

Update: Ascertaining barriers to Anal Cancer Prevention in people living with HIV from the patient perspective

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Purpose: We sought to ascertain barriers to adherence to anal cancer screening recommendations among people living with HIV/AIDS, PLWH)

Background: The general population in the U.S. has a 1 in 500 lifetime risk of developing anal cancer. There is 19-fold increase in anal cancer risk among all HIV positive people and a 37-fold increase in risk for HIV+ MSMs. Despite modest improvements in access to anal pap smears and high resolution anoscopy (HRA) in the U.S., these screening modalities remain underutilized by at-risk groups. To date, few studies have explored the factors contributing to non-adherence to anal cancer screening recommendations among HIV positive at-risk people. No studies have focused on HIV positive people living in Louisiana despite the state ranking 4th in the nation for new HIV cases and 3rd in the nation for AIDS case rates in 2019. The goal of this project is to identify barriers to anal cancer screening to facilitate the development of effective advocacy and educational tools.

Methods: An online survey was completed by 50 patients who either attended their anal cancer prevention appointment or did not attend their appointment. The patients were asked to identify any barriers to seeking care as well as the factors that facilitated attendance at clinic appointments. Fifty patients at high risk for anal cancer were interviewed using the Health Belief Model about their understanding of personal risk of anal cancer and perceived barriers to screening adherence. We defined high risk as being over the age of 35, being HIV positive, and having multiple sex partners.

Results: Retrospective chart review found an association with nonadherence and distance from referral facility, race, and age. No significant association was found related to smoking status, level of education or gender. Patient interviews identified themes of not feeling at risk for anal cancer or being unaware of the relationship between HPV infection and anal cancer although participants did recognize the severity of the consequences of anal cancer. The perceived benefits of screening were reduction in risk of death. Perceived barriers included lack of knowledge, lack of access, discomfort from the procedure and stigma associated with an anal cancer diagnosis. Factors that facilitated attendance were having adequate transportation, being in a research study, and having knowledge of their appointment dates and times. Patients identified cues to action as strong recommendation from their primary care or HIV care provider and personal reminders in the form of communication from a trusted care coordinator or care provider.

Conclusion: Patients at the highest risk for anal cancer may have high rates of non-adherence or lack of access to recommended screening including anal paps and HRA. Barriers to adherence include lack of knowledge, fear of discomfort, lack of access related to few trusted providers and long distances to referral sites, and fear of stigma. Health care providers for HIV positive people are often unaware of risk factors for anal cancer or the scope or severity of the disease, are uncomfortable with performing anal paps, and are unaware of resources for follow up of abnormal results. We plan to develop a series of short educational sessions and a referral information sheet for health care providers. In addition, we plan to develop culturally competent educational materials for patients, providers, patient educators and navigators. These educational materials will be written in plain language and include information on risks for anal cancer, methods of reducing risk including anal cancer screening, and contact information for patients or providers seeking additional information or referral sites for anal paps or HRA.