

# Linkage and Retention in HIV Care among Men Who Have Sex with Men in the United States

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**Men who have sex with men (MSM) continue to be disproportionately affected by human immunodeficiency virus (HIV) infection. While the MSM population does better than other HIV infection risk groups with regard to linkage to and retention in care, little is known about engagement in care outcomes for important subpopulations of MSM. There is also a dearth of research on engagement in care strategies specific to the MSM population. Key MSM subpopulations in the United States on which to focus future research efforts include racial/ethnic minority, young, and substance-using MSM. Health care systems navigation may offer a promising engagement in care strategy for MSM and should be further evaluated. As is the case for HIV-infected populations in general, future research should also focus on identifying the best metrics for measuring engagement in care.**

Since the earliest days of the human immunodeficiency virus (HIV) epidemic, men who have sex with men (MSM) have been profoundly affected by the disease [1, 2]. MSM make up the largest risk group of persons living with HIV in the United States, accounting for nearly half of infections (48.1%), despite being only about 4% of the adult population [3]. President Obama's recently released National HIV/AIDS Strategy calls for more emphasis on addressing the HIV prevention and care needs of MSM [4]. While immediate efforts to increase testing and treatment should be implemented, many questions remain with regard to the most effective strategies to link and retain MSM into care.

In this paper, we present data on racial/ethnic disparities in HIV outcomes among MSM that have important implications for engagement in care research in this population. We also discuss the need for conceptual

and operational definitions of linkage to and retention in care with attention to MSM-specific barriers to and facilitators of engagement in care. Finally, we review several promising models to promote engagement in care for MSM. Based on our review, we argue that next directions for research on engagement in care for MSM should include: (1) linkage and retention research agendas that focus on specific subpopulations of MSM, including black and Latino MSM, and MSM-specific barriers to care; (2) evaluation of existing measures for linkage to and retention in care to determine the most useful metrics to assess engagement in care; and (3) attention to how newer strategies to detect HIV infection, such as acute HIV screening and "test and treat" approaches, may affect engagement in care processes and outcomes for MSM.

## RACIAL/ETHNIC DISPARITIES IN HIV OUTCOMES FOR MSM: A KEY GAP IN LINKAGE AND RETENTION RESEARCH

In 2006, the MSM population accounted for 53% of new HIV diagnoses in the United States and 72% of reported adult male and adolescent infections [5]. In contrast to other risk groups for which HIV/acquired immunodeficiency syndrome (HIV/AIDS) diagnoses have

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decreased, cases among MSM increased 8.6% between 2001 and 2006 [6]. When MSM surveillance data are examined by race/ethnicity, black and Latino MSM are those most disproportionately affected by HIV/AIDS [7, 8]. In 2006, 35% of MSM with new HIV infection were black and 19% were Latino, and among MSM ages 13–29, the number of new infections in black MSM was nearly twice the number of infections in white MSM [5]. In addition, 72% of new HIV infections in Latinos were among MSM [5]. In blacks, differences in risk behavior do not account for this disparity: a meta-analysis of 53 peer-reviewed studies showed no significant differences between black MSM and white MSM in many of the risk behavior variables associated with increased risk of HIV transmission, including unprotected anal intercourse, substance use, history of HIV testing, or sex with a known HIV-positive partner [9]. Similarly, a study of young MSM in 7 United States (US) cities found that Latinos reported similar risk behaviors to whites but had twice the odds of becoming HIV infected [10].

These findings have called attention to the potential importance of factors other than individual risk behavior in the continued transmission of HIV infection among racial/ethnic minority MSM. Sexual networks may be one such factor. Indeed, black MSM are more likely to have same-race partners [11], which may facilitate the spread of HIV infection in a population with high rates of HIV infection. Moreover, the prevalence of sexually transmitted diseases other than HIV has been found to be higher among black MSM, also potentially facilitating HIV transmission [9]. Finally, undiagnosed HIV infection may also account for high transmission rates among black and Latino MSM [12]. Although black and Latino MSM may be as likely as white MSM to ever test for HIV, a 5-city study of MSM found that of those with unrecognized HIV infection, 64% were black and 18% were Latino, suggesting more frequent testing may be needed in these urban populations [13].

