

## Perspective

# Improving Engagement in HIV Care: What Can We Do?

*Engagement in HIV care needs to be improved. Important factors to be considered in attempts to improve engagement in care include the following: (1) initial linkage and subsequent retention are distinct processes; (2) engagement in care is vital for HIV treatment success at both the individual and population levels; (3) missed clinic visits can identify patients at high risk for poor health outcomes; (4) engagement in care is worse in groups bearing a disproportionate burden of the domestic HIV epidemic; and (5) ancillary services play a crucial role in improving linkage to and retention in care. This article summarizes a presentation on engagement in HIV care made by Michael J. Mugavero, MD, MHSc, at the 11th Annual Clinical Update for the Ryan White HIV/AIDS Program Clinicians held in August 2008 in Washington, DC. The original presentation is available as a Webcast at [www.iasusa.org](http://www.iasusa.org).*

The “blueprint” for HIV treatment success includes making the diagnosis of HIV infection, linking infected individuals to outpatient care, and retaining patients in care. There is considerable need for improvement in each of these areas (Figure 1). Substantial benefits come by increasing engagement in HIV care. A useful way of conceptualizing engagement as put forth by the US Health Resources and Services Administration (HRSA) is as a continuum from HIV-seropositive people unaware they are infected to patients who are fully engaged in HIV care, with gradations in between of categories including patients who are aware of their HIV status and not receiving any medical care, are receiving medical care but not HIV care, have entered HIV care but dropped out, or are in and out of HIV care or infrequent users of care (Cheever, *Clin Infect Dis*, 2007). For patients anywhere along the continuum, there is an opportunity to move them forward with appropriate interventions.

The design and implementation of effective interventions, however, require taking many factors into account. Using a behavioral model of health services utilization, these factors can be organized into environmental and

patient characteristics to better understand their interplay and their relationship with health behaviors such as engagement in care and adherence to antiretroviral medications that influence health outcomes. This conceptual framework allows for identification of modifiable factors that may serve as targets to affect these behaviors and ultimately improve outcomes (Figure 2).

Improved engagement in HIV care carries the promise of substantially improved outcomes at both the individual and population levels. At the individual

level, better engagement is associated with better antiretroviral therapy receipt and adherence, immunologic and virologic outcomes, and survival (Keruly et al, *Am J Public Health*, 2002; Robbins et al, *JAIDS*, 2007; Giordano et al, *Clin Infect Dis*, 2007; Park et al, *J Intern Med*, 2007). At the population level, improved engagement may help address observed racial and socioeconomic disparities in HIV outcomes (Mugavero et al, *JAIDS*, 2008). Further, it can have a substantial role in reducing transmission of disease because improved engagement has been associated with reduced risk behaviors and improved receipt of and adherence to antiretroviral therapy (Marks et al, *AIDS*, 2006; Metsch et al, *Clin Infect Dis*, 2006; Giordano et al, *Clin Infect Dis*, 2007; Quinn et al, *N Engl J Med*, 2000; Cohen et al, *Ann Intern Med*, 2007).

Although they share many barriers and facilitating factors, linkage to care and retention in care are distinct processes. Characteristics of these processes and elements of strategies to improve engagement are discussed herein.

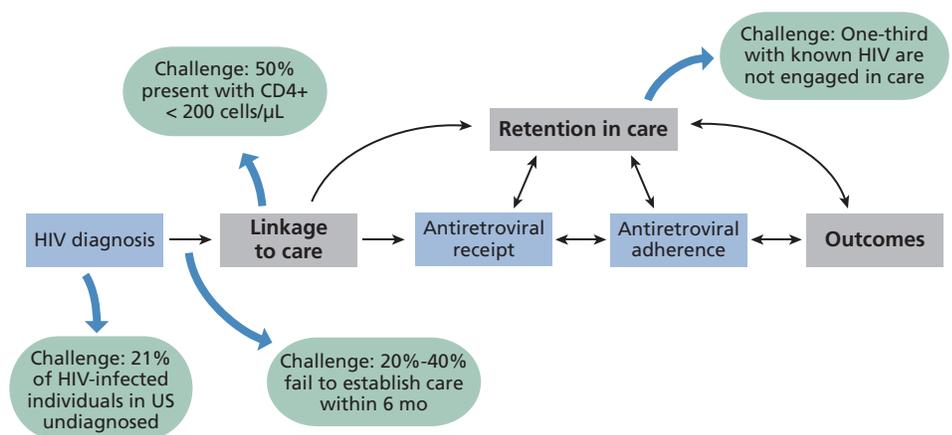


Figure 1. Blueprint for HIV treatment success, indicating the population-level challenges currently faced in the United States (Glynn and Rhodes, NHIVPC, 2005; Gardner et al, *AIDS*, 2005; Mugavero et al, *Clin Infect Dis*, 2007; Gay et al, *AIDS*, 2006; Mugavero et al, *Am J Med*, 2007; Fleming et al, CROI, 2002). Adapted with permission from Ulett et al, *AIDS Patient Care STDs*, 2008.

