical discomfort associated with the instruments required for the screening procedure, especially those used in high-resolution anoscopy. Midway through the focus group, participants were encouraged to examine and manipulate a Pro-scope disposable anoscope, endoscopic biopsy forceps, Dacron swabs, and a microscope. The disposable anoscope measures 18 mm at its widest dimension and is designed with an obturator to ease insertion, while the endoscopic forceps are fewer than 3 mm in width, approximately one third the size of a grain of rice. During the screening procedure, both instruments are inserted 1 to 2 inches at most inside the anal canal. Despite seeing how simple and small the instruments are, participants expressed concerns about simply being penetrated, as well as fear of the pain related to biopsy. Most participants thought the largest instrument we employed was too big and would cause significant discomfort when inserted. One man appropriately challenged his fellow participants, and they had to acknowledge that the size of the largest instrument was still small in comparison to an erect penis.

**Anus as Private and Hidden**—Many participants explained that men have poor knowledge about their perianal genital area, and trepidation about obtaining a Pap test because it would publicize a body part that is so private. The anus is a body part that, for many, is never discussed, seldom seen, and basically neglected:

> This will take a long, long while … because you're talking about a part of the body that men just don't recognize. I don't care what kind of sex they have, it is not something that you talk about…. Even gay men that are really out, they don't talk about it.

Several participants likened the intra-anal space to a woman's vagina: unseen, unknown, and present. One participant elaborated, “it's kind of … like the dynamic of … women not knowing their vaginas. Nobody … sits over a mirror and says, ‘Hey, what's that there?’ That doesn't happen.”
The perianal region is removed from the normal field of vision and is characterized by tags, bumps, and sometimes fissures; the internal and external anal surfaces are not easily examined by untrained individuals. A respondent said, “You can't check your rectum, you just, you can't do it.” Even with a mirror, it is unlikely that external self-examination would benefit the individual greatly, and internal self-examination is an even less practical strategy.

**HIV as a Primary Concern**—Beyond lack of awareness of HPV and anal cancer, and specific concerns about anal cancer screening procedures, the overwhelming presence of HIV and AIDS emerged as a barrier. HIV continues to be the primary health concern in many gay communities and frames most other health problems. Participants generally characterized HIV as “the elephant in the living room,” in regard to discussion of HPV and anal cancer. They suggested that contracting HIV is the most frightening threat, since it is still considered to be an extremely serious and often fatal disease. HPV, in comparison, is poorly understood as a cause of cancer and thus may be contextualized as less immediately serious than HIV infection. The misperception that HPV is not serious may diminish the importance of screening to those at highest risk for malignancy. As one participant said, “HIV is much more of a concern…. It is very hard to find something else that is going to be as high a priority. If I look at anal warts, I am looking at that as curable.” Participants repeatedly correlated genital warts with anal cancer, and many expressed a belief that genital warts were directly related to anal cancer. However, most subjects were unaware that genital warts are caused by low-risk HPVs rarely associated with cancers, while cancers are consistently associated with specific hrHPV types. Among HIV-infected men, the advent of HAART treatment has hastened greater optimism among gay men, which may be challenged by anal Pap test abnormalities.

Additionally, HPV-related atypias (such as warts) and malignancies may be but one of many health concerns faced by gay men. Participants mentioned that gay men were already overwhelmed by the frequency of sexually transmitted diseases, and their comments connoted a general sense of weariness within the community. Participants suggested that this was especially relevant to African American and Latino gay men. For example, one participant said, “The [African American] community is just now kind of getting used to this HIV thing. A lot of people that are dealing with HIV also have to deal with `Hep C,' and now you are talking about HPV!”

**Reluctance to Seek Health Care**—The general reluctance of men in general to seek any type of health care, particularly preventive care, emerged as an important context for understanding the likelihood that at-risk men would seek anal Pap screening. In part, this reluctance was linked to traditional male gender roles:

I don’t see men really thinking about any kind of health issue. It is about having this macho attitude … [being] the breadwinner. When a man gets sick … they … stay home and take care of a cough or sneeze. The doctor is the last resort…. We have grown accustomed to ignore our body when it says something to us.

