Challenges facing the US HIV/AIDS medical care system

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‘... in the USA, not everyone who needs HAART has access to, or chooses to access, HIV care settings in which HAART is delivered.’

With the advent of highly active antiretroviral therapy (HAART), HIV infection has become a chronic disease. Multiple studies have shown increased time to AIDS and death with HAART use. However, in the USA, not everyone who needs HAART has access to, or chooses to access, HIV care settings, in which HAART is delivered. With the diagnosis of HIV infection, patients must learn to negotiate a healthcare system that is quite complex and a portion of patients are unsuccessful in doing so. Multiple barriers prevent individuals and/or groups from taking full advantage of life-saving therapy in this resource-rich country. One significant barrier is concerned with the fragmented and unequal financing of healthcare. Others are posed by personal/cultural, structural and physician–patient relationship concerns. While improving healthcare financing policies may help overcome some obstacles, recently published data reveal that outreach programs may help overcome others. We discuss the steps, or processes, involved in accessing HIV care, including diagnosis, linkage to care and maintenance in care. We discuss disparities and barriers in care and use of HAART in the USA, and will recommend solutions.

What is the problem?

The HIV epidemic in the USA peaked in 1992 and stabilized in 1998 at approximately 40,000 new infections per year. In 2005, the estimated HIV case rate was 19.8 per 100,000 population. This steady incidence coupled with improved survival has resulted in a growing number of people living with HIV/AIDS. In fact, by the end of 2005, there were estimated to be greater than 1 million people living with HIV in the USA [1]. The largest number of new HIV/AIDS cases occurred between the ages of 35 and 39 years

(16%), among black people (49%) and in males (73%). The estimated number of AIDS cases increased by 7% between 2001 to 2005 [1,2]. Trends in new infections and disease progression demonstrate that HIV/AIDS continues to be a problem in the USA and one that disparately impacts ethnic minorities and economically disadvantaged segments of the population.

The CDC estimates that 24–27% of people living with HIV in the USA are unaware of their HIV serostatus [3]. These individuals are thought to be responsible for fueling the epidemic by unknowingly engaging in practices that lead to transmission at times when they may be highly infectious. They account for approximately 55% of the 40,000 new infections that occur each year [4]. In addition, a significant number of those who are diagnosed with HIV are diagnosed when their disease is already advanced. In the USA, approximately 40% of people who were diagnosed with AIDS in 2005 had their first positive HIV test less than 12 months before their AIDS diagnosis [1].

How do individuals with HIV/AIDS access care in the USA?

In order to access care, the first step is to be diagnosed with HIV. Testing is voluntary and can be done anonymously. However, a large number of those who are tested and found to be HIV positive are tested in medical care settings. Thus, in an effort to decrease the number of people who are unaware of their infection or are diagnosed late in the course of HIV disease, the CDC has recently recommended that primary care providers make HIV testing a routine component of medical care that does not require separate written consent [5]. These recommendations are important steps towards making HIV screening routine. Unfortunately, implementing such recommendations presents a number of challenges. Among them is that most states will require a change in their current laws to legally implement the recommendations. Currently, 14 states require specific signed patient consent documenting permission to carry out HIV testing and five of the 19 states that permit oral consent require that consent be documented [2]. Another

challenge is that, apart from testing of pregnant women, routine HIV screening is not reimbursed by insurers because it is not currently recommended by the United States Preventive Services Task Force (USPSTF) [6]. Patients may be asked to pay out-of-pocket for testing, and this may not be practical for the most at-risk patients. A third challenge is that a significant percentage of patients who get tested do not return for test results and a positive test is most useful when it can be acted upon by the patient and provider. Understandably, this challenge relates to diagnosis of HIV through traditional testing in general, rather than a challenge to implementation of routine testing.

