

Engaging HIV-Infected Patients in Care: Their Lives Depend on It

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(See the article by Giordano et al. on pages 1493–9)

The HIV infection epidemic in the United States continues to expand to communities of color and poor populations, which have traditionally been medically underserved, and the health disparities associated with the HIV infection epidemic continue to increase. Up to one-quarter of HIV-infected individuals in the United States are unaware of their infection [1]. Without knowledge of their HIV infection status, patients will not enter into treatment programs and may unknowingly continue to spread the virus. Almost one-half of patients will undergo testing late in the course of HIV disease and will receive a diagnosis of AIDS within 1 year after receiving a diagnosis of HIV infection. [2] One-quarter of individuals who receive a diagnosis of HIV infection will remain outside of care [1]. As a result, only 56% of those who are eligible for antiretroviral treatment in the United States actually receive it [3], which is an appalling statistic, given the survival benefit associated with therapy.

Last year, the Centers for Disease Con-

trol and Prevention released new guidelines for HIV testing that challenge medical providers to make HIV testing routine [4]. This ambitious plan to improve the identification of infected individuals further challenges providers to link individuals with newly diagnosed infection to HIV care and to subsequently retain them in care, so that they may benefit from advances in HIV treatment.

Although HIV-positive patients who fully engage in care reap the maximum benefits, the term “engagement” in care describes a spectrum of patient care, ranging from initial diagnosis to full engagement in care. The Health Resources and Services Administration represents this continuum as outlined in figure 1. Patients can move in both directions across the spectrum. In some cases, patients who become fully engaged in care may go on to

drop out of care for months or years at time [5, 6].

Even though researchers have focused a tremendous amount of resources during the past decade on projects concerning adherence to antiretroviral medication, relatively few projects have focused on the predictors of retention in care, the barriers that patients face that prevent full and continuous engagement in care, and the interventions that improve retention. Few statistics exist to portray the extent of the problem. Current research documents that, consistent with Maslow’s hierarchy of needs, a patient’s need for food, shelter, and other essentials can interfere with the ability to prioritize health care [7, 8].

In this issue of *Clinical Infectious Diseases*, Giordano et al. [9] use data from the Veterans Administration (VA) HIV Immunology Case Registry to demon-

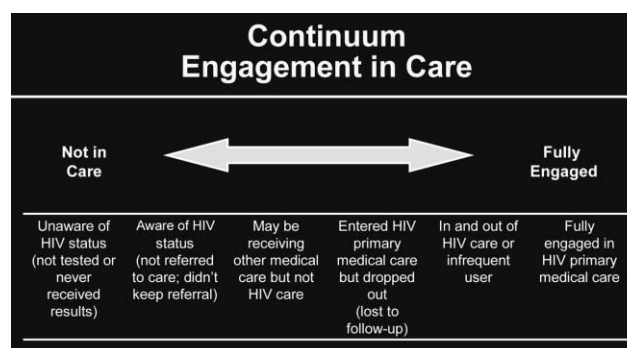


Figure 1. The continuum of engagement in HIV care, as represented by the Health Resources and Services Administration.

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strate a dose response relationship between quarterly medical visits and reduced mortality—a seemingly obvious relationship, given the enormous survival benefit associated with receipt of HAART. However, these are the first data to demonstrate the survival advantage of regular HIV care. Interestingly, this improved mortality rate persisted, even though patients with more frequent visits had more-advanced HIV disease. The article [9] has several of the limitations associated with data obtained from a VA cohort: (1) the VA health care system is unique among health care systems in the United States, and the results, therefore, may not be generalizable; (2) information on care received by these patients at other health care facilities is not available; and (3) because of the small number of female subjects, women were ultimately excluded from the analysis. Given the integrated model, lack of financial barriers within the VA, and findings from several studies indicating that women have more barriers to care than men, the estimates are likely to be conservative. In fact, the impact of health care retention on mortality was amplified in the analysis that excluded those patients who had undetectable viral loads at the first visit; these patients had presumably received prior care elsewhere.

The data from this article [9] should serve as incentives for both researchers and health delivery systems to devote additional attention and resources to the problem of engagement in care. Further research is needed to better understand the barriers encountered across the spectrum of engagement (including the impact of service and health system design on retention) and to design cost-effective interventions that improve engagement. HIV care programs should examine their retention rates, identify those individuals who are at risk for loss to follow-up, and intervene both with patients at risk and with those who have not been retained in care. Quality-management programs should include retention in their portfolios of quality measures, both for new

patients and for those followed longitudinally.