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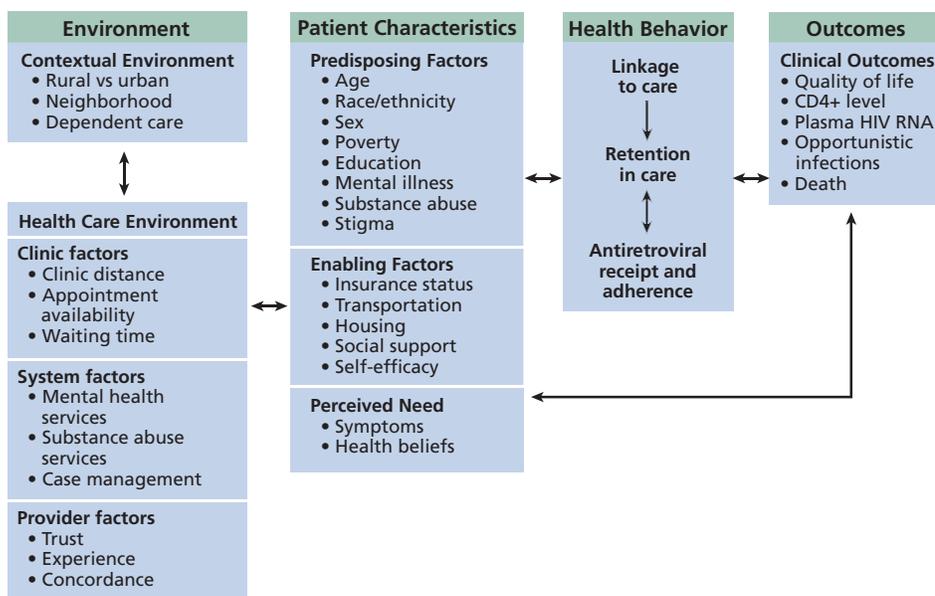


Figure 2. Interplay of environmental factors and patient characteristics with HIV care behaviors and outcomes. Adapted with permission from Ulett et al, *AIDS Patient Care STDs*, 2008, and Andersen RM, *J Health Soc Behav*, 1995.

## Linkage to Care

In September 2006, the US Centers for Disease Control and Prevention (CDC) issued revised HIV testing recommendations advocating routine opt-out testing for adults in all health care settings. An estimated 25% to 50% increase in patients needing outpatient HIV care is anticipated from implementation of these recommendations. The CDC guidelines further highlight the importance of linkage to medical services at the time of diagnosis because newly diagnosed patients frequently delay or fail to establish outpatient HIV care (CDC, *MMWR Recomm Rep*, 2006; Mugavero and Saag, *MedGenMed*, 2007; Samet et al, *AIDS*, 2001; del Rio et al, *CROI*, 2001).

In the only randomized controlled trial reported to date of an intervention to improve linkage to care, the CDC examined the potential role of a strength-based case-management strategy in the Antiretroviral Treatment Access Study (ARTAS). The intervention was based on promotion of empowerment and self-efficacy. Case managers asked clients to identify internal strengths and assets to foster linkage to care, and up to 5 case manager contacts were allowed

within the first 90 days of enrollment (Gardner et al, *AIDS*, 2005). A primary HIV care provider visit was attended within 6 months by 78% of patients in the case-management group versus 60% of patients in the standard-of-care group ( $P < .01$ ), and a second visit occurred within the first 12 months for 64% versus 49%, respectively ( $P < .01$ ) (Gardner et al, *AIDS*, 2005).

On the assumption that a case manager carries a load of 120 clients per year, the cost of the program was estimated at \$599 per client, with a cost of \$3993 per additional client linked to care above and beyond the standard-of-care group. These findings indicate that the intervention is efficacious in terms of both cost and linkage of care. However, the fact that only two-thirds of patients in the case-management group and less than half in the standard-of-care group remained in care after the first year indicates substantial room for improvement.

In a study at the University of Alabama at Birmingham (UAB) 1917 Clinic among patients calling to establish HIV care during 2004 to 2006, 31% (160/522) failed to attend a clinic visit within 6 months of the initial call (Mugavero et al, *Clin Infect Dis*, 2007).