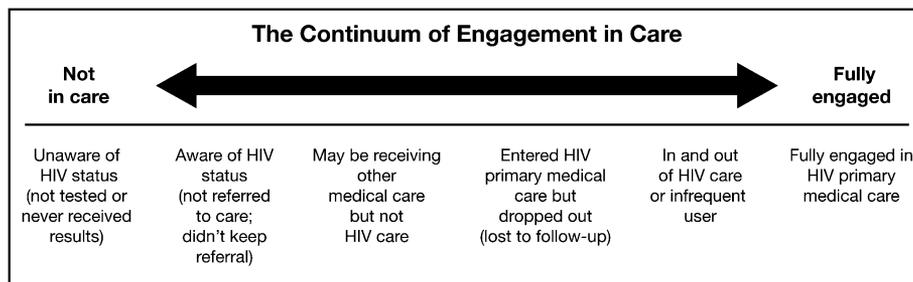
Other factors driving the disparity in HIV infection for racial/ethnic minority MSM may be provider discrimination and patient mistrust of the medical system and antiretroviral therapy (ART), resulting in higher HIV viral loads and greater transmission risk [14]. Health care providers may withhold ART from patients on the basis of race, and patients may mistrust treatment from a medical system they perceive as racist and homophobic. Though the evidence for racial/ethnic disparities in ART prescription practices is mixed, at least 1 multistate study has found that blacks are less likely to receive ART, even after controlling for regular health care utilization [15]. In a large multicity cohort of gay and bisexual men, blacks and Latinos were less likely to report antiretroviral adherence than whites [16]. Conspiracy beliefs on the part of some black MSM may constitute a barrier to adherence. In a study of 214 black men in Los Angeles, California, nearly 80% of whom identified as gay or bisexual, only 22% were found to have >95% adherence, as ascertained by

electronic bottle cap monitoring. Belief in treatment-related HIV conspiracies (eg, “People who take new medications for HIV are human guinea pigs for the government”) was associated with nonadherence, even after controlling for other barriers to care, such as lack of insurance or transportation to the clinic [17]. It is important to note, however, that this study did not have a comparison group of non-black MSM.

How then, do these disparities in HIV outcomes frame an assessment of the engagement in care literature? While data exist for black and Latino MSM on factors related to HIV acquisition and ART receipt and adherence, there is a gap with regard to data on the key intermediate steps of linkage and retention in care. In addition to the prescription of ART, engagement in care allows for the treatment of other medical and psychiatric comorbidities, supports access to social services, and provides a forum for the delivery of prevention messages. Engagement in care has been studied as an outcome in and of itself, as well as a predictor or effect modifier of downstream clinical outcomes, in that failure to link and be retained in care has been associated with delayed ART initiation, virologic failure, and death [18–20]. However, most research has either examined HIV risk group as a predictor of engagement in care by using a dichotomous variable of injection drug user (IDU) versus non-IDU [21, 22] or analyzed the effects of race/ethnicity and MSM risk group separately and with very different results.

Overall, MSM tend to do better than other risk groups with regard to engagement in care. In a recent study of care initiation after HIV diagnosis in Philadelphia, Pennsylvania, MSM entered care earlier than IDUs and heterosexuals [23]. In a national cohort of American veterans, being MSM was associated with improved adherence to a visit in each of the 4 quarters of a year [18]. Indeed, in many studies examining predictors of delayed entry into care or missed care visits, MSM become the referent group for the variable of “HIV exposure category,” with their odds of nonengagement in care used as the optimal case in multivariate regression analyses of predictors of nonengagement in care [19, 20, 24]. In contrast, when data are examined by race/ethnicity, being black is associated with worse retention in care [18–20]. Moreover, in a large HIV clinic in the southern United States, virologic failure among black patients was mediated by missed visits, meaning that black patients who attended the clinic regularly did not have rates of virologic failure different from those of whites [25]. Latinos have been found to delay care after HIV diagnosis when compared with whites [24] as well as to access care more quickly [23]. In an analysis of HIV-infected Latinos from the nationally representative HIV Cost and Services Utilization Study, Latino MSM reported better access to and retention in care than Latino heterosexuals or IDUs, but there was no comparison to white or black MSM [26].