Giordano et al. [9] also found racial disparities between patients who were retained and patients who were not retained in care. This finding may partially explain the racial and sex disparities that occur in antiretroviral use that, in turn, correlate with kept health care provider appointments [10–12]. Improving retention may lessen disparities in antiretroviral use and use of other HIV services by underserved populations.

With limited staff-related and financial resources available for the care of the expanding population of medically underserved individuals living with HIV infection, we must invest wisely in reaching these patients. For that reason, the Health Resources and Services Administration has supported and continues to support a variety of engagement and retention interventions through Special Projects of National Significance initiatives. Many of our programs, which are largely based in clinics, have difficulty identifying those who have truly never been in care. This identification and linkage to care is effective when done at the time of HIV testing. Valuable interventions are being developed to target individuals at that time.

One such intervention, the Antiretroviral Treatment and Access Study, demonstrated that, for patients who have received a new diagnosis, as few as 2 case-management visits could significantly improve linkage to and retention in care [13]. A total of 78% of intervention participants attended 1 clinic visit; only 64% attended clinic visits twice within 1 year. In addition, crack cocaine users did not benefit significantly from the intervention. This and other studies [14, 15] document case management as an important intervention for some patients, but further work is needed to improve retention rates and to effectively reach illicit drug users. Furthermore, getting patients to walk through the clinic doors once does not ensure that they will return for a second clinic visit. Patients need to be engaged in care at their

first clinic visit if they are to return a second time.

Our largely clinic-based programs, funded by the Ryan White Program, have attained a higher degree of success through outreach to patients who are lost to follow-up and who, therefore, are already “known” to the medical programs. The health systems have the names and often have the addresses or other contact information of such individuals. Our Special Projects of National Significance grantees have succeeded in finding those patients who are lost to follow-up by creating linkages with other community-service organizations. Medical programs often have existing relationships with these organizations and need only to start to use them differently.

Although networking often enables health care facilities to track their clients, programs must also commit to these clients’ sustained engagement in care. Key concepts like “meeting clients where they are” have been implemented with impressive results. “System navigators”—guides that take a variety of forms—have helped clients to navigate our complex health care and social service system and to get the assistance that they need. In another successful strategy, peers and near-peers coach patients; for example, they rehearse patient appointments in advance, assist in the processing of information received during appointments, and role play responses to health care barriers.

In addition to targeting those individuals who are lost to care, programs have improved retention rates by targeting newly engaged patients, including both those who have received recent diagnoses and those who are returning to the clinic after a prolonged period without care. Using data from their programs, health care providers have developed risk assessments to identify those at risk of nonretention and to concentrate their resources on those patients who are most vulnerable. Interventions have focused both on navigating the health care system and on in-

tensively fortifying relationships between patients and health care providers.

As well as analyzing data to assess those patients at risk for nonretention, grantees have looked at their own clinic populations and data to understand and address specific barriers to client engagement. For example, the barriers to care for Hispanic immigrant populations in Portland, Oregon, can differ from those for single-room occupancy hotel residents in New York City. To improve HIV care delivery in the United States' fragmented health care system, we must implement the important lessons that our outreach grantees and other researchers have learned.

As we move forward, we must continue to balance our provision of interventions and support services intended to help patients engage in initial care with those that are intended to help them remain in care. Multiple studies have shown that patients who access case management, transportation, mental health support, drug treatment, and other supportive services are more likely to be retained in care than are those who do not [16–18]. Interventions that assist patients to develop and maintain a positive relationship with health care providers [19–23] and to improve their knowledge of HIV infection and dispel negative health beliefs [24, 25] also improve outcomes.

Providers of the health care safety net in the United States have done a remarkable job in reaching the medically underserved by developing models of HIV care that integrate mental health and substance abuse treatment. Engagement and retention in care is also critical in those 2 areas, in which outcomes are associated with the length of time that the patient is in treatment. To continue to provide excellent health care services and reduce HIV-related health disparities—thereby diminishing the HIV infection epidemic—we must use our limited resources to develop, study, and adopt innovative strategies to engage and retain HIV-infected patients in care.