Minority men and women and white women were statistically significantly more likely to be “no shows” compared with white men, as were patients with public health insurance and those without insurance compared with patients with private insurance (Table 1). A longer delay from the time of the initial call to the scheduled appointment was also associated with greater likelihood of not showing for a clinic visit.

To reduce the no-show rate, a program, Client-Oriented New Patient Navigation to Encourage Connection to Treatment (Project CONNECT), was developed and launched on January 1, 2007. In the program, new patients have a scheduled orientation visit within 5 days of their initial call to the clinic. When a prospective client calls, he or she speaks to a team member, who says, in essence, “I’d like you to come over in the next few days—when are you available? I’d like to meet you personally, talk with you, show you around the clinic.” At this visit, the patient has a semistructured interview, completes a psychosocial questionnaire, and undergoes baseline laboratory testing. Uninsured patients also meet with a clinic social worker at this initial orientation visit.

The orientation visit has proved to be very advantageous in facilitating rapid institution of prophylactic medications when necessary. For example, patients coming in with CD4+ counts less than 200 cells/ $\mu$ L are often started on *Pneumocystis jiroveci* pneumonia (PCP; formerly *Pneumocystis carinii* pneumonia) prophylaxis even before their primary provider visit. It has also allowed for prompt referral for substance abuse and mental health services when necessary through problems identified on the psychosocial questionnaire. Although the Project CONNECT questionnaire contains 7 domains, it is administered fairly rapidly because the validated screening instrument for each domain contains few questions. The domains and instruments are medication adherence (ACTU-4), depression (Patient Health Questionnaire, PHQ), anxiety (PHQ), alcohol use (Alcohol Use Disorders Identification Test—Consumption, AUDIT-C),

**Table 1.** Risk of Being a “No Show” at First Scheduled Visit After Initial Call to University of Alabama at Birmingham 1917 Clinic

Characteristic	“Show” Group (n = 362)	“No Show” Group (n = 160)	Odds Ratio (95% confidence interval)
<b>Age in years, mean (SD)</b>	39.3 (9.6)	37.1 (9.5)	0.84 (0.68-1.04) <sup>a</sup>
<b>Race, sex, no. (%)</b>			
White men	125 (34.5)	32 (20.0)	1.0 (Reference)
Minority men	154 (42.5)	76 (47.5)	1.75 (1.05-2.91)
White women	31 (8.6)	20 (12.5)	2.72 (1.30-5.68)
Minority women	52 (14.4)	32 (20.0)	2.39 (1.27-4.52)
<b>Insurance, no. (%)</b>			
Private	127 (35.1)	26 (16.2)	1.0 (Reference)
Public	77 (21.3)	34 (21.3)	1.91 (1.03-3.54)
Uninsured	158 (43.6)	100 (62.5)	2.62 (1.56-4.39)
<b>Days from call to appointment, mean (SD)</b>	25.6 (13.8)	30.2 (13.4)	1.32 (1.14-1.53) <sup>a</sup>

SD indicates standard deviation.

<sup>a</sup>Odds ratio per every 10 years of age, or odds ratio per every 10 days between call and appointment.

Adapted from Mugavero et al, *Clin Infect Dis*, 2007.

substance abuse (Alcohol, Smoking and Substance Involvement Screening Test, ASSIST), health-related quality of life (EuroQOL-5D), and symptoms (HIV Symptom Index). The questionnaire is subsequently repeated every 6 months to identify new needs or barriers that need to be addressed to keep the patient engaged in care.

The preliminary results in improving linkage to HIV care at the UAB 1917 Clinic have been encouraging. For patients scheduling an orientation visit during the 2007 calendar year (with follow-up through June 30, 2008, to allow patients 6 months to attend a primary HIV provider visit), 81% (296/364) attended a primary HIV provider visit. The no-show rate of 19% is statistically significantly lower than the 31% rate identified in 2004 to 2006 ( $P < .01$ ). Cost for the program was estimated at \$200 per client and \$1628 per additional client linked to care through Project CONNECT, indicating a reasonable cost of the intervention. Reimbursement has been set up par-

tially through Ryan White HIV/AIDS Program Part B by working with the local Ryan White HIV/AIDS Program grantee in Alabama. Although these results are encouraging and provide a foundation for continued efforts, more work remains to be done to improve linkage to HIV care.