Another participant concurred, “It’s just not manly…. It's not macho…. They have got to be almost practically dead before they go to the doctor,” referring specifically to Latinos. Respondents explained further that anal Pap testing is likely to be first thought of within the context of a feminine role since it is traditionally performed to detect cervical cancer precursors. This alone may put men off or cause them to ignore their potential risk for HPV infection or HPV-related malignancy—and even more so among Latino men who may identify machismo as a cultural norm.

Similarly, participants noted that many men—across all communities—seek health care only when symptoms of disease become intolerable; for these men, routine screening for a
sexually transmitted disease or a related premalignant condition is simply ignored. As one respondent said, “I don't think gay men do that [routine preventative STD checks] unless, you know, their dicks are dripping.”

Respondents reasoned further that health concerns such as HPV infection and anal cancer screening compete with the many demands of daily life. Participants across all focus groups, especially those serving African American and Latino men, explained that general health maintenance is not a priority in their clients' hierarchy of needs: “A lot of the population you are talking about, if their economics are not up there … health is not going to be the number one issue.” Similarly, another participant said, “With a lot of the Latino gay youth I've worked with, the primary issue is survival.” For men described by participants as having low socioeconomic means, issues such as paying for food and finding a place to sleep likely take precedence over seeking any kind of health care, particularly screening.

Respondents suggested that care seeking, as it relates to anal cancer screening, is related to behavioral trends within particular communities of affiliation among gay men. It was generally agreed that men who identified as part of a mainstream gay community would react to anal cancer screening differently than men who were otherwise identified. Whether men primarily identified themselves with respect to race/ethnicity or culture or their sexual orientation was thought to greatly influence how they would seek care generally, as well as how they would perceive anal cancer screening. For example, participants alleged that many were unlikely to seek care “especially in the Black community…. A lot of Black people stay to themselves. When they are getting diseases they carry it for a long time before they decide to go to the doctors and then it is creating different problems.” The tendency to ignore illness may be understood as a result of multiple social forces, including economic disenfranchisement, racial discrimination, lack of access to care, and community norms.

Facilitators

Several factors emerged that may positively influence the likelihood of adopting anal cancer screening in the community. Facilitators comprised three categories: (a) provision of screening sites, (b) health care system changes, and (c) educational campaigns.

Provision of Screening Sites—Participants suggested community awareness and willingness to participate would increase if access to screening venues were improved. Some posited that screenings could be conducted in novel sites as well as traditional health care venues. Confidential and anonymous home-test strategies would overcome many of the aforementioned barriers, including the psychological discomfort of testing and its associated stigma. For example, one participant said, “The idea of doing it at home would have … better appeal, as opposed to going to a cold clinical room and having a procedure done, even if it’s with your physician.” Another noted that “a home collection device definitely would be preferable than going in to seeing the doctor.”

Additionally, conducting screening in the venues where at-risk men are likely to be found was encouraging to participants. For example, including Pap tests as standard activities for mobile medical units was valued: “Put it on a mobile unit.” Festivals, community rallies, and other social gatherings were suggested as screening sites: “If you want to … reach gay men, and especially HIV-positive gay men, you have to go where they are. You are looking at Gay Pride parades and festivals.” Participants suggested anonymous anal cancer screening could also be offered at sex clubs, bathhouses, and other sites where men go specifically to engage in anonymous sex. This suggestion was particularly relevant for those men who do not adhere to one sexual orientation:
Make it available … like in the clubs, [for] men who don't… necessarily identify as gay. They're, you know, they've got kids, but they'll go to a club because it's safe and anonymous. And if you can get them the [home HPV test] kit there, or provide them with testing there, anonymously … they'll get the picture where they play.

**Health Care System Changes**—A number of system-related changes were suggested that might encourage men to seek anal cancer screening. Generally, participants recognized that a physician's recommendation for screening can be a powerful motivator for the public. However, they also acknowledged that anal cancer screening was not a current priority for providers. For example, one participant stated, “it is going to take one-on-one kind of work educating physicians to help them understand why this is important…. How you put this on their radar screen along with everything else … is what you will have to deal with.” Although the link between professional recommendation and public action was identified, it was unclear whether participants felt public demand would drive clinician concern and education or vice versa. The importance of patients asking their physicians for screening was emphasized: “Educate … the patient … it is okay for the patient to ask. The way to do that would be through a resource center and having posters and handouts.”

