Access to and Use of HIV Antiretroviral Therapy: Variation by Race/Ethnicity in Two Public Insurance Programs in the U.S.

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SYNOPSIS

Objectives. To examine access to and use of HIV highly active antiretroviral therapy (HAART) by race/ethnicity in Medicaid and the AIDS Drug Assistance Program (ADAP) in 1998 in four states.

Methods. The authors analyzed reimbursement claims and AIDS surveillance data in California, Florida, New York, and Texas. Study subjects were identified using diagnostic or medication codes specific to HIV. The race/ethnicity of program enrollees was compared to representation in the HIV epidemic to examine access. Claims for antiretroviral (ARV) use were compared to U.S. Public Health Service treatment guidelines to assess HAART use.

Results. The authors identified 151,000 HIV-infected individuals in these two programs in the four states. Evidence of AIDS or symptomatic HIV was present in 78%–88% of enrollees in Medicaid, versus 31%–48% in ADAP. African Americans participated in Medicaid 10%–53% above and in ADAP 17%–31% below representation in the epidemic. Non-Latino whites exhibited the opposite pattern, being in Medicaid 5%–38% below and in ADAP 9%–65% above epidemic representation. Latinos participated more in ADAP (7%–31%), except in New York. HAART use over 90 days (July-September) ranged from 38% to 76% by program and state. Differences by race/ethnicity were inconsistent and small: African Americans had lower HAART use by 6%–14% in California and Florida Medicaid, and Latinos had higher HAART use by 2%–11% in ADAP and in Texas Medicaid.

Conclusions. African Americans were more likely to access HIV drugs through Medicaid than through ADAP, which may reflect differences in program eligibility criteria as well as care seeking later in HIV disease. Differences in the use of HAART by race/ethnicity within state programs were small.

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In 1996, the high efficacy of combination antiretroviral therapy in preventing the progression of HIV disease was first confirmed and widely publicized. Over the next two years, clinical guidelines for the use of highly active anti-retroviral therapy (HAART) were developed and widely disseminated. Clinical practice changed quickly; by the middle of 1997, HAART use was reported in half to more than three-quarters of individuals with AIDS receiving regular health care.[1] The most influential guidelines, those of the Panel on Clinical Practices for the Treatment of HIV, recommended offering HAART to all individuals with symptomatic HIV infection and to asymptomatic individuals with CD4 cell counts less than 500 cells/mm[3] or viral loads of more than 10,000 HIV RNA copies/ml.[2]

African Americans and Latinos, who are disproportionately affected[3] by the HIV epidemic have had limited access to HIV-related health care services, including antiretroviral therapy.[3] HIV-infected non-whites are less likely to have outpatient visits and more likely to use emergency care than HIV-infected whites.[4–7] National data collected by the HIV Cost and Services Utilization Study (HCSUS) for 1996–1997 indicated that the odds ratios of not having received a protease inhibitor or non-nucleoside reverse transcriptase inhibitor by December 1996 were 2.16 for African Americans compared to non-Latino whites and 1.75 for Latinos compared to non-Latino whites.[8] Data from HCSUS for 1998 indicate that spending on medications was about one-third less for African Americans than for non-Latino whites.[9] A review of the literature on racial/ethnic differences in the use of antiretroviral medications (ARVs) identified 26 studies, of which 14 found non-whites less likely than whites to be using ARVs.[10]

African Americans and Latinos are more likely than whites to have public or no health insurance.[11] Medicaid is the largest health care payer for poor people living with AIDS.[12–16] Federal guidelines require state Medicaid programs to cover outpatient and inpatient hospital services, physician services, and laboratory and X-ray services for all enrollees. States may also offer coverage for prescription drugs, and restrictions on that coverage may vary. For individuals who do not qualify for Medicaid or who still lack adequate medication coverage, the AIDS Drug Assistance Program (ADAP), funded under the federal Ryan White Comprehensive AIDS Resource Emergency (CARE) Act, is an important source of supplemental coverage. Especially with a shift in standards of care toward earlier treatment with HAART, starting in 1997 ADAP became an increasingly important resource for HIV-infected individuals who did not meet Medicaid's financial or categorical (including immigration status) eligibility rules.