### Retention in Care

Missed visits are common after establishment of outpatient care and are associated with delayed receipt of antiretroviral therapy, emergence of antiretroviral resistance, and virologic failure (Ulett et al, *AIDS Patient Care STDs*, 2008; Giordano et al, *JAIDS*, 2003; Lucas et al, *Ann Intern Med*, 1999; Sethi et al, *Clin Infect Dis*, 2003; Robbins et al, *JAIDS*, 2007). However, few studies have examined the relationship between missed visits and mortality after initial linkage to outpatient care. Thus, this relationship was examined in a retrospective study of 543 newly diagnosed patients with no prior out-

patient care who initiated treatment at the UAB 1917 Clinic between 2000 and 2005 (Mugavero et al, *Clin Infect Dis*, 2008). Approximately 60% of patients missed visits during the first year after initial linkage to outpatient care. Younger patients, African American patients, and patients with public health insurance were more likely than other groups to have a missed visit. Missed visits were associated with increased risk of mortality. Mortality rates were 2.3 versus 1.0 per 100 patient-years of follow-up in the missed-visit versus non-missed-visit groups, respectively ( $P = .02$ ).

Although further work is needed to better understand this relationship, these findings should serve to heighten clinician awareness of missed visits among new patients. A missed visit early in care may identify patients at risk of poor long-term outcome and may serve as a marker for providers to identify patients at heightened risk who may require specific attention to retention in care, adherence to medications, and assessment of other factors in their lives that may contribute to the higher observed mortality in this study.

To improve the understanding and assessment of the effects of variation in retention in care, a methodology that allows engagement to be evaluated using multiple measures has been devised. Appointment adherence is measured as the overall proportion of scheduled visits that are attended over a given time period. This measure allows gradations of adherence among patients to be identified, rather than treating it as a dichotomous variable (eg, assigning adherence versus nonadherence on the basis of a missed visit).

Persistence is measured as the proportion of 3- or 6-month intervals during which at least 1 visit was attended over a period of time. A gap in care occurs when a patient goes without a visit for a predefined interval such as 6 months or 12 months.

Appointment adherence was assessed over a 2.5-year period in 1221 patients attending the UAB 1917 Clinic. Figure 3 shows the distribution of appointment adherence rates and the percentage of patients achieving plas-

ma HIV RNA levels of less than 50 copies/mL according to adherence rate. The relationship between appointment adherence and virologic response is similar to the dose-response relationship observed with adherence to antiretroviral therapy. Achievement of plasma HIV RNA levels below 50 copies/mL occurs in approximately one-third of patients with appointment adherence of less than 60% and in approximately three-fourths of those with 100% appointment adherence. Analysis of risk factors for virologic failure, defined as plasma HIV RNA level greater than 50 copies/mL, showed that appointment nonadherence was a statistically significant predictor with roughly twice the odds of virologic failure per additional 25% nonadherence, along with younger age and public health insurance (Table 2) (Mugavero et al, *JAIDS*, 2008).

In a study of US veterans with HIV starting antiretroviral therapy, Giordano and colleagues assessed treatment outcomes by clinic visit persistence,

defined as the number of quarters (3-month periods) with attendance at a scheduled visit during the first year of antiretroviral therapy (Giordano et al, *Clin Infect Dis*, 2007; Cheever, *Clin Infect Dis*, 2007). Visit persistence was associated with 1-year CD4+ cell count and plasma HIV RNA level outcomes, antiretroviral therapy adherence, and long-term survival. Analysis of survival showed increasing risk of mortality with increasing number of quarters with no attended clinic visit. Compared with the 1685 patients (64%) with an attended visit in each quarter, the hazard ratio (95% confidence interval) for survival was 1.41 (1.10-1.82) among 479 patients (18%) who attended in 3 of 4 quarters, 1.68 (1.24-2.26) among 286 patients (11%) who attended in 2 of 4 quarters, and 1.94 (1.36-2.76) among 169 patients (7%) who attended in 1 of 4 quarters (Giordano et al, *Clin Infect Dis*, 2007).

Studies sponsored by HRSA of the US Department of Health and Human

Services have indicated that retention in HIV care is associated with use of ancillary services including case management, transportation, housing, substance abuse, and mental health services (*AIDS Care*, 2002). HRSA-sponsored Special Projects of National Significance initiatives involving peer navigators and other types of patient outreach have also proven effective in promoting retention in care (Tobias, *AIDS Patient Care STDs*, 2007). Currently, the CDC and HRSA are sponsoring a randomized controlled trial to develop and test an intervention to improve retention in HIV care, although results of this study will not be available for several years as it has only recently been launched.

