

# Delayed Medical Care After Diagnosis in a US National Probability Sample of Persons Infected With Human Immunodeficiency Virus

Barbara J. Turner, MD, MEd; William E. Cunningham, MD, MPH; Naihua Duan, PhD; Ronald M. Andersen, PhD; Martin F. Shapiro, MD, PhD; Sam A. Bozzette, MD, PhD; Terry Nakazono, MA; Sally Morton, PhD; Steven Crystal, PhD; Patti St Clair, BS; Michael Stein, MD; Sally Zierler, DrPH, MEd; for the HIV Cost and Services Utilization Study (HCSUS) Access Research Team Members

**Objective:** To identify health care and patient factors associated with delayed initial medical care for human immunodeficiency virus (HIV) infection.

**Design:** Survey of a national probability sample of persons with HIV in care.

**Setting:** Medical practices in the contiguous United States.

**Patients:** Cohort A (N=1540) was diagnosed by February 1993 and was in care within 3 years; cohort B (N=1960) was diagnosed by February 1995 and was in care within 1 year of diagnosis.

**Main Outcome Measure:** More than 3- or 6-month delay.

**Results:** Delay of more than 3 months occurred for 29% of cohort A (median, 1 year) and 17% of cohort B. Having a usual source of care at diagnosis reduced delay, with

adjusted odds ratios (ORs) of 0.61 (95% confidence interval [CI], 0.48-0.77) in cohort A and 0.70 (95% CI, 0.50-0.99) in cohort B. Medicaid coverage at diagnosis showed lower adjusted ORs of delay compared with private insurance (cohort A: adjusted OR, 0.52; 95% CI, 0.30-0.92; cohort B: adjusted OR, 0.48; 95% CI, 0.27-0.85). Compared with whites, Latinos had 53% and 95% higher adjusted ORs of delay ( $P<.05$ ) in cohorts A and B, respectively, and African Americans had a higher adjusted OR in cohort A (1.56; 95% CI, 1.19-2.04). The health care factors showed similar effects on delay of greater than 6 months.

**Conclusions:** Medicaid insurance and a usual source of care were protective against delay after HIV diagnosis. After full adjustment, delay was still greater for Latinos and, to a lesser extent, African Americans compared with whites.

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**D**ELAYED MEDICAL care after the first seropositive test for human immunodeficiency virus (HIV) prevents patients from receiving medical therapies that may preserve the immune system and reduce the risk of serious disease-related complications. Unfortunately, delays of several months or longer between the diagnosis of HIV infection and first medical care for HIV may be common.<sup>1-3</sup> However, our understanding of this problem comes from analyses of convenience samples of patients that do not offer a national view of patient and health care factors related to delay.

To conduct such a broad-based analysis, we examined responses from interviews of a nationally representative sample of HIV-infected persons in care. Patient and

health care factors were assessed in relation to a delay of more than 3 months between diagnosis and first care, an interval used in other investigations of this problem.<sup>1-4</sup> In 1 of these studies, persons who met this definition of delay averaged more than 1 year between diagnosis and treatment.<sup>4</sup> We also explored predictors of even longer delay, more than 6 months between diagnosis and first HIV care, because it could identify factors associated with more substantial estrangement from the health care system.

We concentrated particularly on identifying potentially remediable factors related to delay in care. We hypothesized that being uninsured would be associated with delay, as it presents a powerful barrier to receiving medical care.<sup>5-7</sup> We also expected that persons who lacked a usual source of medical care at the time of HIV

*The affiliations of the authors appear in the acknowledgment section at the end of the article. A complete list of the HCSUS Access Research Team Members appears at the end of this article.*

## SUBJECTS AND METHODS

### DATA

The baseline survey of the HIV Cost and Services Utilization Study (HCSUS) served as the data source for this analysis. The HCSUS cohort is a nationally representative probability sample of HIV-infected adults receiving care in the contiguous United States. For practical reasons, the reference population was limited to persons at least 18 years old with known HIV infection who made at least 1 visit for regular or ongoing care to a nonmilitary, nonprison medical provider other than an emergency department during a specified "population definition period." This period was January 5 to February 29, 1996, in all but 1 sampled geographical area, where the start was delayed until March 1. Full details of the design are available elsewhere.<sup>11,12</sup>

The HCSUS used a multistage design in which geographical areas, medical providers, and patients were sampled. In the first stage, we sampled with certainty the 8 metropolitan statistical areas with the largest caseloads of acquired immunodeficiency syndrome. We also sampled an additional 20 metropolitan statistical areas and 24 clusters of rural counties.<sup>13</sup> In the second stage, we took a stratified sample of medical providers from the geographical locales sampled in the first stage. In the first stratum, we sampled 58 urban and 28 rural "known providers" from lists of all providers known by local informants to provide HIV care. In the second stratum, we randomly sampled approximately 4000 physicians from the American Medical Association's Physician Masterfile; after screening for only providers delivering HIV care and excluding HIV providers already in the "known provider" stratum, this sample yielded 87 urban and 23 rural "other providers." In the third stage, we sampled from anonymous lists of all eligible patients who saw study providers during the population definition period. Where possible, we removed duplicate names across lists to minimize the possibility of persons appearing on more than 1 list. We set the sampling probabilities in the first and second stages to be proportional to the size (caseload) for each sampling unit. For the third stage, we stratified the sample by sex and staff-model health maintenance organization. The overall sampling probability was doubled for women and increased again for members of staff-model health maintenance organizations.