Participants also recommended incorporating anal cancer screening into routine health appraisals, such as an annual physical examination or screenings routinely offered to men, for example, prostate-specific antigen (PSA). A respondent reinforced the notion of combining anal HPV with other male health issues: “If I had this conversation with my physician as part of a broader health care discussion, I may want to do this as a once a year or twice a year kind of thing where he does the same sort of thing for prostate cancer.”

Some participants suggested that men should be counseled in advance and warned that anal cancer screening would be performed as part of an upcoming visit. This was thought to be particularly helpful for men who are concerned about hygiene: “so I would be ready for it and be prepared as opposed to not being in the kind of condition I would like. I don't like to smell.”

Participants who predominantly serve African Americans and Latinos claimed distrust would be a major barrier between at-risk men and their health care providers. Tuskegee was referenced as an example of the watchfulness individuals and communities of color must exercise. As one participant commented, “There's this great distrust … I think it's the medical profession in general for a lot of young African American men and older African American men, regardless of sexual orientation … they distrust the medical community.” Unfortunately, this distrust may have been fostered by a lack of both accurate information and open communication. Clinicians must confront these suspicions by being forward and honest about the procedure and its implications; however, they must carefully balance conveying this information clearly without frightening patients with too many details. Latinos must also face complex socioeconomic barriers, as they are “afraid not necessarily of the medical profession, but afraid of the cost … missing work, and legal issues about immigration.” To ensure the success of implementing anal cancer screening, it needs to be made accessible and affordable in these communities.

**Educational Campaigns**—Participants offered a variety of suggestions for HPV educational campaigns tailored for gay communities. They agreed that advertising in a wide variety of venues would increase awareness of HPV infection and anal cancer screening. As one participant suggested, “have something like a pamphlet … that you see in all the doctors’ offices.” In addition to health care settings, participants suggested using “posters and outreach workers and these kinds of things but [also] media and press.” Participants believed that there are “fun ways of getting this stuff out there,” such as having HPV-related
messages on the toilet paper dispensers at sex clubs: “You could just roll out, `Get your butt checked out.' ” Many recommended publicizing HPV-related information in gay magazines, gay Web sites, phone lines, and Internet chat rooms. For example, “you can put those banners in those chat rooms. … Even have people … go in and act like they're part of the chat room but they're really health educators.” Another suggestion was to have education and even testing in an erotic environment such as a sex club or bathhouse, so that men could acknowledge the necessity of screening without perceiving a threat to their lifestyle:

I really think that in sex clubs and bathhouses is where there is a percentage of non-identified homosexual men. So, this is the place really, where we could do some educating without them even knowing that they're being educated. In a very comfortable setting for them, because they're coming to have sex without anybody knowing who they are, and that's where we should put testing sites. But do it in such a way that it's … non-judgmental … almost even secret … they could go into a room and get tested, and come back for their results without ever being seen going in and out of this room. And still be able to continue playing without feeling that they're being followed everywhere.

Participants discussed how messages and venues that might reach gay-identified men could be very different from those that might reach men who are not gay-identified, including African American and Latino men who predominantly define themselves otherwise, and especially men who are married to or in primary relationships with women. Accordingly, participants explained that it would be beneficial to tailor educational campaigns to particular communities: “It is a community-by-community basis and the needs of one community may be very different [than the needs of another].” Thus, it is useful to educate people about anal cancer screening in as many venues as possible in order to convey its importance, but also to promote awareness beyond the openly gay community.

Participants also offered ideas for the content of the messages involved in HPV health education campaigns. They recommended using frank language to get the point across effectively, as one participant described:

We're much more at ease using words like butthole, stuff like that, than just about anybody, other populations. So, that you can communicate … by saying a little more frank, open. Say, “Is your asshole okay? Have you been using it lately?”

