A Community-Based Study of Barriers to HIV Care Initiation

Robin A. Pollini, Ph.D., M.P.H.,¹ Estela Blanco, M.P.H., M.A.,²
Carol Crump, M.F.T.,³ and María Luisa Zúñiga, Ph.D.^{1,2}

Abstract

Timely treatment of HIV infection is a public health priority, yet many HIV-positive persons delay treatment initiation. We conducted a community-based study comparing HIV-positive persons who received an HIV diagnosis at least 3 months ago but had not initiated care ($n=100$) with a reference population of HIV-positive persons currently in care ($n=115$) to identify potential barriers to treatment initiation. Study participants were mostly male (78.0%), and persons of color (54.9% Latino, 26.3% black), with median age 37.8 years. Median time since HIV diagnosis was 3.7 years. Univariate analysis revealed that those never in care differed substantially from those currently in care with regard to sociodemographics; HIV testing and counseling experiences; perceived barriers to care; and knowledge, attitudes, and beliefs regarding HIV. Factors independently associated with never initiating HIV care were younger age (adjusted odds ratio [AOR]=0.93; 95% confidence interval [CI]: 0.88, 0.99), shorter time since diagnosis (AOR=0.87; 95% CI: 0.77, 0.98), lacking insurance (AOR=0.11; 95% CI: 0.03, 0.35), not knowing someone with HIV/AIDS (AOR=0.09; 95% CI: 0.03, 0.30) not disclosing HIV status (AOR=0.13; 95% CI: 0.02, 0.70), not receiving help making an HIV care appointment after diagnosis (AOR=0.04; 95% CI: 0.01, 0.14), and not wanting to think about being HIV positive (AOR=3.57; 95% CI: 1.22, 10.46). Our findings suggest that isolation and stigma remain significant barriers to initiating HIV care in populations consisting primarily of persons of color, and that direct linkages to HIV care at the time of diagnosis are critical to promoting timely care initiation in these populations.

Introduction

TIMELY TREATMENT of HIV infection has been shown to improve clinical outcomes and reduce medical care costs.¹ Persons who initiate treatment at higher CD4⁺ levels experience lower morbidity and mortality than those who delay care until substantial immune system damage has occurred.^{2,3} Reducing viral load among persons living with HIV has been proposed as a public health strategy to reduce HIV transmission at the population level, underscoring the importance of timely HIV treatment to reduce the risk of transmission to non-infected partners.⁴⁻⁷ For these reasons, reducing delays between HIV diagnosis and initiation of HIV care is viewed as a public health priority.

Despite the importance of initiating timely HIV treatment and care, as many as 20–40% of HIV-positive persons in the United States do not initiate care within the first 6 months after their diagnosis.⁸ In one of the earliest studies of delayed entry into HIV care, Samet et al.⁹ found that 89% of HIV-positive persons

in Massachusetts and Rhode Island delayed care for more than 1 year. In Alabama, 34% of HIV-positive persons delayed care for more than 1 year following diagnosis¹⁰ and a study using a nationally representative sample found that 17–29% of HIV-positive persons delayed care for more than 3 months, with a median delay of 1 year.¹¹ Other studies looking at median time from HIV diagnosis to care initiation show delays ranging from 33 days to 8 months.^{12–15} Importantly, however, all of these studies used retrospective clinic- and hospital-based samples of persons *who eventually initiated HIV care*; their related findings regarding barriers to care may not be generalizable to HIV-positive persons who have never initiated care at all.

Recent study findings suggest major improvements in HIV care initiation when compared to earlier studies; for example, a recent San Francisco study found that only 12% of newly diagnosed HIV-positive persons did not access HIV care within three months of diagnosis,¹⁶ and another study in San Francisco found that 85% of HIV-positive persons entered care within 3 months and 95% within 12 months of diagnosis.¹⁷

¹Department of Medicine, Division of Global Public Health, ²Department of Pediatrics, Division of Child Development and Community Health, University of California, San Diego, La Jolla, California.

³California Department of Public Health, Center for Infectious Diseases, Office of AIDS, Sacramento, California.

However, important work remains to be done to engage HIV-positive persons in care. For example, the latter San Francisco study found marked disparities in timely entry into care by age, Latino ethnicity, history of immigration to the United States, and testing site. Two studies elsewhere found that: (1) 28% of facility and population-recruited HIV-positive persons from 18 states did not enter HIV treatment within 3 months¹⁸ and (2) 21% of hospitalized HIV-positive crack cocaine smokers in Miami and Atlanta had never been to a doctor or clinic for HIV care, even though two thirds had received their diagnosis more than 5 years ago.¹⁹ Such disparities and delays in care perpetuate avoidable morbidity, mortality, and costly medical care^{20–23} as well as HIV transmission.⁶

The Centers for Disease Control and Prevention (CDC) is currently implementing a population-based system to estimate the number of persons diagnosed with HIV who have not initiated care, identify their reasons for delaying care and provide regional population comparisons.²⁴ To date, however, very few studies have undertaken research on HIV-positive persons who have never initiated care. This is likely due to the difficulties inherent in both identifying persons who are not receiving care and engaging them in research. For example, one study sought to identify subjects by following up with HIV-positive persons who received an HIV diagnosis at sexually transmitted disease (STD) clinics in Baltimore, Miami, and Newark in the previous 6 to 24 months; only 34% of eligible patients could be located and interviewed, and of these 25% said that they never received medical care for their HIV infection.²⁵