These data suggest that studies to date on linkage to and retention in care have not sufficiently characterized engagement



**Figure 1.** The continuum of engagement in human immunodeficiency virus (HIV) care, as represented by the Health Resources and Services Administration (HRSA). Reprinted from Cheever [27] with permission from the University of Chicago Press.

in care outcomes for black and Latino MSM; this situation also applies to other MSM of color. If, for example, blacks in general do worse with regard to engagement in care than MSM in general, it may be worth reanalyzing existing data for an interaction between race/ethnicity and MSM in order to determine whether engagement in care outcomes are different for MSM of different races/ethnicities. Future research should focus on describing engagement in care outcomes for racial/ethnic minority MSM and assessing whether missed visits play a role in their rates of ART initiation, virologic suppression, and death. If there are differences, it will then be necessary to identify the underlying social, cultural, and economic contextual factors that may explain them. It is also worth noting that the studies cited above have obtained data on sensitive topics such as drug use and sexual behavior through a range of methods (medical or public health database query, in-person interview, audio and computer-assisted interview, etc). Studies undertaking primary data collection in the future should continue to employ techniques such as rapport-building and computer-assisted interviewing to help overcome the possible reticence of their subjects in disclosing sensitive information.

## **DEFINING OPTIMAL MEASURES AND IDENTIFYING KEY BARRIERS TO MSM ENGAGEMENT IN HIV CARE**

### **Definitions of Linkage to and Retention in Care**

In order to better evaluate engagement in care outcomes for MSM, a conceptual understanding of engagement in care is necessary, and thus it is worth reviewing the general HIV literature on this topic. Linkage to care and retention in care are distinct processes on the engagement in care continuum. The Health Resources and Services Administration (HRSA) represents this continuum in the schematic in Figure 1 [27].

A successful connection to the HIV clinic must occur before patients can be retained in care over time [28]. However, it is crucial to note that retention in care is not an “all or nothing” phenomenon and that patients may demonstrate a cyclical pattern of being in and out of care [29]. Indeed, at least 3

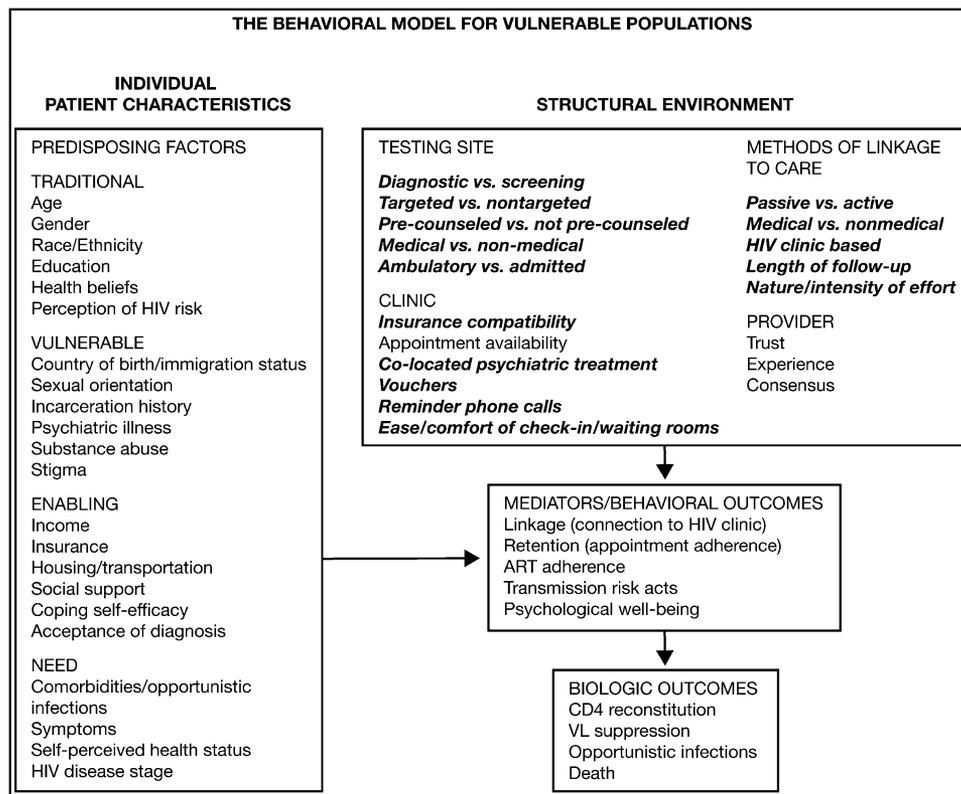
different approaches to quantifying retention in care have emerged in the peer-reviewed literature: using measures that incorporate missed visits, setting a standard for an expected number of HIV care visits in a given time period, and categorizing patients according to their patterns of health care usage (regular, sporadic, or nonengaged) [30]. Variation exists with regard to the type of visit (eg, primary care, nurse only, or subspecialty) that has been used in research employing these approaches, and indeed, standards for retention in care may be different for a patient with a new HIV diagnosis than for the patient who is doing well and is stably engaged in care.