The HCSUS enrolled 57 of 58 urban known providers and replaced the sole refusal with a similar institution in the same city (98% to 100% response rate). We enrolled 22 (79%) of 28 rural known providers, 61 (70%) of 87 urban other providers, and 19 (83%) of 23 rural other providers. In these latter strata, we handled provider nonresponse by weighting rather than by replacement. Of 4042 eligible participants sampled, we interviewed 76%, with 71% yielding long-form interviews (N=2864) and 5% yielding short-form or proxy interviews. For a further 16%, we obtained basic nonresponse data from providers. The overall coverage rate (ie, the ratio of the population directly

represented to the population that would have been represented if we had had complete responses at all levels) was 73% for all interviews and 68% for long-form interviews. This article used only the baseline long-form data, with adjustment for nonresponse by means of data described below.

The reciprocal of a respondent's sampling probability is his or her sampling weight, which adjusts for the differential sampling probabilities across population subgroups. We constructed nonresponse weights by using supplemental data (ie, short-form and proxy interviews, and nonresponse data) collected on nonrespondents. We used multiplicity weights to adjust for the fact that patients seeing several sampled providers had more than 1 opportunity to enter the sample. The product of these 3 weights formed the analytic weight for each respondent,<sup>14</sup> which is equivalent to an estimate of the number of persons represented by that respondent.

All interviews were conducted with computer-assisted personal interviewing instruments designed for this study.<sup>15</sup> Interviews began in January 1996 and ended 15 months later. Of long-form interviews, 91% were in person and the rest by telephone. We approached anonymously selected subjects for interview after providers or their agents obtained permission. The RAND and a local institutional review board reviewed all consent forms and informational materials. Whenever a local board was unavailable, selected providers signed single-project assurances or independent investigator agreements as appropriate.

The study population can be conceptualized as staircase rectangles (Duan-Shapiro-Turner rectangles; **Figure**) defined by the time since diagnosis of HIV and the year of diagnosis. The overall study population (N=2864) includes persons who sought care no later than the HCSUS population definition period (early 1996). In other words, the HCSUS sample is truncated and does not represent those who delayed care beyond early 1996. The extent of sample truncation varies with the year of diagnosis. For those diagnosed in January 1990, the truncation is likely negligible because only those who delayed care by more than 6 years are truncated from the HCSUS sample. For persons diagnosed in January 1995, the truncation is more severe because those who delayed care by more than 1 year are truncated. To avoid biasing our results toward observing less delay in persons diagnosed more recently, we restricted this analysis to 2 subsamples with comparable time at risk for delayed care. First, we used the subsample of persons diagnosed by February 1993 and in care within 3 years of diagnosis (cohort A, union of rectangles 1 and 2; n=1540). All individuals in this subsample received their first care for HIV within 3 years of diagnosis; we used this cohort to examine whether they initially received HIV care in the early part (the first 3 or 6 months) of this 3-year period. Second, we used the subsample of persons diagnosed by February 1995 and in care within 1 year of diagnosis (cohort B, union of rectangles 2

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diagnosis would be more likely to delay care. A usual source of care is perceived by patients as improving access to care<sup>8</sup> and may facilitate care for common symptoms to a greater extent than having insurance.<sup>9</sup> We also predicted that the site of HIV counseling and testing would be related to delay. Persons tested in anonymous testing

centers or who receive "routine" screening such as in blood donation centers, family planning clinics, or sexually transmitted disease clinics, or through postpartum screening, might not be referred to care or might not even learn, involuntarily or on purpose, about their test results.<sup>10</sup>

and 3; n=1960). All individuals in this subsample were in care within 1 year of diagnosis; we used this cohort to examine whether they first received care in the early portion (the first 3 or 6 months) of this 1-year period.

#### INTERVIEW DATA

The key outcome variable was defined from the following question: "After you got your first positive HIV test result, how long was it until you got medical care for HIV—by which I mean more testing or an examination." Clinical status was assessed by responses to questions regarding the reason that the patient was tested (response option: "I was sick") and by the level of the first CD4 count.