The message should be easy to understand, without disclosing too many details that might promote fear instead of concern. Participants emphasized that discouraging or scolding risky behaviors would be counterproductive: “Don't [say], `You shouldn't do that, you're dirty, bad, and wrong.' ” There was concern that if faced with a negative message, men would simply ignore the whole issue and there would be a backlash against the informational campaign.

Participants believed that focusing on anal cancer screening as a form of routine maintenance would be more effective than stressing the risks and consequences of illness; in essence, preventive screening was perceived as unappealing unless framed within the context of a general health checkup. In a broader sense, HPV educational campaigns should emphasize that “the general population should not be afraid to ask their doctor about something like this.” Participants also suggested slogans for an HPV educational campaign integrating anal cancer screening as part of an overall health inspection:

“Keep it tight and tidy.”

“Is your asshole okay?”

“If you use it, take care of it.”
DISCUSSION

This study of community health advocates who serve ethnically diverse gay communities suggests that awareness of and access to information about anal cancer and Pap test screening is limited in these communities. HPV awareness and access to information were seen to be particularly low among African American, Latino, and younger gay men, and men who were less likely to be part of self-identified gay male communities. In addition to the general lack of awareness about anal cancer and Pap test screening, participants described specific health care barriers for gay-identified and ethnic minority MSM. These included pervasive heterosexism in health care settings (i.e., the presumption of heterosexuality) as well as anti-gay stigma that affects all men who have sex with men, both gay-identified and not. Participants stressed the importance of accessible community-based screening sites and the critical role of physicians and other primary care providers as powerful advocates who could facilitate HPV screening among at-risk men. Educational campaigns aimed at normalizing anal cancer screening were recommended, including culturally appropriate messages tailored to particular communities, whether defined by race, ethnicity, or sexual self-identification, and across diverse venues (e.g., local community health clinics, gay bars, sex clubs), both gay- and nongay-identified.

Stigma was seen as a potent barrier to anal cancer screening. As described by Goffman (1963), the mechanisms of stigma operate not only to affect those already labeled, for example, as gay (“discredited”), but also to strongly affect those who are potentially “discreditable” (e.g., men who are not gay-identified). Merely seeking out or submitting to anal cancer screening was seen as a marker for male-to-male sex, which may elicit internal psychological distress as well as fear of being “outed,” particularly among men who do not self-identify as gay or bisexual. Even for gay-identified men, engagement in anal cancer screening may be experienced as humiliating, demasculinizing, and as forcing self-disclosure to health care providers who otherwise may not recognize or acknowledge the patient’s sexual orientation.

The stigma of anal cancer screening may negatively impact health care decisions made by gay men, but the now normalized practice of cervical cancer screening among women may be instructive. Cervical cancer screening was introduced before the sexual revolution of the 1960s when the prevalence of HPV infection changed significantly (Koutsky, Galloway, & Holmes, 1988). Women participated in cervical cancer screening with increasing frequency through times of significant role and sexual behavioral change (Christopherson & Scott, 1977; Kim et al., 1978), yet there is no data to suggest they were stigmatized for being screened. Also, recent international data suggest stigmatization may not be especially problematic even for women who have frank disease. For example, Ohaeri and colleagues report that although women with cervical cancer do report concern about hygiene and odor, they only infrequently reported social interactions suggestive of social stigmatization (Ohaeri, Campbell, Ilesanmil, & Ohaeri, 1998). Nevertheless, the present findings suggest that the stigma regarding screening for men is compounded by implicit or explicit acknowledgment of having sex with other men; thus promotion of anal Pap screening for men requires acknowledging and addressing anti-gay stigma and discrimination, and concerted efforts to address anal Pap screening as a public health rather than a sexual identity or sexual morality issue.