### What Can We Do?

Important messages to be gleaned from our current experience with linkage to and retention in care are as follows:

- Linkage and retention are distinct processes
- Engagement in care is vital for HIV treatment success at the individual and population levels
- Early missed visits can identify patients at high risk of poor health outcomes
- Engagement in care is worse in groups bearing a disproportionate burden of the HIV epidemic in this country
- Ancillary services have a crucial role in improving linkage to and retention in care

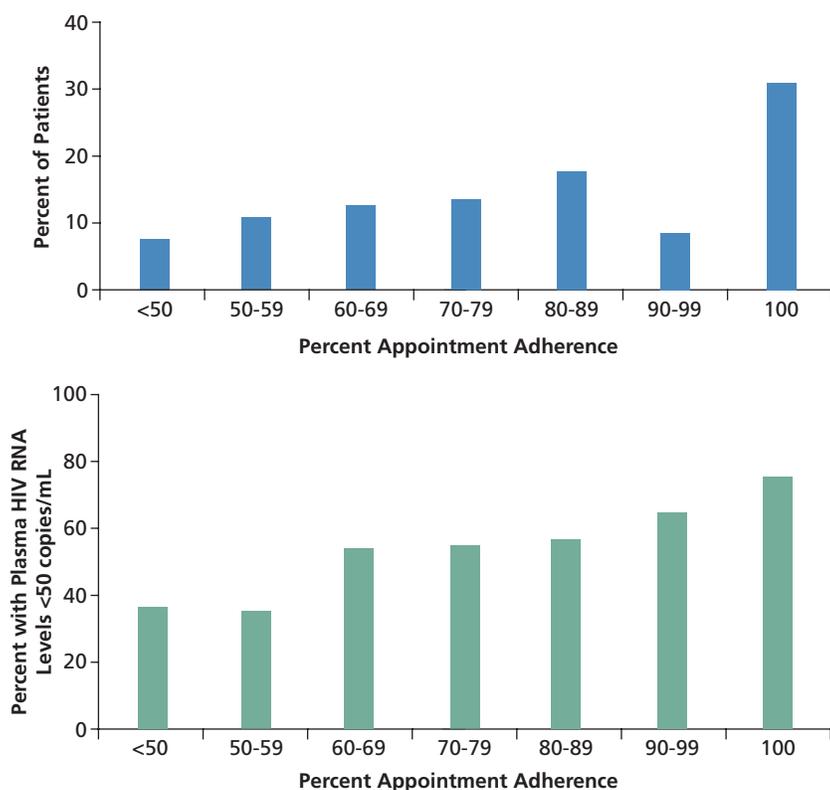


Figure 3. Appointment adherence (top) and virologic response (plasma HIV RNA level < 50 copies/mL) according to adherence rate (bottom) in patients at the University of Alabama at Birmingham 1917 Clinic (adapted from Mugavero et al, *JAIDS*, 2008).

Several initiatives for improving linkage and retention can be implemented relatively promptly. Partnerships can be established among local Ryan White HIV/AIDS Programs, public health departments, community-based organizations, and hospital emergency departments in implementing HIV testing coupled with the ARTAS case-management program to improve linkage to care. Clinics can evaluate their own no-show profiles and consider revising their new patient orientation processes; implement routine psychosocial screening to identify barriers to engagement in care (eg, substance

**Table 2.** Odds Ratio (OR) for Virologic Failure (Plasma HIV RNA Level < 50 Copies/mL) According to Characteristics in Patients at University of Alabama at Birmingham 1917 Clinic

Characteristic (n = 1088)	Odds Ratio (95% confidence interval)
<b>Age, per 10 years</b>	<b>0.78 (0.68-0.91)</b>
Female	0.82 (0.59-1.13)
African American	1.30 (0.98-1.72)
<b>Public health insurance</b>	<b>1.62 (1.20-2.20)</b>
Uninsured	1.21 (0.86-1.72)
Affective mental health disorder	1.18 (0.90-1.54)
Alcohol abuse	1.00 (0.66-1.51)
Substance abuse	1.27 (0.90-1.80)
<b>Appointment nonadherence (per 25% nonadherence)</b>	<b>1.78 (1.48-2.13)</b>

Adapted from Mugavero et al, *JAIDS*, 2008.

abuse); and attempt to strengthen social-worker and case-manager, mental health, and substance-abuse programs as resources allow. Clinics can also develop partnerships to implement and strengthen patient-outreach and peer-navigation programs with existing community organizations currently providing these services. Discussion with patients about their need to adhere to antiretroviral therapy is commonplace in the clinic. Similarly, patients need to be informed that adherence to visits is also associated with improved outcomes—that patients who remain engaged in care do better.

Presented by Dr Mugavero in August 2008. First draft prepared from transcripts by Matthew Stenger. Reviewed and edited by Dr Mugavero in November 2008.

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## Suggested Reading

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