In the United States, the problem of delayed entry into HIV care is of critical importance to vulnerable populations, including ethnic and racial minority groups, who bear a disproportionate burden of HIV/AIDS morbidity and mortality. In 2006, HIV prevalence rates for U.S. blacks and Latinos were substantially higher (1715.1 and 585.3 per 100,000, respectively) than the rate for non-Latino whites (224.3 per 100,000).²⁶ Latinos living with HIV are among the U.S. racial/ethnic groups most likely to delay HIV testing and treatment, often receiving an AIDS diagnosis within 1 year of their HIV diagnosis.²⁷ Factors associated with delayed testing and care among Latinos include older age, being foreign-born, having less than a high school education, and preferring to communicate in Spanish.²⁸ Black communities in the United States also suffer from substantial disparities in HIV infection and care; young black men are more likely than other ethnic/racial groups to be diagnosed with HIV only after being diagnosed with an opportunistic infection and to delay care for several months after an HIV diagnosis.^{1,11,12}

To address the dearth of information on barriers to care among HIV-positive persons who have never accessed HIV care, and to provide critical information to inform interventions to improve HIV treatment engagement, we partnered with a network of community outreach workers in California to identify barriers to care among persons who were diagnosed with HIV but never initiated HIV care. Specifically, the study was undertaken to identify factors independently associated with never receiving care among an ethnically/racially diverse population of California residents.

Methods

Study population

The study was conducted in collaboration with the Early Intervention Program, Bridge Project, a California-wide out-

reach program designed to decrease the amount of time it takes for HIV-infected persons—particularly persons of color—to engage in HIV care, treatment, and prevention services.²⁹ The program partners with Bridge Workers, certified HIV treatment educators with strong ties to and trusted by their communities, who are able to identify HIV-positive persons who are not receiving routine care and treatment services. The Bridge Workers provide related health information, decision making support, and linkages to medical and social services to facilitate entry or reentry of HIV-positive persons into appropriate medical care. Eleven of 21 Bridge Projects agreed to participate in the study: 4 sites from Northern California, 2 from Central California, and 5 from Southern California. Three quarters (73%) of the sites were located in urban areas. While sites differed somewhat with respect to specific target populations (e.g., migrant farm workers in rural areas versus former/current drug users in urban areas), the recruitment approach was uniform across all Bridge Projects.

Between January 2006 and July 2009, Bridge Workers enrolled persons into the study who had never received HIV care ($n = 100$). To be eligible (i.e., “never in care”) participants had to be aged 18 years or older, and either (1) were diagnosed with HIV at least 3 months ago and reported never having CD4⁺ or HIV viral load testing or (2) received their first HIV test and diagnosis after presenting to an emergency department or community clinic with an AIDS-related opportunistic infection. Because the study was designed to leverage the existing Bridge Project infrastructure with minimal disruption, study participants were identified and invited to participate as part of the Bridge Workers’ usual outreach efforts, which was a convenience sample rather than a representative sample of persons never in care.

The study was originally designed as a cross-sectional study of persons never in care; however, 2 years into the study and facing lower than anticipated recruitment the researchers, Bridge Workers and community collaborators from partner sites made the mutual decision to expand recruitment to assess barriers to care that had been experienced by same-region populations who were in care ($n = 115$). This allowed us to compare the barriers to care and other characteristics of the “never in care” participants to a population that eventually accessed care. Accordingly, beginning in October 2008, Bridge Workers also began enrolling HIV-positive persons “currently in care” who were aged 18 years or older, and either (1) received their HIV diagnosis more than 3 months but less than 1 year ago, and reported having at least one HIV-related laboratory test (e.g., CD4⁺ cell count), or (2) were diagnosed more than 1 year before and had at least two CD4⁺/viral load tests within the prior year. Bridge Outreach Workers concurrently bolstered their efforts to continue reaching and enrolling persons never in care.

The study was approved by Institutional Review Boards at the University of California, San Diego and at the California Department of Public Health. All participants provided informed consent and were offered a \$30 gift card to a local retail establishment (e.g., Target, McDonalds) in appreciation for their time.

Data collection

Following in-depth training in research ethics and interviewing techniques, volunteer Bridge Workers administered surveys to participants in their preferred language (Spanish or

English). The instrument drew on questions from the CDC's standard questionnaire for the "Never in Care" Project²⁴ and the Antiretroviral Treatment Access Study (ARTAS) survey³⁰ and included detailed questions on demographics; circumstances surrounding their HIV diagnosis; perceived barriers to accessing HIV medical care; health history; medical care history; knowledge, attitudes, and beliefs about HIV and its treatment; and sexual and drug use behaviors. Questions regarding barriers to HIV care were based on the existing literature and the model of health care access proposed by Andersen and colleagues^{31–33} that proposes that barriers to care exist at both structural and individual levels and include predisposing factors (e.g., embarrassed or ashamed to go) enabling factors (e.g., insurance, transportation), and need-based factors (e.g., severity of illness). Completed surveys were mailed to the University of California, San Diego, for review and data entry.

Data analysis

To identify factors associated with never initiating HIV care, we compared the characteristics of persons "never in care" to those "currently in care." Univariate analysis was conducted using Wilcoxon rank-sum tests for continuous variables and Pearson's χ^2 test for categorical variables. Variables significant at <0.10 were manually entered into a multiple logistic regression model to identify factors independently associated with never being in care at a significance

level of 0.05. All analyses were performed using Stata statistical software (StataCorp, College Station, TX).³⁴

Results

Table 1 presents sociodemographic characteristics of the 215 study participants. The majority were male (78.0%) and Latino (54.9%), and 39.7% preferred receiving health information in Spanish or another language other than English. Median age was 37.8 years and median time since HIV diagnosis was 3.7 years. Nearly one half (49.1%) were employed, 40.6% had medical insurance, and 22.2% reported using illicit drugs in the past 3 months.

