

Perspective

Linkage, Engagement, and Retention in HIV Care Among Vulnerable Populations: "I'm Sick and Tired of Being Sick and Tired"

There are disparities in engagement and retention in HIV care and outcomes of care across segments of society. For example, HIV mortality rates remain markedly elevated among black women and men compared with their white counterparts. These differences reflect broader disparities across social, economic, and cultural lines. Improvement in engagement and retention in HIV care requires interventions that account for forces present in the socioecologic framework of health behaviors. Improvement in linkage to care at HIV testing is crucial to overall engagement and retention in care. Strategies for linkage to care at testing can help overcome many of the forces that result in failure to engage and remain in care by starting the patient on a solid path to clinical care. This article summarizes a presentation by Victoria A. Cargill, MD, MSCE, at the IAS–USA continuing education program held in New York, New York, in May 2013.

Keywords: HIV care disparities, linkage to care, socioecologic framework, engagement and retention in care, practitioner behavior

"I Don't Want To Go to the Hospital"

Patient A is a 34-year-old African American woman who tested positive for HIV infection at 19 years of age. She has given birth to 4 HIV seronegative children, but her first child died at age 6 months due to crib death and another (one of a set of fraternal twins) died at age 9 years from sickle cell crisis. Patient A dropped out of care for 9 years and has since been intermittent in her treatment follow-up. She is non-adherent to medications and appointments. Her mother brought her to the clinic, where she presented with a 70 lb weight loss, thrush, fever, cough, tachypnea, and diarrhea. She stated, "I don't want to go to the hospital."

Syndemics of Disparities

The above scenario is unfortunately all too common. Since 1985, more than 27 antiretroviral drugs have been approved for use in the United States, an

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indicator of the progress that has been made in HIV therapy. Unfortunately, all segments of society have not equally benefitted from this progress. At the same time that the NA-ACCORD (North American AIDS Cohort Collaboration on Research and Design) data have highlighted the increased life expectancy of HIV-infected patients starting antiretroviral therapy,¹ the WIHS (Women's Interagency HIV Study) data reemphasize that black HIV-infected women are twice as likely to die with AIDS as their white counterparts.²

Overall, Latinos and blacks are substantially more likely to present late for care and experience higher morbidity and mortality than other

population groups. Persons dying with HIV infection increasingly are women, blacks/African Americans, residents of the US South, and individuals aged 45 years or older. HIV infection remains one of the leading causes of death among persons aged 25 years to 44 years in the United States, particularly among blacks/African Americans.

As shown in Figure 1 (top), although there have been marked reductions in annual mortality from HIV disease in the United States since 1996 among all racial and ethnic groups, the rate in black/African Americans remains strikingly elevated.³ Figure 1 (bottom) shows the disparity when mortality rates for black men are compared with those for white men by age group.⁴

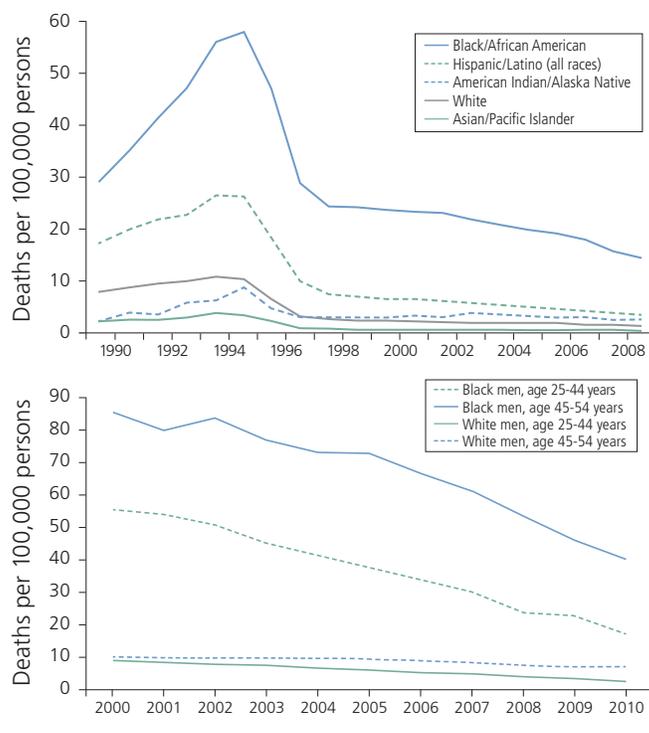


Figure 1. Age-adjusted HIV-related death rates by race and ethnicity (top). Rates are standardized on the age distribution of the US population in 2000. Adapted from National Center for HIV/AIDS.³ HIV-related death rates in black men and white men by age group (bottom). Adapted from National Vital Statistics System.⁴