Definitions of linkage to care are also variable. Though many studies of patients initiating HIV care use “1 visit with a provider” as a marker of linkage [31], these visits range from receipt of confirmatory results after a rapid test to a comprehensive HIV clinic intake (medical and social work assessment) to a visit with the patient’s assigned primary care provider [32–34]. Public health departments using HIV/AIDS case registry data often use evidence of CD4 cell count and viral load measurements as markers of linkage [35], though these laboratory measurements do not necessarily mean that a medical provider evaluated the patient, that the patient received the results, or that these data guided ART decisions.

### **Individual and Structural Barriers to Care**

The Behavioral Model for Vulnerable Populations has been used successfully to understand use of primary care by persons living with HIV [36]. The model was adapted by Ulett et al for linkage and retention research by including features of the HIV clinic and the patient–provider relationship as key structural factors [19]. We have expanded upon this adaptation by incorporating characteristics of the HIV testing site and the linkage to care process as important components that also influence health behaviors and outcomes. These additions are outlined in the bold italic text of Figure 2.

Individual factors affecting engagement in care include “predisposing” factors that have a “traditional” domain (eg, demographics, health beliefs, and social structure) and



**Figure 2.** The behavioral model for vulnerable populations. The model has been adapted by the authors, with additional components that influence health behaviors and outcomes shown in bold italics. Adapted with permission from Gelberg et al [36] and Ulett et al [19].

a “vulnerable” domain (eg, mental illness and substance abuse). Individual-level factors affecting engagement in care for MSM not specifically mentioned in Figure 2 include the individual’s ongoing development of sexual identity and “coming out,” since difficulty with self-acceptance or disclosure may affect willingness to engage in care [37]. Homophobia, racism, stigma, and discrimination, including when codified by law, social mores, or religious institutions, may preclude or limit engagement in care. The role of substance abuse with or without injection as a potential barrier to engagement in care for MSM should be further explored. Multiple analyses have demonstrated prevalent non-injection substance use, including the use of methamphetamine, cocaine, poppers, and club drugs, and associated sexual risk behavior among MSM; however, little research has been conducted on how MSM substance use influences care [38–43]. “Enabling” factors either enable or impede access to care and include personal/family resources and community resources. “Need” factors influence an individual’s perception of the need for care (eg, self-perceived health status and comorbid illnesses).

The above factors do not stand in isolation from one another. A phenomenon important to understanding increased rates of HIV infection in MSM that may also prove useful in addressing MSM-specific barriers to engagement in care is that of “syndemics,” or the additive interplay of psychosocial conditions in

amplifying HIV infection risk [44]. In a cross-sectional study of MSM in 4 large American cities, childhood sexual abuse, poly-substance use, partner violence, and depression were independently associated with one another; as the number of these health problems increased, the odds of high-risk sexual behavior and being HIV infected also increased [45]. These data suggest that comprehensive primary care for HIV-infected MSM should involve an understanding of the interrelatedness of psychosocial conditions in the health of MSM and the potentially synergistic role of these conditions in health care utilization and ART adherence. Future studies should focus on the relatedness of social and cultural factors that potentially influence engagement in care among MSM. Such work should include qualitative studies, which may better address contextual issues for specific sub-populations of MSM with a view toward defining culturally appropriate targets for intervention.