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Diagnosing HIV infection, while important, is clearly not sufficient. Once the diagnosis of HIV infection is made, it is imperative that the patient be linked to care and prevention services. Linkage to care is good both for the patient and public health practice for the community as a whole as it could, in theory, decrease HIV transmission. Currently, the CDC estimates that approximately a quarter of individuals who receive a diagnosis of HIV infection fail to enter care and, as a result, only 56% of those who are eligible for antiretroviral therapy in the USA actually receive it. Among persons living with HIV aged 15–49 years, the CDC estimates that only 70% are diagnosed and in care and 55% of those eligible are receiving HAART [7].

Patients who have been successfully linked to and are engaged in care have, in general, good clinical outcomes when provided with comprehensive care from experienced clinicians and case management. In a study conducted in Seattle more than a decade ago, patients cared for by physicians with the most experience had a 31% lower risk of death than the patients cared for by physicians with the least experience [8]. A multi-centered study with sites in Los Angeles, Miami, Baltimore and Atlanta, the Antiretroviral Treatment Access Study (ARTAS), proved that case management intervention increased access and usage of HIV care services [9]. The ARTAS intervention was a brief behavioral intervention, guided by strengths-based case management, aimed at linking patients to primary medical

care and connecting them with case management services at their care clinic. It was designed to increase knowledge, motivation and skills as a way to reduce barriers and facilitate use of primary medical care. The major finding from ARTAS was that intervention participants were more likely than controls to be linked to HIV primary care at the 6- and 12-month follow-up, compared with standard-of-care participants (relative risk: 1.3; $p = 0.002$). Specifically, 78% of participants in the intervention arm were linked to care at 6-months follow-up compared with 60% of participants in the control arm.

Following linkage to care, patients must be retained in care. A review of one cohort that had been linked to care (defined as having had an initial HIV care visit) demonstrated that poor retention in care predicts poor survival [10]. In over 2000 patients studied with more than 4 years of follow-up, those with only one outpatient visit per year had the worst survival, whereas those with four visits in a year (one per quarter) had the best survival ($p = 0.02$). A dose–response relationship was observed where the fewer the visits a group had, the worse their survival rates.

How is HIV care financed in the USA?

As of 2005, approximately two-thirds of the US population under the age of 65 years receive health insurance coverage as an employer benefit, and Medicare (a federally funded entitlement program) covers virtually all those aged 65 years or older. The remaining third of the population who do not have access to or cannot afford private insurance go without health coverage unless they qualify for the Medicaid program, the Medicare program by way of disabled status, the State Children's Health Insurance Program (SCHIP), or other state-subsidized insurance programs for the poor. This leaves approximately 46.1 million nonelderly Americans (18% of those under 65 years of age) without health coverage [101]. For people with HIV/AIDS, data indicate that the situation is worse, with only 16% having private insurance and approximately two-thirds being uninsured (28%) or covered by Medicaid (34%) [11]. This marked difference in insurance coverage between the general population in the USA and those living with HIV is partially explained by unemployment and income differences. People with HIV/AIDS are far more likely to be unemployed and much more likely to be poor compared with the overall US population. In the USA, private

insurance is usually employment based and is expensive for the individual and, thus, those who are unemployed or self-employed tend to be uninsured or underinsured.

In order to provide funding for medical care of persons living with HIV, the federal government enacted the Ryan White Care Act (RWCA) in 1990. The following year, funds allocated through this new program totaled US\$220 million. Congress established the RWCA as the ‘payer of last resort’: the act funds care for uninsured or underinsured individuals who have no other resources to pay for care. However, rather than becoming, as intended, the ‘funder of last resort’, today the RWCA has become a critical source of funding for uninsured and low income individuals and is vital to support the network of outpatient care clinics that provide medical care for persons with HIV/AIDS. In 2007, total funding to the RWCA totaled over US\$2100 million, which was allocated to the states and to the most heavily affected metropolitan areas. RWCA funds are rationed, based on the number of AIDS cases in a given geographic area (although this is now changing to take into consideration all HIV-infected individuals, rather than AIDS cases) and includes four programs:

- Part A (Title I) that provides funding for metropolitan areas that have large HIV-infected populations;
- Part B (Title II) that funds states and territories and includes the AIDS Drug Assistance Program (ADAP);
- Part C (Title III) funds early intervention services;
- Part D (Title IV) funds services for women, children and families.