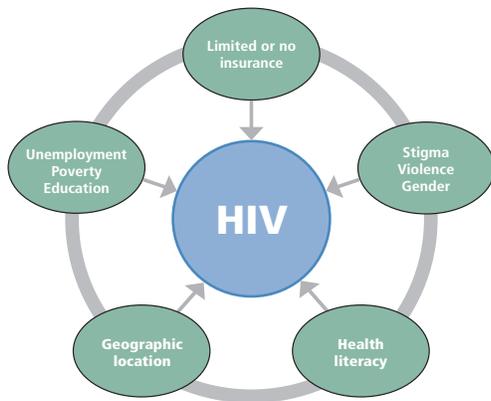


Figure 2. HIV infection: A single factor among many potential socioecologic disparities.

HIV infection presents as a health disparity but is only one disparity among many that affect both the quality and quantity of life among the vulnerable populations in society (Figure 2). These disparities overlap and intersect to present a web of challenges for many racial and ethnic minorities living with HIV infection and those who provide care for them.

Poverty is one such disparity. Poverty rates for blacks and Hispanics exceed the national average. According to National Poverty Center data, 27.4% of blacks and 26.6% of Hispanics are poor, compared with 9.9% of non-Hispanic whites and 12.1% of Asians.⁵ Foreign-born noncitizens in the United States also have high poverty rates.⁵

Health illiteracy and limited or non-existent health insurance coverage negatively impact the management of HIV infection and are particularly relevant to vulnerable and marginalized populations in that health literacy can be correlated with HIV knowledge⁶ and HIV treatment adherence.⁷ However, the impact of low health literacy can be moderated by self-efficacy⁸—namely, people’s belief that they can take control in their lives to improve their circumstances. Among individuals with self-efficacy, the impact of low health literacy is not as profound.

Several large studies on health insurance coverage have demonstrated an association between earlier initiation of antiretroviral therapy⁹ and having commercial or private insurance. Although less striking, a similar

association has been found between antiretroviral therapy initiation and having Medicare coverage. Individuals enrolled in Medicaid consistently initiated antiretroviral therapy at a more advanced stage of disease, corroborating earlier findings.^{9,10} Health insurance coverage is also correlated with employment, and unemployment rates are

much higher for blacks and Latinos. The unemployment rate for blacks was twice that for whites in 2012—a ratio that has not changed since the US Bureau of Labor Statistics began reporting unemployment by race in 1972.⁵

Along with poverty, unemployment, underemployment, and limited health literacy, violence must be included as a factor that can negatively affect HIV care. Violence and suicide rates are disproportionately higher in racial and ethnic minority populations. Native Americans have the second-highest rate of suicide across all age groups. Blacks account for 48.7% of homicide deaths, which is the highest rate for any population group, and more than half of these deaths occur in men aged 15 years to 34 years. Native Americans rank second in homicide deaths, followed closely by Hispanics.¹¹

In addition to these disparities, many other factors may affect an individual’s ability to access and remain in health care, including:¹²

- Stigma
- Homophobia
- Language barriers
- Incarceration
- Shame
- Privacy concerns
- Distrust of practitioners
- Active substance use
- Unstable housing
- Limited education
- Isolation
- Lack of support
- Fear of disclosure
- Mental health status

Moving Beyond the Individual—A Socioecologic Framework

Correcting the disparities in HIV care and the differential outcomes for the marginalized and vulnerable sectors of society will require addressing the larger sociocultural context in which these individuals live. Thus, examining the socioecologic framework in which individuals participate allows for an examination of and accounting for the external factors that influence individuals at interpersonal, organizational, community, and public policy levels—all of which can impact HIV care-seeking behavior, as well as an individual’s general knowledge, attitudes, and skills. The socioecologic approach has been particularly useful in addressing health behaviors that are influenced by factors such as culture, trust, and beliefs, with prenatal care and weight loss interventions being prime examples.