Table 1 also compares the characteristics of those never in HIV care to those currently in care. Those never in care were significantly ($p < 0.05$) more likely to be younger, single, and prefer a language other than English. They were more likely to be either partially or fully employed and to have their own car. Those never in care were also diagnosed more recently and were significantly less likely to know someone with HIV/AIDS or know someone who had died from HIV/AIDS. In addition, they were less likely to have told other people they had HIV and to have medical insurance.

Table 2 summarizes participants' experiences with HIV testing. The most common reasons for HIV testing were having sex with other men, having multiple sex partners and having a sex partner who had sex with other men. Compared to those in HIV care, those never in care were more likely to

TABLE 1. SOCIODEMOGRAPHICS OF HIV-POSITIVE PERSONS, BY HIV CARE STATUS^a

Sociodemographics	Total n = 215	Never in care n = 100	Currently in care n = 115	p Value
Male	163 (78.0)	79 (80.6)	84 (75.7)	0.39
Median age	37.8 (29.3–46.6)	30.7 (25.8–40.7)	42.1 (33.2–48.8)	<0.01
Race/ethnicity				
Latino	117 (54.9)	55 (59.1)	54 (49.1)	0.10
Black	56 (26.3)	19 (19.4)	36 (32.7)	
Non-Hispanic white/other	40 (18.8)	20 (21.5)	20 (18.2)	
Born in United States	128 (60.1)	54 (54.6)	74 (64.9)	0.12
Single, never married	137 (64.3)	71 (71.7)	66 (57.9)	0.04
Median no. of children	0 (0–1)	0 (0–1)	0 (0–1)	0.49
Graduated high school	143 (66.8)	65 (65.7)	78 (67.8)	0.74
Preferred language				
English	129 (60.3)	47 (47.8)	82 (71.3)	<0.01
Spanish or other language	85 (39.7)	52 (52.5)	33 (28.7)	
Living location past 3 months				
House (own, parent, other)	180 (84.5)	84 (85.7)	96 (83.5)	0.65
Other	33 (15.5)	14 (14.3)	19 (16.5)	
Employment past 3 months				
Full or partially employed	104 (49.1)	63 (65.0)	41 (35.7)	<0.01
Unemployed	108 (50.9)	34 (35.1)	74 (64.4)	
Have medical insurance	86 (40.6)	17 (17.5)	69 (60.0)	<0.01
Transport				
Own car	86 (41.6)	46 (47.4)	40 (36.4)	0.02
Public transportation	87 (42.0)	31 (32.0)	56 (50.9)	
Other	34 (16.4)	20 (20.6)	14 (12.7)	
Illicit drug use past 3 months	47 (22.2)	26 (26.8)	21 (18.4)	0.15
Median years since HIV diagnosis	3.73 (0.85, 9.22)	0.82 (0.43, 2.80)	8.18 (3.73, 13.29)	<0.01
Know someone with HIV	138 (68.0)	42 (46.2)	96 (85.7)	<0.01
Know someone who died of HIV	77 (38.3)	15 (16.7)	62 (55.9)	<0.01
Told other people you have HIV	159 (77.6)	56 (59.0)	103 (93.6)	<0.01

^aValues are n (%) or median (interquartile range).

TABLE 2. HIV TESTING EXPERIENCES OF HIV-POSITIVE PERSONS, BY HIV CARE STATUS^a

<i>HIV testing experiences</i>	<i>Total n=215</i>	<i>Never in care n=100</i>	<i>Currently in care n=115</i>	<i>p Value</i>
Reasons for HIV testing				
Had sex with other men (males only)	82 (50.9)	45 (60.0)	37 (43.0)	0.03
Multiple sex partners	81 (38.8)	36 (38.3)	45 (39.1)	0.90
Sex partner had sex with other men	47 (22.5)	21 (22.3)	26 (22.6)	0.96
Sex partner thought you might have HIV	40 (19.1)	18 (19.2)	22 (19.1)	1.00
Sex partner had multiple sex partners	40 (19.1)	19 (20.2)	21 (18.3)	0.72
Sex partner had HIV	30 (14.4)	7 (7.5)	23 (20.0)	0.01
Sex partner injected drugs	23 (11.0)	7 (7.5)	16 (13.9)	0.14
Had an infection or illness	74 (35.2)	29 (30.5)	45 (39.1)	0.19
High risk injection behavior	35 (16.8)	13 (13.8)	22 (19.1)	0.31
Offered screening at clinic	30 (13.4)	12 (12.8)	18 (15.7)	0.55
Location of first positive HIV test				
HIV counseling/testing site	50 (23.9)	26 (27.7)	24 (20.9)	0.25
STD clinic	44 (21.1)	24 (25.5)	20 (17.4)	0.15
Emergency room	19 (9.1)	7 (7.5)	12 (10.4)	0.46
Jail/prison/detention	19 (9.1)	6 (6.4)	13 (11.3)	0.22
Private physician	18 (8.6)	4 (4.3)	14 (12.2)	0.04
Prenatal/family planning clinic	13 (6.2)	5 (5.3)	8 (7.0)	0.63
Drug treatment clinic	6 (2.9)	4 (4.3)	2 (1.7)	0.28
Blood bank	5 (2.4)	4 (4.3)	1 (0.9)	0.11
Someone from the facility where you tested positive				
Explained the importance of getting HIV care	167 (84.3)	67 (80.7)	100 (87.0)	0.23
Explained where you could go for HIV treatment	155 (80.3)	62 (75.6)	93 (83.8)	0.16
Helped you set up an appointment for HIV care	109 (55.1)	31 (36.1)	78 (69.6)	<0.01
Offered to go with you to your appointment	52 (26.1)	20 (22.7)	32 (28.8)	0.33
Spent enough time with you after your diagnosis	127 (68.7)	45 (59.2)	82 (75.2)	0.02
Gave you enough emotional support	113 (61.8)	40 (54.8)	73 (66.4)	0.12
Answered all your questions				
Yes	117 (58.2)	40 (45.5)	77 (68.1)	0.01
No	42 (20.9)	20 (22.7)	22 (19.5)	
Didn't have questions	42 (20.9)	28 (31.8)	14 (12.4)	
Comfort with person who gave the HIV diagnosis				
Very comfortable	61 (31.4)	21 (24.1)	40 (37.4)	0.13
Comfortable	72 (37.1)	32 (36.8)	40 (37.4)	
Uncomfortable	36 (18.6)	20 (23.0)	16 (15.0)	
Very uncomfortable	25 (12.9)	14 (16.1)	11 (10.3)	