There is also a section of the RWCA that funds Special Programs of National Significance (innovative HIV/AIDS service delivery models that have potential for replication in other areas), physician education and expansion of programs in minority communities, and includes funding for dental programs. The RWCA has provided life-saving care to many individuals who otherwise would not have access to adequate services and has helped develop an infrastructure for providing high-quality care that would not exist in the absence of the Act. It is impossible to know the exact number of clients served, however, because individuals may receive care under several parts of the Comprehensive Aids Resources Emergency (CARE) Act and most areas do not

report unduplicated client-level data, it has been estimated that the RWCA served 533,000 individuals in 2003.

Despite the clear successes of the RWCA in improving access to care there are important regional differences largely dependent on the degree to which each state supports their own Medicaid program. Thus, in states such as New York, California or Massachusetts, which have generous Medicaid programs, the RWCA funds supplement their State-run aid program. However, in poorer states such as Alabama or Mississippi, ADAP funds a restrictive formulary, and waiting lists to begin antiretrovirals are not uncommon [12].

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Why do some patients not receive HIV care?

There are multiple barriers in accessing HIV/AIDS medical care and they occur at different steps in the process. Patients may forgo testing because of fear of stigmatization or cost. Some patients simply fail to enter outpatient care after diagnosis [13]. Others enter care but are unable to be engaged and retained in regular HIV medical care [14,15]. Others have comorbidities such as mental illness and substance abuse that severely limit their ability to access and remain in medical care. More pressing basic subsistence needs such as food, clothing, housing, childcare or transportation, may compete with medical care priorities [16]. As alluded to above, lack of insurance (or type of insurance) presents a barrier to care and multiple studies have shown this [15,17,18].

Reasons for delays in care have been elucidated from the HIV Cost and Services Utilization Study (HCSUS), which surveyed a national probability sample. Less delay was associated with having a usual source of care, Medicaid coverage at diagnosis, and high trust in the medical provider [19]. A total of 14% of women in the study and 8% of men reported delaying care as a result of caring for another person [20].

To elaborate, the Health Resources and Services Administration (HRSA) funded an initiative called the Special Projects of National Significance (SPNS) Outreach Initiative, whose purpose was to implement and evaluate outreach models. The outreach models at ten locations

around the country designed to increase engagement and retention in care contribute to our understanding of barriers to HIV care. At one site serving a predominance of gay men and evaluating loss to follow-up, survey respondents cited personal/cultural, structural and financial issues as perceived barriers to care [15]. A total of 30% said they were dissatisfied with their primary care provider and 10 and 80% said transportation and parking were barriers, respectively. A qualitative study conducted at seven of the ten sites examined the process of engagement in care and found a central theme to be the perception of client-provider relationships. Provider behaviors that were engaging, validating and partnering facilitate retention, while paternalistic behaviors were barriers [14].

'Despite unprecedented advances in diagnosis, treatment and care ... HIV/AIDS remains a serious public health problem in the USA.'

HIV-positive patients in urban and rural areas of a midwestern state were interviewed using a questionnaire to measure geography/distance, medical and psychosocial resources, community stigma and personal resource barriers to HIV care adherence. In descending order, rural participants identified the following factors as negative influences on their adherence to HIV care: the level of knowledge about HIV among citizens in the community; community residents' stigma against people with HIV; lack of employment opportunities and supportive and understanding work environments; and personal financial resources. Like rural residents, urban residents ranked knowledge about HIV and lack of employment opportunities level as the primary and tertiary barriers, but personal financial resources, community residents' stigma and lack of supportive and understanding work environments were ranked second, fourth and fifth, respectively. Rural residents had significantly longer distances to medical facilities and personnel, lack of transportation, lack of healthcare providers adequately trained in HIV/AIDS care, a shortage of mental health professionals and community residents' stigma against people living with HIV/AIDS [21]. Consistent with these findings, a qualitative study in urban men who have sex with men identified medical distrust and a fear of both sickness and discrimination based on being a member of a risk group as barriers to care [18].