Mugavero and colleagues have provided a detailed picture of the socioecologic framework for HIV care in which they demonstrate the complex multilevel factors that can affect an individual’s engagement in care (Table).¹³ For example, at the individual level, there are numerous factors, such as age, sex, race, and ethnicity, that may predispose patients not to engage or remain in care. But there are also enabling factors that may tend to keep them engaged, including health insurance, transportation, social support, self-efficacy, and resiliency (ie, the ability to navigate barriers inherent to seeking and engaging in care). Relationships with case managers, health care practitioners, and social networks, for example, can facilitate or impede engagement in care.

“Are You Sure I’m HIV-Positive?”

Patient B is a 35-year-old African American man who describes himself as a “player.” He also has a known factor VIIa deficiency. Four weeks before presentation to clinic, he was treated for syphilis and was encouraged to undergo HIV testing. His rapid HIV test was positive, as was confirmatory

Table. Sociologic Factors in HIV Care

Policy	Health Care System	Community	Relationships	Individual
<ul style="list-style-type: none"> ■ HIV testing guidelines ■ HIV treatment guidelines ■ Quality measures ■ Best practices ■ Workforce ■ Reimbursement ■ Funding <ul style="list-style-type: none"> - CDC - Health departments - CMS - SAMHSA - HRSA Ryan White (distribution of funds; ADAP) - Coordination 	<ul style="list-style-type: none"> ■ Surveillance ■ Testing services ■ Prevention services ■ Medical services ■ Supportive services ■ Service integration ■ HIV clinic distance ■ HIV clinic culture ■ Appointment availability ■ Medical home 	<ul style="list-style-type: none"> ■ Neighborhood ■ Poverty ■ Education ■ Social norms ■ Stigma ■ Employment ■ Corrections facilities 	<ul style="list-style-type: none"> ■ Intimate partners ■ Family members ■ Friends ■ Social networks ■ Medical provider ■ Case manager ■ Mental health provider ■ Peer mentor/navigator ■ Relationship factors <ul style="list-style-type: none"> - Trust - Communication - Longevity - Compatibility 	<ul style="list-style-type: none"> ■ Potential predisposing factors <ul style="list-style-type: none"> - Age - Race - Ethnicity - Sex - Mental health - Substance use ■ Perceived needs <ul style="list-style-type: none"> - Health benefits - Symptoms - Comorbidities - Past experiences ■ Potential enabling factors <ul style="list-style-type: none"> - Insurance coverage - Transportation - Housing - Income - Education - Social support - Empowerment - Self-efficacy - Spirituality - Coping skills - Resiliency

ADAP indicates AIDS Drug Assistance Program; CDC, Centers for Disease Control and Prevention; CMS, Centers for Medicare and Medicaid Services; HRSA, Health Resources and Services Administration; SAMHSA, Substance Abuse and Mental Health Services Administration. Adapted from Mugavero et al.¹³

testing. Posttest counseling included a discussion about the meaning of a positive test result, the importance of getting into care, the role of barrier protection in sexual safety, and the need for cleansing of any drug equipment or sex toys. He was given a list of treatment sites, with those closest to his stated address circled. He never showed up at any of the treatment sites—another common scenario.

Engagement in HIV Care

Failure to follow up after HIV testing is a common scenario in the HIV care cascade. As discussed below, several studies have convincingly demonstrated that engagement in HIV care *begins at the testing site*. How closely the HIV counseling, testing, and referral (CTR) experience correlates with subsequent linkage to care appears to be related to the tone and expectation for future engagement in care established during CTR. The Never in Care Project conducted in 5 locales with mature HIV epidemics (New York City, Philadelphia, and sites in Indiana, Washington state, and New Jersey) highlights the

importance of this experience.¹² HIV-infected individuals who never sought care beyond testing were predominantly male (71%) and African American (54%), with almost half being younger than 30 years. Dissatisfaction with the CTR experience was a pervasive theme. Some of the factors reported were lack of empathy, insufficient counseling, and incorrect information. Being given the wrong address for a practitioner discouraged some individuals from pursuing care. One 25-year-old African American man stated, “They acted like they could not have cared less. It’s a good thing I have support. And if you think this means I’m going to go back and see anyone about this, I won’t. No. Never. Never.”¹²

The method of referral also had an effect on linkage outcomes. Passive referral in the form of a card, brochure, or verbal direction was often perceived as constituting little or no help. Patients receiving passive referral were less likely to go to a treatment location. Active referral in which the tester made the treatment appointment or accompanied the patient was associated with a feeling of support and a

higher likelihood of follow through. One patient reported, “When they did the quick test she gave me her card, she talked to me and my mom then.... Not knowing if I would have that support group, she made herself a support group [for me] until I could get to the [AIDS service organization].”¹² Such challenges are part of the rationale for test-and-treat interventions presently being devised, tested, and implemented in a number of settings.