^aValues are *n* (%).

STD, sexually transmitted disease.

cite having sex with other men as a reason for HIV testing and less likely to cite having a sex partner with HIV. The most common locations where participants tested positive for HIV were dedicated HIV counseling and testing sites and STD clinics; notably, participants never in care were less likely to have been diagnosed by a private physician. Regarding HIV post-test counseling experiences, slightly more than one half of the study participants said someone at the testing facility helped them set up an appointment for HIV care after their HIV diagnosis and 1 in 4 said someone at the testing facility offered to go to the appointment with them. Compared to persons in care, participants who had never received care were significantly less likely to report being offered assistance in setting up a medical appointment. They were also less likely to report that someone at the testing facility spent enough time with them after informing them of their positive diagnosis or answered all their questions regarding their HIV diagnosis. Notably, however, almost one third (31.8%) of those never in care, compared to 12.4% among those in care, said they had no questions at the time of their diagnosis.

Reported barriers to HIV care are presented in Table 3. Among all HIV-infected persons in the study, a majority cited not wanting to tell anyone they were HIV positive and not wanting to think about being HIV positive as barriers to care, and almost one half said they were not in care because they did not feel sick. More than one third of the HIV-positive persons in the study said they thought the test result was wrong or that they were too ashamed or embarrassed to receive care. When compared to persons currently in care, those never in care were more likely to say they did not want to think about being HIV positive but, interestingly, were less likely to cite jail/prison, homelessness, or fear of discrimination based on their HIV status as barriers to receiving HIV care.

Table 4 presents knowledge, attitudes, and beliefs regarding HIV care. Overall, almost one third of participants thought the government had not adequately tested HIV medications. Those never in care differed significantly from those currently in care in almost every category. They were more likely to think that they did not need HIV medications until they got very sick, that the medications would do more

TABLE 3. PERCEIVED BARRIERS TO CARE AMONG HIV-POSITIVE PERSONS, BY HIV CARE STATUS^a

Barriers to care	Total n = 205	Never in care n = 94	Currently in care n = 111	p Value
Didn't want to tell anyone I was HIV-positive	110 (53.7)	52 (55.3)	58 (52.3)	0.66
Didn't want to think about being HIV-positive	117 (50.1)	66 (70.2)	51 (46.0)	<0.01
Didn't feel sick	92 (44.9)	46 (48.9)	46 (41.4)	0.28
Believed the HIV-positive test result was wrong	75 (36.6)	40 (42.6)	35 (31.5)	0.10
Too embarrassed/ashamed to go	64 (31.2)	30 (31.9)	34 (30.6)	0.84
Drinking and/or using drugs	61 (29.8)	22 (23.4)	39 (35.1)	0.07
Had no insurance	59 (28.8)	23 (24.5)	36 (32.4)	0.21
Didn't want to be forced to take medications	44 (21.5)	20 (21.3)	24 (21.6)	0.95
There is no cure for HIV/AIDS	38 (18.5)	12 (12.8)	26 (23.4)	0.05
Afraid of discrimination because of HIV status	37 (18.1)	11 (11.7)	26 (23.4)	0.03
Treatment for HIV would be unpleasant or painful	37 (18.1)	14 (14.9)	23 (20.7)	0.28
I was too busy	37 (18.1)	20 (21.3)	17 (15.3)	0.27
I was living on the street/homeless	34 (16.6)	10 (10.6)	24 (21.6)	0.04
I was in jail or prison	33 (16.1)	8 (8.5)	25 (22.5)	0.01
I moved	28 (13.7)	14 (14.9)	14 (12.6)	0.64
Care costs too much	27 (13.2)	11 (11.7)	16 (14.4)	0.57
Couldn't get transportation to the clinic	24 (11.7)	8 (8.5)	16 (14.4)	0.19
Didn't know where to go	22 (10.7)	11 (11.7)	11 (9.9)	0.68
Missed my appointment	22 (10.7)	8 (8.5)	14 (12.6)	0.34
Don't like doctors and/or medical clinics	22 (10.7)	9 (9.6)	13 (11.7)	0.62

^aValues are *n* (%).

harm than good, that they should wait for better HIV medications to come along, that doctors want to start all HIV-positive persons on HIV medications even if they do not need them, that most people do not benefit from HIV medicines and that it is safer to use natural remedies than HIV medications. Those never in care were also significantly less likely to want to be actively involved in their HIV care.