## EXISTING STRATEGIES TO IMPROVE ENGAGEMENT IN CARE FOR MSM

Given the burden of the HIV infection epidemic among MSM, the lack of research on strategies that successfully engage MSM in care is striking. Acknowledging the urgent public health need to identify effective services for MSM, and in particular for young

HIV-positive MSM of color, the HRSA HIV/AIDS Bureau funded 8 sites across the United States in 2003 for a 5-year Special Project of National Significance (SPNS) [46]. Engagement in care strategies at these sites in the Bronx, New York; Chapel Hill, North Carolina; Chicago, Illinois; Houston, Texas; Los Angeles, California; Detroit, Michigan; Oakland, California; and Rochester, New York included intensive case management, motivational interviewing, youth-centered support with groups and educational offerings, and youth-directed outreach.

Of 224 MSM clients enrolled in the study, a large proportion were black (72.7%), were  $\leq 22$  years of age (85.5%), and had experienced physical or emotional abuse (70.9%). Nearly half (47.4%) reported problems with drugs or alcohol in the past 3 months, and 50.2% had active depressive symptoms. Clients were followed up every 3 months between June 2006 and September 2008. Only 11.5% of scheduled follow-up visits were missed. Participants who reported receiving any program service and feeling respected at their site of HIV care were significantly less likely to miss a visit. However, this study did not report clinical outcomes, such as uptake of and adherence to ART, CD4 reconstitution, or virologic suppression.

Case management in particular has been identified as a promising strategy to promote engagement in care [47–49]. However, its specific effects on MSM were not assessed in the only randomized trial of a linkage-to-care intervention to date, the Centers for Disease Control and Prevention–funded Antiretroviral Treatment Access Study (ARTAS), which consisted of strengths-based case management (promotion of self-efficacy) versus passive referral to care [50]. This study found that at 6 months, 78% of those who received the 5-session intervention had kept a visit with an HIV provider versus 60% of those who did not receive the intervention ( $P < .01$ ), whereas at 12 months, 64% of intervention recipients had kept 2 visits versus 49% of controls ( $P < .01$ ) [50].

In a recent secondary analysis of the ARTAS data, which used sexual behavior reported by 273 participants to define MSM and non-MSM strata (67 vs 206 subjects, respectively), MSM did slightly better than non-MSM with regard to the overall proportion of subjects engaged in care at 6 and 12 months, although this difference did not reach statistical significance (63% vs 54%;  $P = .23$ ). When the comparison of the intervention to standard of care was stratified by MSM and non-MSM, the effect of the intervention was significant only for non-MSM. In the MSM stratum, both the intervention and standard-of-care arms did comparably (65% vs 61%;  $P = .73$ ), whereas in the non-MSM stratum, the intervention arm did significantly better than the standard-of-care arm (64% vs 45%;  $P = .008$ ). This significant result for the non-MSM population held true in a multivariate analysis with the other effect modifiers used in the original model, including housing, depression, and Hispanic ethnicity (L. Gardner, May 4, 2010 private communication). Given the

small sample size in this subanalysis, these results should be interpreted with caution. Additional study of case management in MSM populations is needed.

## **NEW INITIATIVES TO IDENTIFY HIV-INFECTED MSM, ENGAGE THEM IN CARE, AND MONITOR THEIR TREATMENT**

A number of new initiatives are underway in an effort to prevent and treat HIV infection. While not all are specific to MSM, in order to be effective in many communities, they will need to include MSM. We review both general and MSM-specific approaches.