Psychological and physical discomfort directly related to the implementation of the anal screening test were identified as concerns by participants in this study. Facilitating anal cancer screening and allaying fears requires a distinction between the fears related to the
physical examination and anxiety related to the information contained in screening test results. The possibility of being diagnosed with cancer is inherently anxiety provoking, especially as a disease the public often perceives as ominous and life-threatening. Our data suggest that anxiety about instrumentation associated with this procedure is high, although unrealistic in practical terms. Therefore, it may be helpful to offer information about the procedures as well as to provide opportunities for those men who wish to manipulate and explore instruments prior to an examination. Nevertheless, repeated screening using Pap test and high-resolution anoscopy is necessary to detect precursor lesions and cancers at a stage where treatment can still effectively prevent invasion into underlying structures and distant organs.

For men living with HIV, the diagnosis of anal squamous intraepithelial lesions may challenge optimism that has been hard gained with the advent of HAART therapy. Since the introduction of HAART, overall survival has increased while the incidence of opportunistic infections, including many AIDS-related cancers, has diminished (Eltom, Jemal, Mbulaiete, Devesa, & Biggar, 2002; Grulich et al., 2001; Rabkin, 2001). However, greater duration of survival may inadvertently provide time for HPV-related cancers to develop, as HIV-infected men are at significantly greater risk than uninfected men for hrHPV infections and high-grade anal neoplasias (Palefsky, 1999, 2000; Palefsky, Holly, Ralston, Jay, et al., 1998; Sobhani et al., 2001). Recently published data suggest that high-grade anal neoplasias may not regress rapidly after treatment with HAART (Palefsky et al., 2001; Piketty et al., 2004). Additionally, the Pap screening test performs better in populations where the prevalence of disease is high (Rothman & Greenland, 1998). Thus, for HIV-infected men, receiving an abnormal Pap test result may be an even greater threat to survival, as well as a perceived threat to the optimism that may have accompanied immune reconstitution using HAART.

Beyond concerns and barriers specifically related to anal cancer and Pap screening tests, participants identified a context of low engagement in preventive health care among men in general, and even more so for low socioeconomic and ethnic minority MSM. Some of the gendered concerns are further conditioned by cultural norms that prescribe masculine behavior among Latino and African American men, including the equation of machismo, such as not going to the doctor and seeking health care only as a last resort. These cultural norms are compounded for men of low socioeconomic status who may face competing needs, such as food, rent, and basic survival, which often leaves preventive health care as a low priority. In this context, experiencing structural barriers to access to and utilization of health care, due to lack of community-based clinics, inability to pay, stigma, racism, and homophobia, makes anal cancer screening even less likely. Thus, it is particularly important that educational messages are coupled with structural interventions in the design and delivery of culturally appropriate and accessible screening services.

Notwithstanding the many barriers, participants offered a number of suggestions to increase anal cancer screening among diverse communities of gay men. These included overcoming practical limitations through the provision of accessible screening sites, and health care system changes necessitating provider training and education, and routinization of anal screening. Participants stressed the importance of increasing accessibility and convenience of screening through a variety of different venues. This suggestion is similar to what has been done in various communities with mobile mammography vans and HIV testing vans. In the case of anal cancer screening and its associated stigma, it would be important for the mobile unit to not be designated as HPV specific or even sexually transmitted disease (STD) specific—depending on the local venue and context. As participants described, the stigma raised by anal cancer screening may be reduced by offering the HPV test in addition to other tests seen as more innocuous, such as cholesterol screenings and blood pressure checks. For
gay male communities, the addition of anal cancer screening to existing HIV testing services—including mobile vans that park outside of areas with a high concentration of gay bars—may increase both awareness and implementation of screening. Additionally, it may be feasible to develop safe and effective self- and home-collection devices for anal Pap testing; the present data and clinical experience suggest that home sampling kits may increase testing. Ethical practice requires that we as health care providers develop better detection and treatment strategies, as well as provide a cadre of well-trained clinicians to diagnose and treat anal dysplasias identified through enhanced screening strategies.