Results of the multiple logistic regression analysis are presented in Table 5. Those never in care were younger, less likely to have medical insurance, less likely to know someone with HIV/AIDS, less likely to have told others they were HIV positive, less likely to report someone at the testing facility helped them set up an appointment for HIV care, and had a shorter time since HIV diagnosis. They were also more likely

to say that they did not want to think about being HIV positive. None of the knowledge, attitude, and beliefs variables were independently associated with never being in care after controlling for other significant factors.

Discussion

This study examined barriers to initiating HIV care in a community-based HIV-positive population comprised largely of persons of color. After 3 years of intensive recruitment efforts, we were able to enroll only 100 participants who had never accessed care; however, we feel that our community-investigator collective response to this slow recruitment, which consisted of expanding recruitment to local clinic

TABLE 4. KNOWLEDGE, ATTITUDES, AND BELIEFS REGARDING HIV CARE AMONG HIV-POSITIVE PERSONS, BY HIV CARE STATUS^a

Knowledge, attitudes, and beliefs	Total n = 215	Never in care n = 100	Currently in care n = 115	p Value
You want to be active in making decisions about your HIV care	191 (92.7)	82 (88.2)	109 (96.5)	0.02
You do not need medical care and HIV medicines until you get very sick	45 (23.7)	25 (31.7)	20 (18.0)	0.03
You do not want to start taking HIV medicines because they will do you more harm than good	46 (24.5)	32 (40.5)	14 (12.8)	<0.01
You do not want to take HIV medicines because you are waiting for something better to come along	30 (15.6)	20 (25.3)	10 (8.9)	<0.01
The government hasn't tested the new HIV medicines long enough to be sure they are safe	49 (29.7)	25 (36.2)	24 (25.0)	0.12
Doctors want to start all people with HIV on HIV medicines, even if they do not need them	49 (28.0)	29 (39.7)	20 (19.6)	<0.01
Most people don't benefit from taking HIV medicines	24 (13.0)	19 (25.3)	5 (4.6)	<0.01
It is safer to use natural remedies than to take HIV medicines	34 (20.6)	21 (31.8)	13 (13.1)	<0.01

^aValues are *n* (%) in agreement with the statement.

TABLE 5. FACTORS INDEPENDENTLY ASSOCIATED WITH NEVER BEING IN HIV CARE

	<i>Adjusted odds ratio (95% confidence interval)</i>
Age	0.93 (0.88, 0.99)
Years since diagnosis	0.87 (0.77, 0.98)
Have medical insurance	0.11 (0.03, 0.35)
Know someone with HIV/AIDS	0.09 (0.03, 0.30)
Told other people you have HIV	0.13 (0.02, 0.70)
Someone at the testing facility helped you set up an appointment for HIV care	0.04 (0.01, 0.14)
Didn't want to think about being HIV-positive	3.57 (1.22, 10.46)

populations who had engaged in care, is a real-world adaptation that allowed for enriching the study with a comparison group. Despite the fact that California Bridge Workers are highly skilled in HIV outreach and are well known and respected in their communities, it was a difficult and labor-intensive task to identify persons who are not engaged in care, among whom many were newly diagnosed and could be in denial about their HIV, and build the trust necessary to secure their participation in research. Concerns about HIV treatment and limited medical coverage also played a role in care avoidance behavior. The effort needed to locate individuals who have not accessed care speaks to the need to understand the characteristics of persons at highest risk for delaying HIV care initiation and develop effective interventions to work closely with these populations to engage them into services. ARTAS has demonstrated success in linking some subgroups (e.g., Latinos, unstably housed) to HIV care using a "strength-based" approach to case management that emphasizes the new positive's internal strengths and development of a personal plan to engage into care,³⁵ however, not all groups benefited significantly from this intervention.³⁶

At the individual level, our study suggests considerable isolation and denial among HIV-positive persons who have never engaged in care, especially among younger persons. Less than one half knew someone with HIV/AIDS. A majority had not told even one person that they were HIV positive (despite a median diagnosis time of almost 1 year) and cited not wanting to think about being HIV positive as a barrier to initiating care. All three of these factors were independently associated with not initiating care. Denial has been identified as a barrier to seeking treatment for HIV in prior studies, particularly when the disease is asymptomatic.^{11,37,38} HIV-positive persons in denial about their disease may decide not to tell other people about their infection. Others may be very selective regarding whom they tell about their HIV infection because of fear of discrimination and stigma.¹¹ However, not telling anyone about one's HIV-positive status precludes the possibility of social support, lack of which is associated with delays in HIV care.^{9,11,13,38} Our study underscores the pervasive nature of HIV-related stigma among persons who have not accessed HIV care. Mitigating this stigma constitutes an integral component of interventions designed to facilitate timely HIV care initiation.

With regard to structural factors, we found that persons who lacked medical insurance and/or did not receive assis-

tance in setting up an appointment for HIV care at the time of their diagnosis were significantly less likely to have engaged in HIV care. Prior studies have demonstrated an association between not having insurance or being underinsured and delaying entry into HIV medical care.^{10,11,14,18,38–40} The underlying reasons why HIV-positive patients are not accessing Medicaid (in California known as Medi-Cal), Ryan White-funded clinics, or other public clinics or coverage mechanisms (e.g., AIDS Drug Assistance Program [ADAP]) need to be determined. Although these services were available in the regions where study participants were interviewed, there may be factors other than eligibility that are driving low utilization of available insurance programs or services designed for uninsured persons. For example, ADAP provides drug coverage but does not cover medical visits, which can present a structural barrier to HIV care. A majority of participants in our study who were never in care were either fully or partially employed, and less than one fifth had medical insurance. These individuals may perceive that they do not qualify for HIV care or medication coverage because they work, and among Latinos the perception may be that their immigration documentation status or type of visa makes them ineligible for services. Persons employed in informal sector work (e.g., landscaping, housekeeping, childcare, etc.) may also lack the proof of income needed to apply for certain types of public insurance. Poor understanding of the insurance or care coverage options that are available and difficulties navigating the enrollment process may also serve as a barrier for these populations, as may difficulties in getting time off work for medical appointments. Interventions that effectively address these barriers, both perceived and real, to help newly diagnosed persons gain the coverage they need are necessary components of efforts to ensure timely HIV care initiation.