Regarding health care delivery factors, we examined responses to a question about where the patient had his or her first positive HIV test result. Response options included a clinic or physician's office, an anonymous testing site, a jail or prison, a blood donation center, in the military or other place where routine testing is done, or some other place. A series of questions were asked regarding the usual source of care, defining this concept as "one place in particular, like a doctor's office or clinic, where you usually go for most of your medical treatment." The question on the usual source of care used in this analysis was: "At the time of your first positive test for HIV, did you have a usual source of medical care?" Insurance status at the time of the first positive HIV test result was derived from several variables concerning the date when specific types of insurance began. Regarding Medicaid coverage at diagnosis, we asked the date when a respondent was first enrolled in Medicaid and created a flag when this date preceded the first HIV diagnosis date. However, some persons might have been included in the Medicaid group but lost their eligibility by the time of HIV diagnosis. Information about other forms of insurance was less ambiguous about coverage at the time of HIV diagnosis because of a battery of specific questions about the periods of insurance coverage. Finally, subjects were asked 2 questions about trust in the medical provider: "How much do you trust your doctor or clinic to offer you high quality medical care?" and "How much do you trust your doctor or clinic to put your health above all other concerns?" The 5-point Likert response scale ranged from "completely" to "not at all."

These self-report data are subject to the usual limitations of such information, including inaccurate recall, omission of certain events, and invalid information. As noted above, 12% of the HCSUS sample could not recall their date of HIV diagnosis. Overall, we successfully obtained high-quality self-reported data. With the exception of the lowest CD4 cell count (4.9% missing) and income (3.6% missing), the rate of items missing was less than 3% for all variables.

#### ANALYSIS

The study dependent variables were (1) greater than a 3-month and (2) greater than a 6-month delay between the

patient's report of the date of his or her first positive HIV test result and the date of first medical care for HIV infection (cohort A only). Patient characteristics in this analysis were age, sex, racial-ethnic group, educational attainment, HIV exposure or risk group, highest annual income, and national region of residence. The answers to the 2 trust questions described above were averaged and, because of clustering at complete or high trust (ie, the highest level on the Likert scale for both questions) and nonlinear association with the outcomes, a dichotomous variable of high vs limited or no trust was created.

The first CD4 T-lymphocyte count was categorized into 4 groups for analysis (ie,  $<0.050 \times 10^9/L$ ,  $0.050-0.199 \times 10^9/L$ ,  $0.200-0.499 \times 10^9/L$ , and  $\geq 0.500 \times 10^9/L$ ) because imprecision on estimates obviated use of a continuous variable. For patients without a reported first CD4 count, we analyzed their lowest count. When more than 2 years intervened between HIV diagnosis and initial CD4 T-lymphocyte count, we assumed that the CD4 count would have declined because antiretroviral therapy was unlikely before immunologic status was monitored. Therefore, we estimated the "true" CD4 count at HIV diagnosis on the basis of the first reported CD4 count and the time interval between the first seropositive test and the first CD4 count. To place bounds on the estimate, we examined 3 assumptions about CD4 count decline over time consistent with estimates by Muñoz and colleagues<sup>16</sup> for persons not taking antiretroviral therapy: (1) none; (2) slow ( $0.020 \times 10^9$  cells/L per year); and (3) faster ( $0.080 \times 10^9$  cells/L per year). Patients without CD4 count data were considered to have missing values. Since the main effects were similar regardless of our assumptions about change in CD4 count, we report models that use the reported categories of CD4 count without accounting for decline.

As previously noted, our analysis incorporates analytic weights to estimate population prevalence variables. Because HCSUS uses a complex multistage sampling design involving stratification and clustering, analysis strata and primary sampling unit variables were used to estimate SEs. All reported analyses account for clustering. The SUDAAN (Research Triangle Institute, Research Triangle Park, NC) and STATA (STATA Corporation, College Station, Texas) statistical software packages use these variables to test and model samples collected by means of complex designs.<sup>14</sup> SUDAAN and STATA were used in our bivariate and multivariate analyses, respectively.

We examined bivariate associations of patient and health care delivery factors with the various delay outcomes in cohorts A and B. For these 2 groups, we constructed multivariate logistic regression models, using delay of more than 3 months as the dependent variable. Delay of more than 6 months as the dependent variable was examined only for cohort A because of the small proportion of persons in cohort B with this outcome.

We examined delay in persons diagnosed in the early years of the HIV epidemic as well as those diagnosed after the introduction of combination therapy for HIV but before the widespread use of highly active antiretroviral therapy. Health care delivery factors that have been strongly associated with timely receipt of care after HIV diagnosis

are likely to still have a powerful effect in an era of more aggressive antiretroviral therapy. This unique national survey offers an opportunity to identify key areas for policy-making efforts and future research to prevent serious human and economic consequences of delay in the initiation of care for HIV infection among infected persons.