A majority of southeastern HIV/AIDS case managers surveyed identified lack of housing for persons living with HIV/AIDS (69%) and stigma against persons living with HIV/AIDS (57%) to be 'major' problems. A majority of them identified long traveling distances to receive healthcare services (62%), lack of accessible transportation for clients (68%), lack of adequately trained health professionals (52%), a shortage of mental health professionals (65%) and lack of substance abuse treatment facilities willing to work with HIV clients (57%) to be at least 'somewhat of a problem' [22].

Receipt of HAART

A way to determine who is fully accessing HIV services is to evaluate who, among those eligible, is receiving HAART, as when medications are offered, accepted and adhered to, success does not depend upon race, gender or social class [23]. Multiple studies have evaluated HAART use. Reduced HAART use has been associated with African-American race/ethnicity, non-white race, illegal drug use, history of physical or sexual abuse, lack of outpatient clinic attendance, lack of health insurance, Medicaid-only insurance, homelessness, female gender, being new to the hospital, living in poorer neighborhoods and being hepatitis B surface antigen positive [24–28]. Analysis of nearly 3000 admissions of AIDS patients to a public hospital showed that female gender (odds ratio [OR]: 0.72), African-American race (OR: 0.64), active substance abuse (OR: 0.49), homelessness (OR: 0.36) and new patient status (OR: 0.26), were negatively associated with HAART use [29]. Having no usual source of care was associated with decreased use of *Pneumocystis jiroveci* pneumonia prophylaxis [25].

Several studies have examined elements of socioeconomic status, insurance and HAART use. San Francisco's AIDS surveillance data demonstrated that persons living in poorer neighborhoods were less likely to use HAART [26]. Interviews conducted with HIV-positive volunteers in Los Angeles, Milwaukee, New York City and San Francisco revealed that uninsured patients with CD4 counts less than 350 units were less likely than insured patients to use a recommended regimen of antiretroviral therapy (OR: 0.51) [24]. No difference in HAART use and outcomes was found among beneficiaries with AIDS who were on traditional Medicaid versus Medicaid managed-care plans [30]. A study of reimbursement claims in four states found that Medicaid users have less use of HAART than ADAP users [31].

In the Women's Interagency HIV Study (WIHS), women with CD4 counts less than 200 (OR: 1.78) and detectable viral loads (OR: 1.69) were more likely to use HAART [28]. Of AIDS patients admitted to a hospital, outpatient clinic visit within 6 months of admission (OR: 3.44), heterosexuality (OR: 1.53) and male homosexuality (OR: 2.03) were associated with receiving HAART on admission [29]. The HCSUS data have also revealed racial/ethnic disparities in access to HIV expert physicians [32], and physician expertise may influence quality of care, including the use of HAART. Furthermore, the HCSUS data also shows that racial concordance between patient and physician has been related to time of receipt of protease inhibitors, with African-American patients receiving them later if their physician is a race other than black [33].

Despite unprecedented advances in diagnosis, treatment and care for HIV infection and the commitment of substantial resources to this disease, HIV/AIDS remains a serious public health problem in the USA and one that disproportionately affects minority and marginalized populations that have historically had poor access to healthcare. Recently published results of the SPNS Outreach Initiative make it clear

that outreach is the next important step to take as an intervention to ameliorate these disparities. It is encouraging that at all ten sites where outreach was implemented through the SPNS project there was success in bringing minorities into HIV care. Now resources need to be used to support replication of such models throughout the nation [34]. Also, because HIV-infected populations are increasingly affected by mental health and/or substance abuse problems, care should not be narrowly defined as medical care but should integrate access to mental health and substance abuse programs.