Although a majority of participants in this study said someone at the testing facility talked to them about the importance of getting HIV care at the time of their first positive test, only one half said that someone at the facility helped them set up an appointment for HIV care. Those who did not get appointment assistance were significantly more likely to have never received care. The absence of direct linkages between the HIV diagnosis and care initiation has been documented in just a few other studies.^{9,11,19} Most recently, Bell et al.¹⁹ found that among a sample of hospitalized, HIV-positive crack cocaine users 40% did not report being helped into care since their HIV diagnosis, and these patients were significantly less likely to have ever been in HIV care than those who reported help getting into care. The CDC's HIV Prevention Strategic Plan has promoted the strengthening of linkages between diagnosis and care since 2001⁴¹ and funded the Never in Care Pilot Project²⁴ and ARTAS studies to address this issue. Our study, along with the study by Bell and colleagues,¹⁹ suggests that improvements in posttest linkages to care remain an area of needed improvement. Interestingly, we found very limited evidence of differences between study groups by testing location, which is different from other studies. For example, Hsu and colleagues found that having been tested at a public counseling and testing site was associated with delayed engagement into care.¹⁷ Mimiaga and colleagues found that not having a recent HIV test was associated with lack of prior testing at a community clinic, STD clinic or jail, which illustrates potential contextual factors that may influence testing behaviors.⁴² Future studies should

characterize in greater detail the circumstances surrounding decision making regarding selection of testing venues and their implications for care engagement.

Our findings that study participants who had never initiated HIV care were significantly younger than those currently in care are similar to study findings by Hsu and colleagues.¹⁷ In our earlier work with HIV-positive Latinos in the U.S.–Mexico border region, younger age was also independently associated with increased barriers to care.⁴³ The extent to which younger persons encounter different or more intense barriers to HIV care than their older counterparts remains to be determined. Given that circumstances surrounding care access and positive coping may be different for younger populations, our findings can also inform future interventions that can identify age at diagnosis as a risk factor for delayed care entry and improve efforts to engage recently diagnosed young people into care. A recent study that used college and community-based social marketing and media to promote youth testing and engagement and retention of HIV-positive youths in care shows great promise, and the study authors recommend that use of mobile phone and internet-based interventions should next be considered for this population.⁴⁴

Shorter time since diagnosis was also significantly associated with not being in care in our study and with encountering barriers to care in the aforementioned study of HIV-positive Latinos. This suggests that barriers to care and their relative impact may differ as time progresses from diagnosis and that post-counseling messages may need to be tailored to client characteristics, like age. The latter modification may pose challenges for agencies with limited resources. This suggests a temporal nature to HIV care barriers, wherein those encountered shortly after the diagnosis may be more influential than those encountered as time since diagnosis increases.

Finally, although knowledge, attitudes, and beliefs regarding HIV care did not retain significance in our final model, our univariate findings regarding these variables warrant careful consideration. A substantial proportion of our “never in care” participants agreed with statements that suggest they lack faith in antiretroviral therapies and HIV care providers and may be misinformed regarding the appropriate use and effectiveness of HIV treatment. Furthermore, they were significantly more likely to agree with these statements than participants who were in care. The majority of our study participants were persons of color, and recent research has documented that cultural differences between patients and HIV care providers may affect patient trust in providers.⁴⁵ Our findings add to this literature, suggesting that any interventions to improve HIV care initiation among persons of color must include efforts to reduce mistrust and misconceptions regarding HIV treatment.

Because this study was cross-sectional and we primarily targeted persons never in care for enrollment, the study does not accurately represent the incidence or prevalence of never initiating HIV care among HIV-positive persons. The cross-sectional nature of the study also limited our ability to understand the temporal nature of factors that impede HIV care and determine whether study participants eventually engaged in care. Limitations in our ability to obtain HIV clinical data for study participants resulted in the need to rely on self-reported HIV care history and we did not have information on co-morbid health conditions that might contribute to delays in care (e.g., diagnosed mental health disorder). Bridge Workers

did not have access to testing information to follow up on clients who never presented for care and we did not have a practical means of verifying self-report in regions outside the Bridge Study geographic regions. However, to the extent we are able to surmise, the likelihood of self-report validity is supported by the following: (1) the Bridge Worker was familiar with local clinic populations who were and were not engaged into care by virtue of their primary work objective to work with clinics to engage persons into care and (2) the trusting relationship that was developed over time with community members who, in many cases after numerous contacts, agreed to be interviewed and were willing to respond to other sensitive questions. Finally, since the Bridge Project focuses on outreach efforts to HIV-positive persons of color, our study population may not be representative of the entire population of HIV-positive persons in California not currently engaged in care. Locating a representative sample of HIV-positive persons who have never engaged in care will require improved tracking and follow up with persons who have tested positive for HIV. Furthermore, individuals who seek care outside of the geographic location where they were tested, especially those who may seek care outside the United States, would not be easily accounted for. Lastly, because of the limited size and uneven distribution of our sample across recruitment sites, we were unable to control for any differences by site in our final model. While we were able to determine through sensitivity analysis that the findings were not unduly influenced by any particular site, our findings should not be construed as representative of barriers in any particular California county.