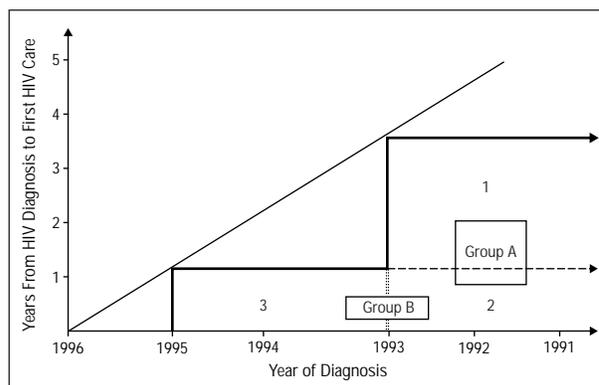
## RESULTS

Weighted samples in cohorts A and B represent 122 299 and 157 480, respectively, of the HIV-infected persons in care as of early 1996. **Table 1** shows the unweighted study sample numbers, while the proportions representing delay and *P* values are weight adjusted. Among those in cohort A, 29% had a delay of more than 3 months from their first seropositive HIV test result until their first HIV medical care, with a median delay of 1 year for this group. Those who delayed more than 6 months represented 21% of this cohort (not shown), with a median delay of 2 years. Only 17% of persons in cohort B delayed more than 3 months (Table 1), while 8.5% delayed more than 6 months (not shown). Because of the restrictions we placed on the maximum delay until receipt of care for these 2 groups (3 years for cohort A and 1 year for cohort B), these proportions are smaller than they would have been otherwise.

As Table 1 shows, 3 patient-related variables—highest annual income, sick when first tested for HIV, and year of first positive HIV test—showed significant differences in delay in both cohorts A and B. Persons who were not sick and those who tested positive for HIV in 1991 or earlier were more likely to have delayed care. The association with peak annual income was more complex, because those who earned \$25 000 to \$40 000 a year had a lower proportion delaying care than those with a higher peak annual income as well as those who earned less money. In cohort A, significant differences in delay appeared for additional patient factors, including age group, racial or ethnic group, and exposure or risk group. Specifically, persons aged 25 years or younger, Latinos and African Americans, and those with HIV exposure from intravenous drug use were more likely to report more than 3 months' delay in receiving care.

In both groups, all health care study variables had significant unadjusted associations with more than a 3-month delay. Persons without a usual source of care at the time of HIV diagnosis were much more likely to delay. The proportions of patients without a usual source of care and who did not have insurance at diagnosis were large, composing more than 50% and approximately 30%, respectively, of cohorts A and B (data not shown). A high level of trust in the medical provider was associated with a lower proportion with delay. Delay was more likely for persons who were tested in an anonymous testing center or a non-health care setting (ie, prison, the military, or a blood donation center). The highest proportions with delay were observed for persons who, at the time of HIV diagnosis, had Medicare or Veterans Affairs insurance, no insurance, or missing insurance information.

Bivariate analyses with more than a 6-month delay in cohort A (data not shown) disclosed similar directions of associations, but fewer factors significantly associated this outcome than in analyses of more than 3 months' delay. Significant associations with more than a 6-month delay appeared for age ( $P=.04$ ), HIV exposure ( $P=.02$ ), year of diagnosis ( $P=.003$ ), being sick at the time of HIV diagnosis ( $P=.003$ ), having a usual source of care at diagnosis ( $P=.003$ ), lowest CD4 count ( $P<.001$ ), and type of insurance at diagnosis ( $P=.02$ ).



Duan-Shapiro-Turner rectangles: study cohort definition. HIV indicates human immunodeficiency virus.

After adjustment in the multivariate logistic regression models, the only patient characteristics that remained significantly associated with more than a 3-month delay in both groups were racial or ethnic group, year of diagnosis, and being sick at the time of diagnosis (**Table 2**). Compared with whites, Latinos were significantly more likely to delay care. African Americans had significantly increased adjusted odds of delay than whites only in cohort A, but their adjusted odds in cohort B were still higher. In both cohorts, persons diagnosed in 1992 or 1993 had significantly decreased adjusted odds of delaying care compared with those diagnosed before 1992, but, in cohort B, there was no significant difference between persons diagnosed before 1992 and those diagnosed in 1994 or 1995.

Looking at the associations of health care delivery variables with more than a 3-month delay in HIV care, Medicaid insurance at HIV diagnosis was associated with approximately half the adjusted odds of delay compared with private insurance. No other type of insurance or lack thereof showed a similar significant protective effect. Independent of insurance, persons with a usual source of care when first testing positive for HIV had approximately 30% to 40% lower adjusted odds of delay in both cohorts. Individuals in cohort A who responded that they were tested in sites other than a hospital, an anonymous testing center, or a routine site such as the military had more than 30% lower adjusted odds of delay than persons tested in a physician's office or a clinic. The survey did not specify the location or setting of these sites. Of note, we did not find any interaction between having a usual source of care and the site of HIV testing.

