A Qualitative Study Among Southern Healthcare Providers Managing Patients at Risk of or Living With HIV

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#### Introduction

IV/AIDS rates have reached epidemic proportions in the southern United States.<sup>1</sup> This grouping of 16 states plus the District of Columbia account for 50% of newly diagnosed HIV cases, 46% of new AIDS diagnoses, and 43% of the HIV-infected population.<sup>1,2</sup> All but 1 of the 10 states with the highest HIV fatality rates are located in the South, and, whereas rates have largely stabilized across the US as a whole, new HIV-infection rates and mortality continue to trend upward in this region.<sup>1,2</sup> The factors driving these disparities are complex and not completely understood. However, a better understanding of common challenges experienced by practicing healthcare providers is essential to developing and implementing solutions to address the southern epidemic.<sup>1</sup>

This paper details findings from a qualitative study that explored perspectives of healthcare providers from 8 practices across the southern US related to current recommendations for screening patients for HIV, offering pre-exposure prophylaxis (PrEP) to patients with high-risk behaviors and managing the care of individuals living with HIV/AIDS. The goal of the study was to identify educational and practice gaps of participating healthcare providers and to characterize patient-specific, system, and sociocultural barriers preventing the implementation of evidence-based strategies in their own settings of care. These findings would then, in turn, inform the development of relevant continuing education initiatives to support healthcare professionals on the front lines of the HIV pandemic who are well positioned to mitigate the disproportionate burdens of delayed diagnoses, poor engagement in HIV medical care, and suboptimal rates of viral suppression rates borne by individuals in this region of the country.

# The Initiative

The project was a collaborative effort between Med-IQ, the Southeast Consortium for CME (consisting of the continuing medical education offices of the University of Virginia, the Medical University of South Carolina, and the Medical College of Georgia at Augusta University), and HealthHIV. To gain frontline perspectives about the identification and management of HIV in the South and uncover practical solutions for addressing barriers to care, between March and December 2014, we conducted an interview-based, in-depth assessment of several practices in the southern US. The objectives of the study were to:

- Understand factors contributing to interruptions in HIV care
- Detect barriers to identifying patients at risk for HIV infection
- Identify strategies to link, engage, and retain HIV-positive patients in care
- Outline practical strategies to overcome barriers to optimal HIV screening and care

The intention of this type of practice assessment is to uncover educational needs based on the feedback of "in-the-trenches" healthcare providers that may have otherwise been overlooked or gone undocumented. Gathering first-hand accounts of current practices and barriers to inform the development of relevant education is an important and unique supplement to issues identified via more traditional educational needs assessments, such as published reports in the clinical literature, electronic surveys, and expert faculty input. This approach provides a first-hand look at practice patterns, identifies potential barriers to the implementation of guideline recommendations and evidence-based care, and illuminates potential root causes of educational gaps.

HIV specialists, primary care physicians, and other care-team colleagues were invited via e-mail to participate. Each practice received a small stipend, and clinician interviewees were able to claim *AMA PRA Category 2* credit. Interview questions pertained to HIV screening and testing procedures, use of PrEP for HIV prevention, referral practices to infectious disease specialists, antiretroviral therapy (ART), adherence, and retention in care. The answers were compiled, and aggregate data were analyzed to identify common themes and overall trends.

## Results

Twenty-three individuals (7 physicians, 6 nurses or nurse assistants, 3 nurse practitioners, 2 case managers, 2 social workers, 2 program directors, and 1 physician assistant) representing 8 practices were interviewed. The practices included 4 HIV specialty clinics, 3 primary care clinics, and 1 hospital-based care team. Other geographic characteristics of the participating practices were as follows:



- Practices were located in Florida, Georgia, Mississippi, South Carolina, and Texas
- Three practices were in rural settings, 3 were in nonmetropolitan urban settings, and 2 were in urban metropolitan settings.

In response to an open-ended question about potential reasons underlying the high prevalence of HIV in the southern US, the participants' answers fell into 6 major categories:



HIV testing was offered in 7 of the 8 practices; the exception was an HIV specialty clinic solely providing treatment services. Interviewees indicated awareness of CDC HIV screening recommendations3 and reported testing consistent with these guidelines "most of the time." One physician stated that her screening philosophy was "given the high prevalence of human papillomavirus, by extrapolation I should assume that everybody has [HIV] until I prove otherwise." Observed patientrelated challenges to testing were denial, fear, and stigma. To overcome these barriers, 1 practice placed signage throughout the clinic with the statements, "free HIV testing/everyone needs to be tested/know your status" to normalize HIV testing as a routine practice. In addition, interviewees from 5 of the 8 practices reported clinician bias in the community as a hindrance to routine testing. For example, 1 physician noted homosexual patients reporting that they experienced discrimination with other healthcare providers and were "happy to have found a practice that is accepting of their lifestyle and this disease."