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References

1. Fleming P, Byer RH, Sweeney PA, et al. HIV prevalence in the United States, 2000 [abstract 11]. In: Program and abstracts of the 9th Conference on Retroviruses and Opportunistic Infections, Seattle, Washington. Alexandria, VA: Foundation for Retrovirology and Human Health, 2002:56.
2. Centers for Disease Control and Prevention. Late versus early testing of HIV—16 Sites, United States, 2000–2003. *MMWR Morb Mortal Wkly Rep* 2003;52:581–6.
3. Teshale E, Kamimoto L, Harris N, et al. Estimated number of HIV-infected persons eligible for and receiving HIV antiretroviral therapy, 2003—United States [abstract 167]. In: Program and abstracts of the 12th Conference on Retroviruses and Opportunistic Infections, Boston, Massachusetts. Alexandria, VA: Foundation for Retrovirology and Human Health, 2005:125.
4. Centers for Disease Control and Prevention. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR Morb Mortal Wkly Rep* 2006;55:1–17.
5. Rajabiun S, Mallinson RK, McCoy K, et al. “Getting me back on track”: the role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. *AIDS Patient Care STDS* 2007 (in press).
6. Rumpitz M, Tobias C, Rajabiun S, et al. Factors associated with engaging socially marginalized HIV positive persons in primary care. *AIDS Patient Care STDS* 2007 (in press).
7. Cunningham W, Andersen RM, Katz MH, et al. The impact of competing subsistence needs and barriers on access to medical care for persons with human immunodeficiency virus receiving care in the United States. *Med Care* 1999;37:1270–81.
8. Raveis VH, Seigel K, Gorey E. Factors associated with HIV-infected women's delay in seeking medical care. *AIDS Care* 1998;10:549–62.
9. Giordano TP, Gifford AL, White AC Jr, et al. Retention in care: a challenge to survival with HIV infection. *Clin Infect Dis* 2007;44:1493–9 (in this issue).
10. Lucas Gm, Cheever LW, Chaisson RE, Moore RD. Detrimental effects of continued illicit drug use on the treatment of HIV-1 infection. *J Acquir Immune Defic Syndr* 2001;27:251–9.
11. Gebo KA, Fleishman JA, Conviser R, et al. Racial and gender disparities in receipt of highly active antiretroviral therapy persist in a multistate sample of HIV patients in 2001. *J Acquir Immune Defic Syndr* 2005;38:96–103.
12. Giordano TP, White AC Jr, Sajja P, et al. Factors associated with the use of highly active antiretroviral therapy in patients newly entering care in an urban clinic. *J Acquir Immune Defic Syndr* 2003;32:399–405.
13. Gardner LI, Metch LR, Anderson-Mahoney P, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS* 2005;19:423–31.
14. Harris SK, Samples CL, Keenan PM, et al. Outreach, mental health, and case management services: can they help to retain HIV-positive and at-risk youth and young adults in care? *Matern Child Health J* 2003;7:205–18.
15. Magnus M, Schmidt N, Kirkhart K, et al. Association between ancillary services and clinical and behavioral outcomes among HIV-infected women. *AIDS Patient Care STDS* 2001;15:137–45.
16. Ashman J, Conviser R, Pounds MB. Associations between HIV-positive individuals' receipt of ancillary services and medical care receipt and retention. *AIDS Care* 2002;14(Suppl 1):S109–18.
17. Sherer R, Stieglitz K, Narra J, et al. HIV multidisciplinary teams work: support services improve access to and retention in HIV primary care. *AIDS Care* 2002;14(Suppl 1):S31–44.
18. Messeri PA, Abramson DM, Aidala AA, et al. The impact of ancillary HIV services on engagement in medical care in New York City. *AIDS Care* 2002;14(Suppl 1):S15–29.
19. Saha S, Arbelvez JJ, Cooper SA. Patient-physician relationships and racial disparities in the quality of health care. *Am J Public Health* 2003;93:1713–9.
20. Schneider J, Kaplan S, Greenfield S, et al. Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *J Gen Intern Med* 2004;19:1096–103.
21. Heslin KC, Andersen RM, Ettner SL, Cunningham WE. Racial and ethnic disparities in access to physicians with HIV-related expertise. *J Gen Intern Med* 2005;20:283–9.
22. Ding L, Landon BE, Wilson IB, et al. Predictors and consequences of negative physician attitudes toward HIV-infected injection drug users. *Arch Intern Med* 2005;165:618–23.
23. Mallinson K, Coleman S, Rajabiun S. The provider role in client engagement in HIV care. *AIDS Patient Care STDS* 2007 (in press).
24. Tobias C, Cunningham W, Cabral H, et al. Living with HIV but without medical care: barriers to entry. *AIDS Patient Care STDS* 2007 (in press).
25. Rumpitz M, Tobias C, Rajabiun S, et al. Factors associated with engaging socially marginalized HIV positive persons in primary care. *AIDS Patient Care STDS* 2007 (in press).