In multivariate analyses using more than a 6-month delay as the outcome in cohort A, all study variables showed associations in similar directions to those in the model that used more than 3 months' delay as the dependent variable. However, fewer adjusted associations were significant ( $P<.05$ ): usual source of care (adjusted odds ratio [OR], 0.59; 95% confidence interval [CI], 0.45-0.77); year of diagnosis in 1992 or 1993 vs 1991 or earlier (adjusted OR, 0.51; 95% CI, 0.37-0.70); and sick when received a positive HIV test result (adjusted OR, 0.50; 95% CI, 0.33-0.76). The reduction in the odds of delay associated with Medicaid vs private insurance did not quite achieve statistical significance in this model (adjusted OR,

**Table 1. Unadjusted Associations of Patients and Health Care Factors With Greater Than 3 Months' Delay From HIV Diagnosis to First HIV Medical Care in Persons Diagnosed by March 1993 (Cohort A) and by March 1995 (Cohort B)\***

Characteristic	Cohort A		Cohort B	
	No. (%)	P	No. (%)	P
Total	1540 (29.0)		1960 (16.7)	
<b>Patient Factors</b>				
Age, y				
<25	254 (31.1)	.04	276 (19.3)	.14
25-34	734 (30.7)		897 (18.0)	
35-44	432 (27.9)		588 (16.00)	
>44	120 (16.0)		199 (10.0)	
Sex				
M	1123 (28.7)	.91	1378 (17.0)	.66
F	417 (28.3)		582 (15.7)	
Racial-ethnic group				
White	839 (26.2)	.05	998 (15.0)	.07
African American	453 (31.3)		620 (16.7)	
Latino	199 (33.7)		280 (23.4)	
Other	49 (26.8)		62 (14.3)	
Exposure or risk category				
Male-to-male sex	763 (27.4)	.03	928 (16.7)	.13
Intravenous drug use	413 (35.8)		465 (21.2)	
Heterosexual	250 (23.9)		374 (12.1)	
Other	114 (19.4)		193 (13.3)	
Educational attainment				
No high school degree	356 (29.5)	0.12	471 (18.2)	.07
High school degree	671 (31.0)		881 (18.0)	
Associate degree	118 (23.0)		224 (11.0)	
College degree	223 (28.1)		264 (15.4)	
Graduate or professional	102 (22.5)		120 (15.0)	
Highest income, \$/y				
0-<10 000	142 (32.2)	.02	344 (21.3)	<.001
10 000-<25 000	353 (32.8)		206 (20.6)	
25 000-<40 000	324 (24.6)		464 (11.4)	
≥40 000	459 (27.8)		396 (16.6)	
Missing	262 (28.2)		550 (15.5)	
Region				
Northeast	369 (30.7)	.75	489 (15.6)	.51
Midwest	174 (27.0)		224 (13.4)	
South	444 (27.7)		592 (16.5)	
West	553 (28.6)		655 (19.1)	
Year of first positive HIV test result				
1991 or earlier	1217 (30.6)	.004	1041 (19.0)	.02
1992-1993	323 (20.9)		550 (14.4)	
1994-February 1995	NA		369 (13.7)	
Initial CD4 T-lymphocyte count ×10 <sup>9</sup> /L				
<0.050	93 (22.4)	.09	157 (7.8)	.02
0.050-0.199	172 (28.8)		255 (14.5)	
0.200-0.499	494 (27.3)		656 (18.3)	
≥0.500	726 (31.2)		807 (19.3)	
CD4 count missing	55 (22.2)		85 (7.8)	
Tested when sick				
Yes	377 (20.7)	.005	575 (11.2)	.002
No	1161 (31.2)		1385 (19.1)	
<b>Health Care Factors</b>				
Usual source of medical care when first diagnosed HIV positive				
Yes	709 (22.9)	.001	907 (13.5)	.007
No	829 (33.2)		1050 (19.2)	
Trust in medical provider				
High	695 (25.8)	.02	907 (14.7)	.04
Limited or none	845 (31.3)		1050 (18.6)	
Site of HIV test				
Clinic or physician's office	713 (27.1)	.006	947 (15.5)	.002
Hospital	345 (26.2)		437 (13.7)	
Anonymous	271 (32.6)		303 (20.0)	
Non-health care setting	131 (39.5)		169 (26.7)	
Other place	79 (21.6)		103 (12.6)	
Insurance at time of HIV-positive diagnosis				
Private or CHAMPUS	641 (24.9)	.03	773 (14.0)	<.001
Medicaid	221 (19.0)		325 (9.3)	
Medicare or VA	48 (33.5)		76 (20.6)	
None	459 (36.7)		612 (22.2)	
Missing	171 (32.0)		174 (21.2)	

\*Weighted proportions and P values are given. Cohort A was diagnosed as having human immunodeficiency virus (HIV) infection before February 1993 and was in care within 3 years. Cohort B was diagnosed as having HIV infection before February 1995 and was in care within 1 year. NA indicates not applicable; CHAMPUS, Civilian Health and Medical Program of the Uniformed Services; and VA, Veterans Affairs.