Participants specifically suggested that clinicians should receive additional education about anal cancer screening and serve as point-persons for disseminating information to their patient populations. It remains unclear whether the community's perceived lack of knowledge is a reflection of limited communication between clinicians and patients on this topic, or whether there is true ignorance among clinicians in this regard. A growing and significant literature concerning anal cancer risk and the need for screening in at-risk populations is available (Daling et al., 1987; Frisch et al., 1999; Klencke & Palefsky, 2003; Melbye, Rabkin, Frisch, & Biggar, 1994; Palefsky, 1999, 2000; Palefsky, Ralston, & Jay, 1998). A parallel literature specifically targeted to at-risk men and women dates, at least, to 2000 (Anal cancer, 2000; Anal cancer risks, 2001; Clinicians, 2003; Nearly 40%, 2002). Thus, there is both perceived risk within the community and published data on which these opinions are formed, but it remains unclear whether and how clinicians have accessed, absorbed, and then disseminated this information to their patients.

Educating patients about anal cancer and screening options requires that clinicians are comfortable with the discussion and that they accurately perceive their patients to be at risk for disease. Primarily, to perceive risk, clinicians must first correctly understand the relationship between intra-anal HPV infection and cancer, and, second, collect comprehensive sexual history data that correctly classifies patients who are at risk and have the greatest likelihood of benefiting from anal cancer screening. Screening barriers may diminish if providers themselves can overcome personal discomfort and biases that limit effective patient counseling. Similarly, Pap test sample collection requires some training that is not routinely provided as part of medical or nursing education. Comfort and care should be integrated into sample collection as intimately as in educational messages to help overcome barriers to screening.

Anecdotally, our experience suggests that there may be confusion among gay men about visual screening techniques for colorectal and anal cancer. Screening for colorectal cancer includes testing for fecal occult blood, sigmoidoscopy, and colonoscopy. Although the anal canal could be examined using an endoscope or sigmoidoscope, it is often not the case. Most experts suggest that direct visualization using bright light and an external magnifier, called a colposcope, is a better way to locate affected areas for biopsy. This procedure, high-resolution anoscopy, or HRA, can be performed by clinicians who have been specially trained.

Anal cancer screening is currently limited to routine palpation for masses by digital examination; there is no national consensus for screening among clinicians beyond this technique. However, experts generally agree that men and women whose history includes receptive anal intercourse, including gay men, may benefit by Pap testing and cytology, followed by biopsy when medically indicated (Chin-Hong & Palefsky, 2005; Goldie et al., 1999). These expert recommendations are predicated on several facts. First, currently available data underestimate the risk for anal cancer among gay men, because all men are included in the denominator when most men are not at risk for intra-anal exposure to HPVs. Second, cervical cancer screening is credited with reducing cervical cancer by
approximately 70% since its introduction in the mid-1950s (American Cancer Society, 2003; National Center for Health Statistics & Centers for Disease Control and Prevention, 1999). Both the anus and the cervix can be infected and affected by HPVs (Palefsky et al., 2005); however, treatment of intra-anal dysplasias is less well developed than is cervical treatment. Thus, the ethical debate that continues suggests we should not screen for diseases that we cannot adequately treat, including malignancies. Nonetheless, some estimates suggest the occurrence of anal cancer among gay men is more frequent than was cervical cancer in women when we introduced annual Pap testing for women in 1955. Some argue that diagnosis of disease may drive development of effective therapies and that continued ignorance will only support the status quo.

A “quadrivalent” virus-like protein (VLP) vaccine was approved for prevention of HPV types 16, 18, 6, and 11 infections in June 2006 by the U.S. Food and Drug Administration and the Centers for Disease Control and Prevention’s Advisory Committee on Immunization Practices (Markowitz et al., 2007; U.S. Food and Drug Administration, 2006). Despite the recent media attention and policy focus on HPV vaccination for young women, little discussion has addressed HPV among gay men. The current recommendation for its use is limited to 9- to 26-year-old females, and data are being gathered to evaluate effectiveness in men (Tuller, 2007). Unfortunately, therapeutic vaccine strategies for HPV infections largely remain elusive, and it is unlikely that this or other VLP vaccines are effective as therapeutic treatment for existing infections or dysplasia. Thus, it is crucial to continue stressing prevention and regular screening for those at highest risk. The Healthy People 2010 companion document for gay, lesbian, bi-sexual, and transgender health underscores a goal of decreasing sexually transmitted infections, including HPV, through targeted, culturally sensitive education, and also calls for more research to test the effectiveness of Pap testing as a preventive strategy for anal cancer (Gay and Lesbian Medical Association, 2001).