Two practices used a counseling tool with patients awaiting test results after a positive rapid test result. Staff members described to patients the process of sending blood samples to an external laboratory and explained the importance of practicing safe sex and exercising other safety precautions during the 2-week waiting period. Social workers and nurses were also available to answer questions during this time. One practice took a preemptive approach by asking patients "Who will you contact if the test is positive?" and "What will you do if the test is negative?" At all practices, positive blood test results were delivered in person, and 3 practices used a team-based approach-including a social worker and nursing staff-to inform their patients.

Only 2 practices—1 HIV specialty clinic and 1 primary care practice—reported offering PrEP to patients at high risk of contracting HIV. Another primary care practice referred eligible patients to an infectious disease specialist for PrEP counseling. Of the 2 clinics offering PrEP, only the primary care clinic reported currently managing patients on PrEP. Notably, 2 clinicians responded to the interviewer's question about PrEP with anecdotes about how post-exposure prophylaxis is used in their practice, suggesting a lack of understanding about what PrEP is and for whom it is indicated.

Timely linkage of patients to HIV care following diagnosis is an important predictor of treatment initiation and viral suppression.4 Formal linkage procedures existed at 5 of the 8 practices, whereas the remaining 3 practices described their referral relationships as "informal." Nearly all (7 of 8) sites reported information sharing between primary care and HIV practices, either by sending clinical notes or via electronic health record systems. Half of all primary care sites regularly contacted patients to ensure that referral appointments to infectious disease specialists were kept. All 4 HIV specialty clinics had a system—peer counselors or outreach workers who visit patient homes—to reengage patients who missed appointments.

The most frequently cited barriers to retaining HIV-positive patients were lack of transportation, issues relating to substance abuse, unstable housing/homelessness, and mental health issues. Several solutions were in place to help mitigate these barriers, including vouchers for gas, transportation, food, and utility bills as well as substance abuse and mental health programs. One specialty clinic educated Medicaid patients about available subsidies for the cost of transportation to their appointments. Another purchased a dedicated cell phone for clinic staff to send appointment reminders via text message.

Interviewees from the 4 specialty practices reported that ART may be delayed at the time of diagnosis regardless of viral load or CD4 count. Many clinician- and patient-related factors were responsible for this divergence from guidelinerecommended care (<u>Table 1</u>);<sup>5</sup> for example, participants frequently cited that co-morbid mental health disorders required intervention before ART could be initiated.

TABLE 1. Reported barriers to antiretroviral treatment initiation.	
Clinician-Related Factors	Patient-Related Factors
Patient deemed not ready to initiate treatment	Denial of diagnosis/fear of HIV stigma
Substance abuse issues	Insurance/cost-related issues
Homelessness/unstable living situation	Unwillingness to start treatment
Presence of comorbidities	Misinformation about medication



Challenges experienced by primary care clinicians concerning ART management included addressing treatment side effects, evaluating adherence, and navigating payment-related challenges. HIV clinic personnel also noted adherence issues with ART and perceived these to be a result of substance abuse, unstable living situations, psychosocial issues, and medication side effects. To overcome adherence challenges, clinicians recommended counseling at every visit about the importance of adherence, cell phone reminders, direct patient outreach, the use of pill boxes or other reminder systems, and tailoring medications to reduce pill burden and attenuate side effects.

### Discussion

This qualitative study of primary care and HIV specialty clinics in the South revealed that many clinicians were keenly aware of the societal issues that prevent timely identification and optimal management of HIV patients. Interviewees presented several practical solutions to enhance communication between patients and providers, which were subsequently shared with all practices participating in this project. Together, these observations support a continued need for education and mobilization of stakeholders in the South who are vital to combating the HIV/AIDS epidemic in the US. Indeed, opportunities to enhance patient care involve the need to reduce barriers to routine HIV testing, increase education about the rationale for and appropriate use of PrEP for HIV prevention, and improve methods that support linkage to care and adherence to treatment.

## References

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