**Table 2. Adjusted Odds of Delay Greater Than 3 Months From HIV Diagnosis to First HIV Medical Care in Persons Diagnosed by March 1993 (Cohort A) and by March 1995 (Cohort B)\***

Characteristic	Cohort A		Cohort B	
	Adjusted OR	95% CI	Adjusted OR	95% CI
<b>Patient Factors</b>				
Age at HIV diagnosis	0.99	0.97-1.00	0.99	0.97-1.01
Male sex	0.98	0.56-1.72	0.92	0.52-1.64
Racial-ethnic group				
African American	1.56†	1.19-2.03	1.32	0.96-1.80
Latino	1.53‡	1.09-2.15	1.95§	1.33-2.86
Other	1.00	0.55-1.81	1.26	0.70-2.26
HIV exposure category				
Intravenous drug user	1.37	0.90-2.08	1.30	0.82-2.05
Heterosexual	0.80	0.47-1.34	0.68	0.43-1.08
Other	0.73	0.32-1.69	0.91	0.39-2.12
Educational attainment				
No high school degree	1.13	0.63-2.00	1.28	0.74-2.22
High school degree	1.26	0.68-2.35	1.28	0.74-2.21
Associate degree	0.86	0.37-1.99	0.71	0.34-1.52
College degree	1.30	0.68-2.49	1.11	0.63-1.94
Highest income, \$/y				
0-<10 000	1.10	0.57-2.12	1.20	0.63-2.26
10 000-<25 000	1.12	0.61-2.08	1.15	0.70-1.91
25 000-<40 000	0.74	0.52-1.06	0.58†	0.40-0.84
Missing	0.83	0.50-1.39	0.76	0.42-1.36
Geographic region				
West	1.03	0.61-1.78	1.01	0.63-1.62
Midwest	0.85	0.61-1.19	1.04	0.67-1.61
South	0.95	0.65-1.37	1.20	0.76-1.90
Diagnosis in 1992-1993	0.58§	0.44-0.76	0.72†	0.56-0.92
Diagnosis in 1994-1995	NA	NA	0.83	0.61-1.14
Initial CD4 T-lymphocyte count, ×10 <sup>9</sup> /L				
<0.050	0.60	0.20-1.75	0.47	0.18-1.17
0.050-0.199	0.75	0.46-1.23	0.60‡	0.39-0.94
0.200-0.499	0.82	0.58-1.15	0.97	0.72-1.31
Missing	0.60	0.29-1.22	0.30‡	0.10-0.87
Tested when sick	0.55‡	0.34-0.89	0.61‡	0.41-0.91
<b>Health Care Factors</b>				
Insurance at time of HIV diagnosis				
No insurance	1.30	0.78-2.16	1.28	0.84-1.93
Medicaid	0.52‡	0.30-0.92	0.48†	0.27-0.85
Medicare or VA	1.33	0.59-3.02	1.47	0.65-3.32
Missing	1.29	0.71-2.24	1.42	0.76-2.64
Usual source of medical care at time of HIV diagnosis	0.60§	0.47-0.77	0.70‡	0.50-0.99
High trust in medical provider	0.78‡	0.62-0.99	0.83	0.64-1.08
Site of HIV test				
Hospital	1.03	0.69-1.52	1.00	0.63-1.59
Anonymous testing center	1.25	0.97-1.61	1.17	0.81-1.68
Nonmedical setting	1.13	0.57-2.20	1.33	0.89-1.99
Other	0.62‡	0.39-0.99	0.69	0.40-1.17

\*Reference groups were as follows: female sex, white, male-to-male sex exposure category, graduate or professional degree, highest income \$40 000 or more, northeastern geographic region, diagnosis before 1992, initial CD4 T-lymphocyte count  $\geq 0.500 \times 10^9/L$ , not sick when tested, private insurance at time of human immunodeficiency virus (HIV) diagnosis, no usual source of care at HIV diagnosis, limited or no trust in medical provider, site of HIV testing in physician's office or clinic. Cohort A excludes persons delaying care more than 3 years after HIV diagnosis, and cohort B excludes persons delaying care more than 1 year after HIV diagnosis. OR indicates odds ratio; CI, confidence interval; NA, not applicable; and VA, Veterans Affairs.

†P  $\leq .01$ .

‡P = .05.

§P = .001.

0.52; 95% CI, 0.26-1.04). Only in this longer delay model, a significantly lower likelihood of delay (P = .03) was associated with increasing age specified as a continuous variable (adjusted OR, 0.98; 95% CI, 0.96-1.00).