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Bibliography

Papers of special note have been highlighted as either of interest (•) or of considerable interest (••) to readers.

- Centers for Disease Control and Prevention: HIV/AIDS Surveillance Report, 2005 (Revised Edition). 17, 1–54 (2007).
- Wolfe LE, Donoghoe A, Lane T: Implementing routine HIV testing: the role of state law. *PLoS ONE* 2, e1005 (2007).
- Glynn M, Rhodes P: Estimated HIV Prevalence in the United States at the end of 2003. Presented at: *National HIV Prevention Conference*. Atlanta, Georgia, USA, 12–15 June 2005 (Abstract T1-B1101).
- Marks G, Crepaz N, Janassen RS: Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. *AIDS* 20, 1447–1450 (2006).
- Centers for Disease Control and Prevention: Revised recommendations for HIV testing of adults, adolescents, and pregnant women in healthcare settings. *MMWR* 55, 1–17 (2006).
- US Preventive Services Taskforce: Screening for HIV: recommendation statement. *Ann. Intern. Med.* 143, 32–37 (2005).
- Teshale E, Kamimoto N, Harris N, Li J, Wang H, McKenna M: Estimated number of HIV-infected persons eligible for and receiving HIV antiretroviral therapy, 2003 – United States. Presented at: *12th Conference on Retroviruses and Opportunistic Infections (CROI)*. Boston, MA, USA, 22–25 February 2005 (Abstract 167).
- Kitahata M, Koepsell T, Deyo R, Maxwell C, Dodge W, Wagner E: Physician experience with acquired immune deficiency syndrome as a factor in patient survival. *N. Engl. J. Med.* 334, 701–706 (1996).
- Gardner L, Metsch L, Anderson-Mahony P *et al.*: Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS* 19, 423–431 (2005).
- Giordano TP, Gifford AL, White AC *et al.*: Retention in care: a challenge to survival with HIV infection. *Clin. Infect. Dis.* 44, 1493–1499 (2007).
- Fleishman JA, Gebo KA, Reilly ED *et al.*: Hospital and outpatient health services utilization among HIV-infected adults in care 2000–2002. *Med. Care* 43, 40–52 (2005).
- Saag MS: Which policy to ADAP-T: waiting lists or waiting lines? *Clin. Infect. Dis.* 43, 1365–1367 (2006).
- Mugavero MJ, Lin H-Y, Allison JJ *et al.*: Failure to establish HIV care: characterizing the 'No Show' phenomenon. *Clin. Infect. Dis.* 45, 127–130 (2007).
- Mallinson KR, Rajabun S, Coleman S: The provider role in client engagement in HIV care. *AIDS Patient Care STDs* 21, S77–S84 (2007).
- Coleman S, Boehmer U, Kanaya F, Grasso C, Tan J, Bradford J: Retention challenges for a community-based HIV primary care clinic and implications for intervention. *AIDS Patient Care STDs* 21, 691–701 (2007).
- Tobias C, Cunningham W, Cunningham C, Pounds M: Making the connection: the importance of engagement and retention in HIV medical care. *AIDS Patient Care STDs* 21, S3–S8 (2007).
- Morales LS, Cunningham WE, Galvan FH, Andersen RM, Nakazono TT, Shapiro MF: Sociodemographic differences in access to care among hispanic patients who are HIV infected in the United States. *Am. J. Public Health* 94, 1119–1121 (2004).
- Malebranche D, Peterson L, Fullilove R, Stackhouse R: Race and sexual identity: perceptions about medical culture and healthcare among black men who have sex with men. *J. Natl. Med. Assoc.* 96, 97–107 (2004).