### **New HIV Testing Venues with Integrated Linkage to Care Mechanisms**

A renewed emphasis on finding individuals with undiagnosed HIV infection in the United States occurred in 2006 when the Centers for Disease Control and Prevention issued guidelines supporting routine HIV screening in all medical settings, including primary care clinics, urgent care clinics, and the emergency department [51]. While these testing initiatives provide new opportunities to find individuals unaware of their HIV infection or to re-engage out-of-care persons with known HIV infection back into care, they also highlight the need for well-defined mechanisms for linkage to care, especially for patients who may have accessed care for a reason other than HIV testing. Bridging the gap between the testing site and the treatment clinic may offer a successful way to guide these patients into HIV care.

As an example, the Positive Health Access to Services and Treatment (PHAST) intervention at the San Francisco General Hospital (SFGH) represents a model linkage-to-care strategy for patients newly diagnosed with HIV in a medical setting as well as for out of care HIV-infected patients who are hospitalized. Based in the SFGH HIV clinic, which serves a vulnerable urban population, including the poor, the homeless, and the uninsured, the PHAST team draws on the distinct but complementary skills of a nurse practitioner, registered nurse, and social work associate. All care settings of SFGH use central laboratory blood-based rapid testing and the lab pages all positive test results to PHAST. A PHAST team member then meets patients at the time of disclosure to provide intensive support and education. PHAST also handles confirmatory test results; performs the clinic intake, including CD4 cell count, viral load, and resistance testing; assists with insurance applications; and provides appointment reminders and primary care until transfer of care to an assigned primary care provider is possible (Table 1). Of 48 patients newly diagnosed with HIV infection over the first 25 months of the SFGH emergency department HIV testing program who were referred for outpatient care, 47 patients (98%)

**Table 1. Features of a Successful Linkage to Care Intervention**

Presence at time of disclosure of positive test result to bridge the gap between the testing site and the clinic
HIV-clinic based (“bringing patients in” vs. referring out)
Multidisciplinary (combination of medical and social work skill sets to provide bridging medical care as well as assistance with insurance applications, housing, etc.)
Appointment reminders
Thoughtful matching of patient with a primary care provider
Availability of and expedited access to on-site psychiatric and substance abuse treatment

kept an HIV care visit. Twenty patients were MSM, and the PHAST team successfully guided 19 of these MSM (95%) to a first appointment with their assigned primary care provider within 6 months of diagnosis [52].

### New HIV Testing Technologies

Another evolving area of HIV testing with important care and prevention implications for MSM and other populations with high HIV infection incidence is screening for acute HIV infection (AHI). For these populations, antibody testing alone may be inadequate, since individuals may be falsely reassured by a negative antibody result when they are really in the window period of infection [53, 54]. Individuals with acute HIV infection are highly infectious, and AHI may result in rates of transmission that are 10–20 times higher than in chronic infection [55–57]. Phylogenetic analyses suggest that one-third to one-half of new infections among MSM in high-income nations may be attributable to AHI [58–60]. In high-risk populations, pooled nucleic acid amplification testing (NAAT) increases the yield of HIV case detection by 5%–10% over antibody testing alone, including in testing programs that target MSM [61, 62].

Linkage to care for individuals with AHI has important clinical and public health significance. From a care standpoint, providing someone with AHI the information necessary to make an informed decision about whether to start ART is of major importance [63, 64]. From a prevention standpoint, breaking the chain of acute HIV transmission is critical and involves partner notification and risk-reduction counseling. In multicenter studies of behavior change after diagnosis of acute/early HIV infection in a predominantly MSM sample, there were large reductions in high-risk sexual behaviors after such notification [65, 66]. New modalities for AHI screening now include fourth-generation antibody tests, which have the capacity to detect protein 24 (p24) antigen and appear to provide a reasonable diagnostic alternative to NAAT [53, 67]. While NAAT remains the territory of public health laboratories, fourth-generation antibody tests have the potential to be deployed more widely; as they enter clinical practice, linkage systems may have to be adapted to account for increased numbers of newly diagnosed individuals and to connect patients to clinicians with expertise in AHI [68].