Because we were surprised to find that Medicaid was associated with a reduced likelihood of delayed care vs private insurance, we examined bivariate associations of

patient and health care characteristics only for persons in these 2 groups (not shown). In cohort A, the proportions of persons delaying more than 3 months did not differ for Medicaid compared with private insurance (P = .13), but in cohort B the difference was significant (P = .03). The unadjusted OR for Medicaid vs private insurance in cohort A was 0.71, whereas, after adjust-

ment, the OR was substantially lower (0.52); for cohort B, the unadjusted and adjusted ORs were 0.63 and 0.48, respectively. Thus, in both groups, adjustment increased the protective effect of Medicaid relative to private insurance. The Medicaid and privately insured groups differed significantly in dimensions that might have contributed to delay. For example, the Medicaid group was more likely to include persons of color and those with lower income levels; both factors were associated with greater delay in care. On the other hand, the privately insured group was more likely to have been diagnosed with HIV before 1992 when the likelihood of delay was greater. No significant differences appeared by the clinical or trust variables for these 2 groups, but, among health care variables, privately insured persons were more likely to have a usual source of care ( $P=.03$ ).

#### COMMENT

Our study population was drawn from HIV-infected persons who were already in care by 1996. We excluded from cohort A (diagnosed by February 1993) persons who had delayed more than 3 years and from cohort B (diagnosed by February 1995) those with more than a 1-year delay. Therefore, our analysis offers a conservative view of the problem of delay between HIV testing and receipt of medical care for HIV infection. Nonetheless, we still observed that substantial proportions of this national sample of HIV-infected persons delayed many months before receiving care for their disease. Nearly one third of cohort A allowed more than 3 months to elapse before receiving care for HIV. On the basis of our sample weights, we estimated that such a delay in care occurred for more than 35 000 persons (29%) of the 122 299 HIV-infected individuals represented by cohort A. In turn, cohort A constitutes 31.5% of the total HCSUS population. Had we not excluded persons with extremely long delays from our analysis to avoid bias due to unequal observation times for the HCSUS population, the rate and number of persons delaying care would have been even higher.

A minimum of 4 months' delay before receiving care may seem trivial, yet persons who delayed at least this long had a median of 1 year from diagnosis to first treatment. Furthermore, in many HIV-infected individuals, the delay in receiving care for HIV is preceded by a lengthy delay between HIV infection and diagnosis. The implications of such a delay are serious. The Centers for Disease Control and Prevention reported that approximately half of the individuals in a national study were diagnosed as having HIV infection within 1 year of developing clinical acquired immunodeficiency syndrome.<sup>17</sup> In our study, one quarter of the persons in both cohorts A and B reported that they were already sick when diagnosed as having HIV infection. Of concern, progression to serious acquired immunodeficiency syndrome—defining complications can occur in susceptible untreated individuals within only a few years after initial infection.<sup>18</sup> Furthermore, delays mean that vital opportunities are lost to educate infected individuals on ways to reduce the risk of transmission to others.

Another reason that the problem of delay was probably even worse than reported herein relates to the identification of the HCSUS population. Persons who died before HIV infection was diagnosed or shortly thereafter were not represented by the HCSUS sample because they were not in care during the HCSUS population definition period. For example, it is plausible that persons in cohort A who delayed care more than 3 months were more likely to die before 1996 than those who entered HIV care within 3 months after diagnosis. Therefore, our estimate for the prevalence rate for delayed care in cohort A is likely lower than the rate that would have been observed in a prospective study.

Despite these limitations resulting from the retrospective nature of our study, this analysis offers national data on a problem first described in analyses of samples of HIV-infected patients in specific practice settings or regions. Samet and colleagues<sup>2</sup> reported a delay of 1 year or more before treatment for 40% of 189 patients treated at 2 urban hospitals in New England. Ickovics and colleagues<sup>1</sup> found that more than half of 48 HIV-infected women delayed at least 3 months between HIV serodiagnosis and first medical care. Siegel et al<sup>4</sup> reported that 31% of a sample of HIV-infected women in New York City delayed care more than 3 months. Since these studies were performed, as well as after the time frame of our analysis, the management and prognosis of HIV infection have been transformed by powerful new classes of antiretroviral agents that reduce virus replication and rejuvenate the immune system.<sup>19,20</sup> It remains to be seen whether these powerful therapies will encourage individuals to accept HIV testing and to receive care more promptly after diagnosis of HIV infection. We found that the problem of delay improved somewhat in the early 1990s but did not continue to show improvement for persons diagnosed as having HIV infection in 1994 and 1995.