Limitations of this study include the use of purposive sampling, thus results may not be generalizable or applicable to communities or individuals outside Los Angeles. Nevertheless, we included diverse representatives among health care advocates serving gay and other MSM in Los Angeles, and we elicited similarities and differences with regard to anal cancer screening barriers and facilitators among different communities. Participants in this study were not gay clients themselves, though many informants in this study were themselves part of the stakeholder communities and could thus present a privileged insight into their clients’ perceptions. Community-based advocates were selected because of their broad access to potentially affected men. Our intention was to gain a broad perspective on various communities’ concerns about anal cancer screening and treatment among gay and other MSM. Although these participants may have filtered perceptions expressed to them by affected individuals, we felt that access to a more diverse set of opinions than traditionally offered in focus groups would outweigh any risks of obtaining biased information. It is possible that interviewing clients directly may offer different or additional perspectives on HPV and anal cancer screening.

**Implications for Social Service Providers**

Anal cancer is an emerging health problem for gay men. Anal HPV infection and associated high- and low-grade dysplasia are common in the community, and men living with HIV are particularly at risk. There is currently no national consensus for screening strategies, and treatment for high-grade anal lesions remains largely unsatisfactory (Berry, Palefsky, & Welton, 2004; Palefsky, 1999). With neither effective treatment to prevent progression nor an indicator as to whether lesions will progress if left alone, it is crucial to improve access to screening and to develop new strategies to increase utilization; this will allow clinicians to determine which men are at highest risk for progression to cancer and facilitate earlier and more effective therapy. Social workers and other social service providers provide a crucial
link to preventive health care and treatment, particularly among communities that are often disenfranchised by the health care system. Nevertheless, this requires education, awareness, and sensitization of social service in addition to health care providers.

First, social workers and other social service providers, including those specifically working with MSM and persons living with HIV who may otherwise have a solid grasp of various community concerns, require education about HPV among men, its association with anal cancer, and the importance of early detection. Second, social service providers have a crucial role to play in addressing the stigma around anal sex and anal Pap screening—including their own biases and prejudices—and in providing respectful, nonjudgmental, and gay-affirmative support and services, including appropriate services to MSM who may not identify as gay. Third, ensuring access to competent and culturally appropriate services requires both a working knowledge of HPV, its detection, and risks among MSM, and awareness of community and public health services. Fourth, social workers need to advocate where services are not available, to ensure MSM access to competent preventive health care. Fifth, a traditional role of social workers, and a particularly important one in the case of anal Pap screening, is to address psychological obstacles by helping clients to work through anxiety associated with the potential malignancy that will likely affect less than 1% of gay men, even using our highest current estimates. Finally, social workers and other social providers, in addition to bearing significant responsibility for increasing early detection, will have an important role in treatment referrals and case management among the subset of men who are diagnosed with anal cancer.

Our goal was to conduct a preliminary study among key informants from diverse communities possessing particular expertise and insights into both gay and other MSM client populations and the health care system, and the interactions between them. In addition to a variety of concerns and barriers that emerged, there arose many possibilities for intervention. Additional research among client populations and their health care providers is needed to develop and test strategies that may increase anal cancer awareness and screening among diverse communities of gay and other men who have sex with men.

**Acknowledgments**

This project was partially (or all) supported by the UCLA Center for Vulnerable Populations Research (CVPR), Grant # P30NR005041, National Institute of Nursing Research/National Institute of Health.

**REFERENCES**


*J Gay Lesbian Soc Serv*. Author manuscript; available in PMC 2010 December 15.
Clinicians call for anal pap tests for gay men. The Advocate, online. February 20;2003
Nearly 40% of gay men infected with dangerous strain of HPV. The Advocate, online. March 9–11, 2002


J Gay Lesbian Soc Serv. Author manuscript; available in PMC 2010 December 15.


We the People of Delaware Valley. Anal cancer tests recommended for gay men with HIV. Being Alive. August;1999