### Integrated HIV Prevention, Care, and Treatment Approaches

In addition to seeking undiagnosed HIV infection in new venues and with new diagnostic tests, there has been increased attention focused on the HIV prevention strategy of “test and treat,” [69] or the related concept of “test, link to care, plus treat (TLC+). Mathematical models have shown that such a strategy could have a profound effect on HIV transmission in communities with high HIV infection prevalence and incidence, assuming high uptake of and adherence to ART [70]. For such strategies to be effective, engagement in care is an outcome of paramount importance. Guided by the TLC+ concept, the National Institutes of Health is sponsoring a 3-year feasibility study to determine the impact of increased availability of HIV testing and to evaluate the effectiveness of a financial incentive to remain in care in six US cities, with the Bronx, New York, and Washington, DC, as intervention sites and Chicago, Illinois; Houston, Texas; Miami, Florida; and Philadelphia, Pennsylvania as comparison sites. In addition, the National Institutes of Health–funded HIV Prevention Trials Network (HPTN) is currently conducting the BROTHERS study to evaluate a multilevel, community-based intervention to reduce HIV incidence among black MSM [71]. A primary aim of this study is to assess the feasibility and acceptability of using peer navigators to assist with primary and secondary prevention of HIV infection. Key outcomes will include the proportion of participants initiating ART, change in HIV RNA level, change in HIV risk behaviors, and satisfaction with the intervention.

There is also increasing interest in HIV care for MSM that integrates resources for substance use treatment and risk reduction. This combination approach may facilitate care delivery and increase ART adherence, based on limited research suggesting that MSM substance users, particularly methamphetamine users, have lower adherence to ART [72, 73]. Although gay-specific interventions for methamphetamine-using MSM have been developed and found to be associated with decreased substance use and HIV risk behavior [74], the effectiveness of such programs for engagement in HIV care needs to be studied.

### A New Measure for Monitoring Engagement in HIV Care and Treatment at the Community Level

At the individual level, reductions in HIV viral load can function as one marker of engagement in care. More recently,

our group and others have examined the measure of community viral load (CVL), in which viral loads reported for public health surveillance are analyzed by geographic area (eg, county, neighborhood, or clinic) or subpopulation (eg, demographic group or transmission risk group) and compared with other epidemiologic and socioeconomic data; this measure offers a potential tool to assess HIV infection care and treatment efforts [75, 76]. Total CVL (the summation of the mean of the most recent viral load measurements of all HIV-infected individuals in a particular community) reflects the total burden of diagnosed HIV disease, while mean CVL (the average of the mean of the most recent viral load measurements of all HIV-infected individuals in a community) can be used to assess differences between subpopulations [76]. For example, in an analysis in San Francisco, California, although the mean CVL of MSM was lower than the overall San Francisco mean and lowest among all transmission risk groups, MSM of color had significantly higher mean CVLs than white MSM (CVL for black, Latino, and white MSM, 20,779 copies/mL, 25,603 copies/mL, and 16,886 copies/mL, respectively;  $P < .001$ ; M. Das, May 12, 2010). As efforts to identify and rectify disparities in HIV care and prevention among MSM move forward, CVL may serve as a way to monitor the effectiveness of treatment at the community level.

## CONCLUSIONS AND NEXT STEPS

Nearly 30 years into the HIV epidemic, the MSM population remains a key population for HIV prevention and treatment efforts in the United States. The lack of research on the best strategies to link and retain MSM in care is concerning, especially among MSM of color, among whom HIV-related disparities are the greatest. In this population, there is also a dearth of research on engagement in care outcomes and whether missed visits predict or modify downstream clinical outcomes such as virologic suppression and survival. As new HIV testing venues, technologies, and public health policies seek to identify individuals with HIV infection earlier in the course of disease, engagement in care efforts must be supported and studied. Many questions remain, including how best to engage MSM of color, substance-using MSM, and those MSM lost to care. Qualitative work can identify the specific barriers for these subpopulations and help shape intervention development and subsequent quantitative evaluations. In addition, research should focus on identifying the best metrics for the engagement in care field. Strategies that may be promising with regard to engagement in care for MSM and deserve further assessment include intensive case management, health systems navigation, and focusing on the synergistic nature of health issues for MSM in the form of culturally competent care.

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