19. Turner BJ, Cunningham WE, Duan N *et al.*: Delayed medical care after diagnosis in a US national probability sample of persons infected with human immunodeficiency virus. *Arch. Intern. Med.* 160, 2614–2622 (2000).
- **A national sample of US adults with HIV from the HIV Cost and Services Utilization Study.**
20. Stein M, Crystal S, Cunningham WE *et al.*: Delays in seeking HIV care due to competing caregiver responsibilities. *Am. J. Public Health* 90, 1138–1140 (2000).
21. Heckman TG, Somlai AM, Peters J *et al.*: Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care* 10, 365–375 (1998).
22. Reif S, Golin CE, Smith SR: Barriers to accessing HIV/AIDS care in North Carolina: rural and urban differences. *AIDS Care* 17, 558–565 (2005).
23. Silverberg MJ, Wegner S, Milazzo MJ *et al.*: Effectiveness of highly-active antiretroviral therapy by race/ethnicity. *AIDS* 20, 1531–1538 (2006).
24. Sambamoorthi U, Moynihan PJ, McSpirt E, Crystal S: Use of protease inhibitors and non-nucleoside reverse transcriptase inhibitors among medicaid beneficiaries with AIDS. *Am. J. Public Health* 91, 1474–1481 (2001).
25. Goldstein RB, Rotheram-Borus MJ, Johnson MO *et al.*: Insurance coverage, usual source of care, and receipt of clinically indicated care for comorbid conditions among adults living with human immunodeficiency virus. *Med. Care* 43, 401–410 (2005).
26. McFarland W, Chen S, Hsu L, Schwarcz S, Katz M: Low socioeconomic status is associated with a higher rate of death in the era of highly active antiretroviral therapy, San Francisco. *J. Acquir. Immune Defic. Syndr.* 33, 96–103 (2003).
27. Cohen MH, Cook JA, Grey D *et al.*: Medically eligible women who do not use HAART: the importance of abuse, drug use, and race. *Am. J. Public Health* 94, 1147–1151 (2004).
28. Burke-Miller JK, Cook JA, Cohen MH *et al.*: Longitudinal relationships between use of highly active antiretroviral therapy and satisfaction with care among women living with HIV/AIDS. *Am. J. Public Health* 96, 1044–1051 (2006).
29. Pulverenti JJ, Glowacki R, Muppiddi U *et al.*: Hospitalized HIV-infected patients in the HAART era: a view from the inner city. *AIDS patient care STDs* 17, 565–573 (2003).
30. Zingmond D, Ettner S, Cunningham W: The impact of managed care on access to highly active antiretroviral therapy and on outcomes among Medicaid beneficiaries with AIDS. *Med. Care Res. Rev.* 64, 66–82 (2007).
31. Kahn J, Zhang X, Cross L, Palacio H, Birkhead G, Morin S: Access to and use of HIV antiretroviral therapy: variation by race/ethnicity in two public insurance programs in the US. *Public Health Rep.* 117, 252–262 (2002).
32. Heslin KC, Andersen RM, Ettner S, Cunningham WE: Racial and ethnic disparities in access to physicians with HIV-related expertise. *J. Gen. Intern. Med.* 20, 283–289 (2005).
33. King WD, Wong MD, Shapiro MF, Landon BE, Cunningham WE: Does racial concordance between HIV-positive patients and their physicians affect the time to receipt of protease inhibitors? *J. Gen. Intern. Med.* 19, 1146–1153 (2004).
34. Bradford J: The promise of outreach for engaging and retaining out-of-care persons in HIV medical care. *AIDS Patient Care STDs* 21, S85–S91 (2007).
- **Summary of the Health Resources and Services Administration Special Projects of National Significance outreach initiative.**

Website

101. Kaiser Commission on Medicaid and the Uninsured: The Uninsured: A Primer, Key Facts About Americans Without Health Insurance. The Henry J. Kaiser Family Foundation 1–48 (2006).
www.kff.org/uninsured/upload/7451-03.pdf

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