This study provides important insights into a population of HIV-positive individuals on whom little data has been previously published. Our findings have implications for efforts to “seek, test, and treat”⁴⁶ HIV-positive persons, improve their timely entry into HIV care, and reduce the HIV transmission, morbidity and mortality associated with delayed care.

Acknowledgments

This study would not have been possible without the dedication and support of Bridge Project workers and study participants. The authors gratefully acknowledge the leadership of Dr. Fred Molitor and Dr. Qiang Xia, whose contributions also made this study possible. The authors also extend their thanks to Karen E. Mark, M.D., M.P.H., and Mark Damesyn, Dr.P.H. who provided feedback and helpful commentary on the manuscript.

The study was funded by the California Department of Public Health; work was supported in part by the National Institute of Mental Health (Grant #s: NIH K01 MH072353-05; NIH R21MH084266-01); NCCAM (Grant #: R21 AT004676-01A1), and the UC San Diego Comprehensive Research Center in Health Disparities (NCMHHD: Grant # 5 P60 MD 000220). Dr. Pollini is funded by a K01 grant from the National Institute on Drug Abuse (K01DA022923) and by the National Center on Minority Health and Health Disparities' Loan Repayment Program.

The contents of this paper are solely the responsibility of the authors and do not represent the opinions or policies of the California Department of Public Health or the National Institutes of Health.

Author Disclosure Statement

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

References

1. Oramasionwu CU, Brown CM, Ryan L, Lawson KA, Hunter JM, Frei CR. HIV/AIDS disparities: The mounting epidemic plaguing US blacks. *J Natl Med Assoc* 2009;101:1196–1204.
2. Egger M, May M, Chêne G, et al. ART Cohort Collaboration. Prognosis of HIV-1-infected patients starting highly active antiretroviral therapy: A collaborative analysis of prospective studies. *Lancet* 2002;360:119–129.
3. Hogg RS, Yip B, Chan KJ, et al. Rates of disease progression by baseline CD4 cell count and viral load after initiating triple-drug therapy. *JAMA* 2001;286:2568–77.
4. Quinn TC, Wawer MJ, Sewankambo N, et al. Viral load and heterosexual transmission of human immunodeficiency virus type 1. Rakai Project Study Group. *N Engl J Med* 2000;342:921–929.
5. Tovanabutra S, Robison V, Wongtrakul J, et al. Male viral load and heterosexual transmission of HIV-1 subtype E in northern Thailand. *J Acquir Immune Defic Syndr* 2002;29:275–283.
6. Montaner JS, Lima VD, Barrios R, et al. Association of highly active antiretroviral therapy coverage, population viral load, and yearly new HIV diagnoses in British Columbia, Canada: A population-based study. *Lancet* (in press).
7. Hamlyn E, Jones V, Porter K, Fidler S. Antiretroviral treatment of primary HIV infection to reduce onward transmission. *Curr Opin HIV AIDS* 2010;5:283–290.
8. Mugavero MJ. Improving engagement in HIV care: What can we do? *Top HIV Med* 2008;16:156–161.
9. Samet JH, Freedberg KA, Stein MD, et al. Trillion virion delay: Time from testing positive for HIV to presentation for primary care. *Arch Intern Med* 1998;158:734–740.
10. Krawczyk CS, Funkhouser E, Kilby JM, Vermund SH. Delayed access to HIV diagnosis and care: Special concerns for the Southern United States. *AIDS Care* 2006;18(Suppl 1):S35–44.
11. 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* 2000;160:2614–2622.
12. Krawczyk CS, Funkhouser E, Kilby JM, Kaslow RA, Bey AK, Vermund SH. Factors associated with delayed initiation of HIV medical care among infected persons attending a southern HIV/AIDS clinic. *South Med J* 2006;99:472–481.
13. McCoy SI, Strauss RP, MacDonald PD, Leone PA, Eron JJ, Miller WC. Social support and delays seeking care after HIV diagnosis, North Carolina, 2000–2006. *AIDS Care* 2009;21:1148–1156.
14. Milberg J, Sharma R, Scott F, Conviser R, Marconi K, Parham D. Factors associated with delays in accessing HIV primary care in rural Arkansas. *AIDS Patient Care STDs* 2001;15:527–532.
15. Bamford LP, Ehrenkranz PD, Eberhart MG, Shpaner M, Brady KA. Factors associated with delayed entry into primary HIV medical care after HIV diagnosis. *AIDS* 2010;24:928–930.
16. Zetola NM, Bernstein K, Ahrens K, et al. Using surveillance data to monitor entry into care of newly diagnosed HIV-infected persons: San Francisco, 2006–2007. *BMC Public Health* 2009;9:17.
17. Hsu LC, Chen M, Kali J, Pipkin S, Scheer S, Schwarcz S. Assessing receipt of medical care and disparity among persons with HIV/AIDS in San Francisco, 2006–2007. *AIDS Care* 2011;23:383–392.
18. Reed JB, Hanson D, McNaghten AD, et al. HIV testing factors associated with delayed entry into HIV medical care among HIV-infected persons from eighteen states, United States, 2000–2004. *AIDS Patient Care STDs* 2009;23:765–773.
19. Bell C, Metsch LR, Vogenthaler N, et al. Never in care: characteristics of HIV-infected crack cocaine users in 2 US cities who have never been to outpatient HIV care. *J Acquir Immune Defic Syndr* 2010;54:376–380.
20. Coquet I, Pavié J, Palmer P, et al. Survival trends in critically ill HIV-infected patients in the highly active antiretroviral therapy era. *Crit Care* 2010;14:R107.
21. Garland JM, Andrade AS, Page KR. Unique aspects of the care of HIV-positive Latino patients living in the United States. *Curr HIV/AIDS Rep* 2010;7:107–116.
22. Rodwell TC, Barnes RF, Moore M, et al. HIV-tuberculosis coinfection in Southern California: evaluating disparities in disease burden. *Am J Public Health* 2010;100:S178–S185.
23. Page LC, Goldbaum G, Kent JB, Buskin SE. Access to regular HIV care and disease progression among black African immigrants. *J Natl Med Assoc* 2009;101:1230–1236.
24. Fagan JL, Bertolli J, McNaghten AD. Understanding people who have never received HIV medical care: A population-based approach. *Public Health Rep* 2010;125:520–527.
25. Kilmarx PH, Hamers FF, Peterman TA. Living with HIV. Experiences and perspectives of HIV-infected sexually transmitted disease clinic patients after post-test counseling. *Sex Transm Dis* 1998;25:28–37.
26. Centers for Disease Control and Prevention. HIV prevalence estimates—United States, 2006. *MMWR* 2008;57:1073–1076.
27. Centers for Disease Control and Prevention. Late versus early testing of HIV—16 sites, United States, 2000–2003. *MMWR* 2003;52:581–586.
28. Wohl AR, Tejero J, Frye DM. Factors associated with late HIV testing for Latinos diagnosed with AIDS in Los Angeles. *AIDS Care* 2009;21:1203–1210.
29. Molitor F, Kuenneth C, Waltermeyer J, et al. Linking HIV-infected persons of color and injection drug users to HIV medical and other services: The California Bridge Project. *AIDS Patient Care STDs* 2005;19:406–412.
30. Gardner L, Metsch L, Mahoney P, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS* 2005;19:423–431.
31. Aday LA, Andersen R. A framework for the study of access to medical care. *Health Serv Res* 1974;9:208–220.
32. Andersen RM. Revisiting the behavioral model and access to medical care: Does it matter? *J Health and Soc Behav* 1995;36:1–10.
33. Phillips KA, Morrison KR, Andersen R, Aday LA. Understanding the context of healthcare utilization: Assessing environmental and provider-related variables in the behavioral model of utilization. *Health Serv Res* 1998;33(3 Pt 1):571–596.
34. StataCorp. Stata Statistical Software: Release 11. College Station, TX: StataCorp LP, 2009.
35. Craw JA, Gardner LI, Marks G, et al. Brief strengths-based case management promotes entry into HIV medical care: Results of the antiretroviral treatment access study-II. *J Acquir Immune Defic Syndr* 2008;47:597–606.
36. Gardner LI, Marks G, Craw J, et al. Demographic, psychological, and behavioral modifiers of the Antiretroviral