Several health care delivery factors associated with delayed care for HIV are still likely to be operative in the era of highly active antiretroviral therapy. First, having a usual source of care at the time of HIV diagnosis was associated with a 30% to 40% reduction in the adjusted odds of delay. Having a usual source of care has also been reported to reduce the risk of hospitalization and to promote receipt of antiretroviral therapy in HIV-infected populations.<sup>21,22</sup> This aspect of health care was seriously deficient in our sample, since less than half reported having a usual source of care around the time of HIV diagnosis. Second, we found that persons with Medicaid coverage at the time of HIV diagnosis were significantly less likely to delay seeking care than persons with private insurance. This surprising result reaffirms the vital safety net that the Medicaid program serves for the indigent and disabled.<sup>7</sup> Perhaps persons with private insurance were more fearful of the socioeconomic consequences of their HIV diagnosis or of losing their insurance coverage once they were diagnosed as having a chronic disease.

A high level of trust in the health care provider was independently associated with a lower likelihood of delay after HIV diagnosis, even though the provider at the time of first diagnosis might have differed. The questions that we used to assess trust were drawn from a mea-

sure that reported differences in trust of providers by persons in various fee-for-service arrangements.<sup>23</sup> In our study, insurance type was not associated with provider trust. However, this trust variable may capture a patient's general view of the quality of his or her relationship with health care providers. The quality of the relationship with a medical provider was cited by both HIV-infected women in New York City and homosexual or bisexual men in San Francisco, Calif, as affecting their willingness to receive care after HIV diagnosis<sup>4</sup> or to be tested for HIV.<sup>24</sup>

Contrary to another study suggesting that persons tested in anonymous centers had earlier receipt of medical care for HIV than persons tested confidentially,<sup>25</sup> we found no significant effect on delay of testing in an anonymous center vs a physician's office or clinic. Persons responding that they were tested in other sites were less likely to delay; this testing might have been conducted for research studies or other programs trying to link persons to care. Even after accounting for a myriad of health care delivery, demographic, and socioeconomic factors, Latinos and, to a lesser extent, African Americans were more likely to delay than whites. Both Latinos and African Americans have been reported to be diagnosed as having HIV at a more advanced stage of disease than whites.<sup>26</sup> Poorer linkage to health care services by persons of color, observed in studies of both HIV-infected and general populations,<sup>27-29</sup> likely contributes to the failure to receive timely care for HIV. Yet, other factors that we could not explore, such as language barriers and a lack of confidence in the value of treatment, may also have led to a delay in care. African Americans have been often observed to have lower adjusted odds of receiving antiretroviral therapy than whites,<sup>30,31</sup> perhaps reflecting skepticism about the benefits of antiretroviral therapy as well as access problems. Since rates of new infection are highest among persons of color,<sup>32</sup> clinicians and counselors must emphasize the importance and value of care for HIV infection when discussing HIV prevention, diagnosis, and treatment with these individuals.

It should be acknowledged that our data come from self-report. Our data are not generalizable to persons who cannot recall when they were diagnosed with HIV. In addition, individuals might not have accurately recalled the timing of their first HIV-related care when these events occurred years before the interview. Yet, important events in one's life, such as having a CD4 count or being diagnosed with a disabling condition such as HIV, appear to be largely accurately recalled.<sup>33,34</sup> The strength of this study lies in its national scope and exploration of diverse health care and patient factors in relation to the key concern of delayed care after HIV diagnosis. These data indicate that essential opportunities have been lost nationwide to arrest and reverse the effects of HIV and to educate infected individuals about ways to avoid transmitting the infection to others. Potential solutions include ensuring access to care through establishing Medicaid insurance or a usual source of care for persons with or at risk of HIV infection. Our study also raises a concern that needs further examination regarding delay in initiating care for HIV infection by persons with private insurance.

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Dr Bozzette is a Health Services Research and Development Senior Research Associate of the Department of Veterans Affairs. Dr Cunningham is a Doris Duke Charitable Foundation Clinical Scientist.

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Members of the HCSUS Access Research Team are as follows: Ronald M. Andersen, PhD, Chair, University of California Los Angeles (UCLA) School of Public Health, Los Angeles; William E. Cunningham, MD, MPH, Co-Chair, UCLA School of Public Health; Stephen Crystal, PhD, Rutgers University Institute for Health, New Brunswick, NJ; Kevin Heslin, MS, UCLA School of Public Health; Kiyoshi Kuromiya (deceased), Critical Path AIDS Project, Philadelphia, Pa; Sally C. Morton, PhD, RAND, Santa Monica, Calif; Terry Nakazono, MA, UCLA School of Public Health; Martin F. Shapiro, MD, PhD, UCLA School of Medicine, Los Angeles; Michael Stein, MD, Rhode Island Hospital, Providence; Barbara J. Turner, MD, MEd, University of Pennsylvania, Philadelphia; and Sally Zierler, DrPH, MEd, Brown University, Providence.

Corresponding author and reprints: Barbara J. Turner, MD, University of Pennsylvania, General Internal Medicine, 1119 Blockley Hall, 423 Guardian Dr, Philadelphia, PA 19104-6021 (e-mail: bturner@mail.med.upenn.edu).

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