Practitioner behavior is a crucial piece of the engagement and retention puzzle. A number of earlier studies suggested that antiretroviral prescribing was racially biased,^{14,15} but repeat studies have failed to corroborate this finding.^{16,17} It is clear, however, that patient trust in the practitioner is an important component of care adherence in some populations, including African Americans,¹⁸ as emphasized by recent data confirming the importance of practitioners to engagement in HIV care.¹⁹ In an urban clinic, more than 1300 patients rated their communication and relationships with their HIV practitioners. Appointment adherence correlated with patients’ perceptions

that they were being treated with dignity and respect, as well as with the opinion that the practitioner listened to their concerns. Patients also kept more appointments if practitioners explained things in a way that they could understand and took the time to get to know them as individuals. Being involved in decision making was not associated with appointment adherence.¹⁹

Beyond improving practitioner and patient interactions, other strategies that can help improve engagement and retention in care include:

- *Easing of Structural Barriers.* Small changes, such as increasing clinic hours, ensuring appointment availability, etc.
- *Novel approaches for specific populations.* STYLE (Strength Through Youth Livin' Empowered) is a Health Resources and Services Administration (HRSA)-funded project that uses social media as a way to reach young black and Latino men who have sex with men.²⁰
- *Easy, low-effort interventions.* Use of brochures, posters, and messages conveying the importance of regular clinic attendance in an urban clinic yielded modest (7%) but consistent improvement in follow-up.²¹
- *Incentives.* Cab vouchers, grocery cards, other inducements to adhere to appointments.
- *Peer navigators.* Peer navigators have been successfully used in a model to increase access to and retention in dental care through help with care coordination and support.²²
- *Medical homes.* HRSA is also interested in developing patient-centered medical homes with retention specialists, staff training, and a variety of programs to increase reengagement. In one study, the retention specialist alone was directly responsible for the return of 116 (16.2%) of 716 reengaged patients.²³
- *Multidisciplinary teams.* Multidisciplinary team approaches have been used for antiretroviral therapy adherence and primary HIV care, with teams often including a case manager, social worker, pharmacist, nurse, and care practitioner.²⁴

Moving Forward—What We Need

In the simplest terms, what is needed to enhance linkage from testing into HIV care can be described as the 4 Es: Easy, Evidence-based, Economical, and Effective interventions targeted to specific populations at increased risk for care disengagement, including youth, minorities, and lower-literacy populations.²⁵ Robust clinical trials of real-world interventions to enhance care linkage, facilitate patient-practitioner communication, build system navigation skills, and encourage reengagement in care for at risk populations continue to be needed, as interventions that work for one population group may not be applicable to another. Enhanced safety nets to quickly identify and engage individuals who do not link to care after testing are needed, as is recognition that, sadly, not everyone can be engaged.

For the HIV practitioner, losing patients despite one's best efforts is an unfortunate and bitter reality. As noted above, patient A refused hospitalization. The practitioner asked the patient's mother to call family members to the office, which led to a gathering of 14 people, including the patient's extended family. Her issues were discussed, and a case manager assured her that her children would not be prevented from seeing her if she were hospitalized. Her mother, who had custody of her children, and her uncle also promised to ensure that her children would be able to visit during her hospitalization. An adherence team member offered to accompany her to the hospital, to which she agreed. Unfortunately, she was so debilitated and emaciated that she was unable to walk, so the practitioner carried her from the room to the waiting stretcher. She was hospitalized and treated for bacterial pneumonia, and antiretroviral therapy and opportunistic infection prophylaxis were initiated. At discharge, her CD4+ cell count was 2/μL and her plasma HIV RNA level was in excess of 375,000 copies/mL.

However, 6 months later, she was nearly unrecognizable—she had gained 20 lbs, her viral load was undetectable, and her CD4+ cell count was

200/μL. She was wearing makeup and appeared to be well on her way to better health. But 8 months later, just 14 months from the time of her last hospitalization, she dropped out of care. Thus, the cycle begins again—a cycle we very much need to stop. 

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