- Treatment Access Study (ARTAS) intervention. *AIDS Patient Care STDs* 2009;23:735–742.
37. Siegel K, Schrimshaw EW, Dean L. Symptom interpretation: Implications for delay in HIV testing and care among HIV-infected late middle-aged and older adults. *AIDS Care* 1999;11:525–535.
 38. Raveis VH, Siegel K, Gorey E. Factors associated with HIV-infected women's delay in seeking medical care. *AIDS Care* 1998;10:549–562.
 39. Stein MD, Crystal S, Cunningham WE, et al. Delays in seeking HIV care due to competing caregiver responsibilities. *Am J Public Health* 2000;90:1138–1140.
 40. Anthony MN, Gardner L, Marks G, et al. Factors associated with use of HIV primary care among persons recently diagnosed with HIV: Examination of variables from the behavioral model of health-care utilization. *AIDS Care* 2007;19:195–202.
 41. Centers for Disease Control and Prevention. HIV surveillance report, 2007. Vol. 19. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2009;1-63. www.cdc.gov/hiv/topics/surveillance/resources/reports/ (Last accessed August 6, 2010).
 42. Mimiaga MJ, Reisner SL, Bland S, et al. Health system and personal barriers resulting in decreased utilization of HIV and STD testing services among at-risk black men who have sex with men in Massachusetts. *AIDS Patient Care STDs* 2009;23:825–835.
 43. Zúñiga ML, Brennan J, Scolari R, Strathdee SA. Barriers to HIV care in the context of cross-border health care utilization among HIV-positive persons living in the California/Baja California US-Mexico border region. *J Immigr Minor Health* 2008;10:219–227.
 44. Hightow-Weidman LB, Smith JC, Valera E, Matthews DD, Lyons P. Keeping them in "STYLE": Finding, linking, and retaining young HIV-positive Black and Latino men who have sex with men in care. *AIDS Patient Care STDs* 2011;25:37–45.
 45. Saha S, Sanders DS, Korthuis PH, et al. The Role of cultural distance between patient and provider in explaining racial/ethnic disparities in HIV care. *Patient Educ Couns* (in press).
 46. Cohen J. Treatment as prevention. *Science* 2010;327:1196–1197.

Address correspondence to:

María Luisa Zúñiga, Ph.D.

Department of Medicine

Division of Global Public Health and Department of Pediatrics

Division of Child Development and Community Health

University of California, San Diego,

La Jolla, CA 92093-0927

E-mail: mzuniga@ucsd.edu