In 1999, reports from the state ADAP grantees indicated that African Americans may have been under-represented in ADAP (Unpublished data, Office of Science and Epidemiology, Health Resources and Services Administration). For example, African Americans represented only 28% of ADAP recipients nationally, versus 36% to 40% of recipients of other CARE Act–funded services. However, it is difficult to draw conclusions about access to pharmaceutical care from these data, most importantly because states differ in their publicly funded coverage of pharmaceuticals for HIV disease. In particular, if Medicaid benefits are generous, it may be unnecessary for individuals requiring pharmaceuticals to use ADAP. The responsiveness of ADAP to the needs of African Americans and Latinos has become an important policy and political issue in the Congressional appropriation process for the Ryan White CARE Act.

To further examine access to and use of publicly supported antiretroviral therapy by race/ethnicity, we conducted case studies using Medicaid and ADAP data from the four states with the largest AIDS populations. We conducted state case studies because national data may obscure the interaction between Medicaid and ADAP, both of which are governed largely by state rules. To evaluate access, we determined rates of enrollment by race/ethnicity in the two major public insurance programs covering HIV medications, Medicaid and ADAP, and compared these rates to racial/ethnic groups' representation in the HIV epidemic. To assess use of antiretrovirals, we explored the utilization of HAART among program enrollees. Companion articles from our project provide a comprehensive literature review,[10] describe patient and provider perceptions regarding programs and antiretroviral therapy,[17] and assess state and federal policy issues and implications.[18]

METHODS

We analyzed Medicaid and ADAP billing claims and AIDS surveillance data from four states: California, Florida, New York, and Texas. Our analysis included three major components: identification and description of study subjects, comparison of program participation patterns with the HIV epidemic to indicate access to ARVs, and analysis of HAART use among program participants.

Claims and surveillance data

We obtained ADAP and Medicaid electronic claims files for all four states for the 1998 calendar year. ADAP files included information only on billing for pharmaceuticals. The state ADAP formularies covered all FDA-approved antiretrovirals during 1998. Medicaid claims were for all covered services (including medications as well as inpatient and outpatient care) and reported International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnostic codes, Clinical Procedural Terminology (CPT) procedure codes, and National Drug Code (NDC) medication codes.

To broaden our search for evidence of HIV infection, we also obtained available data from the state Medicaid agencies for up to four years prior to 1998 for states other than Florida. The procedures used to extract working files of possibly HIV-infected individuals from the Medicaid datasets are available on request. To protect confidentiality, the data extractors created arbitrary and non-traceable personal identifiers for all datasets, except for the New York Medicaid dataset, which was analyzed at the New York State AIDS Institute. Multiple billing records for a service were unduplicated by the MIS groups responsible for maintaining the Medicaid billing data, using codes indicating that records represented updates of prior records; they forwarded to us only the final record in each series.

We obtained estimates of AIDS prevalence and of new AIDS diagnoses in 1998, by race/ethnicity, from the state health departments.

Identification and description of study sample

Our analyses were limited to data on HIV-infected individuals. All ADAP participants were eligible, since HIV infection is a prerequisite for program enrollment. For the Medicaid data, we identified HIV-infected individuals based on the presence of HIV-specific diagnoses (ICD-9-CM codes 042–044) and/or antiretrovirals (drug-specific NDC codes). In addition, we expanded the search as possible and consistent with existing state procedures for HIV-specific searches of claims data. Thus, we searched for codes for asymptomatic HIV infection and HIV opportunistic infections (e.g., pneumocystis pneumonia) in data for all states except California, for HIV-specific lab tests in Florida and Texas data, and for specific HIV clinical service billing codes in New York data. Final inclusion was based on state-specific algorithms that emphasized specificity, e.g., requiring more than one mention of HIV codes for data from states other than California. Details on the search algorithms are available on request.

Although HIV searches were not precisely comparable across states due to differences in data fields and coding practices, we applied the narrowest HIV selection algorithm (used for Florida and Texas data) to data from California, the state with the broadest selection algorithm, and found 88% overlap between the two resulting datasets, primarily due to the shared use of ICD-9-CM HIV diagnostic and NDC ARV codes. California enrollees not chosen by the narrow selection algorithm reflect predominantly single mentions of ARVs or other HIV codes, which may represent coding errors. Excluding these individuals would increase the snapshot estimate of ARV use by decreasing the denominator, likely by less than 12% because of the 90–day continuous participation requirement used for the "snapshot" measure of HAART use (see below).

We obtained demographic information from program eligibility files that included one record per participant. Race/ethnicity was recorded for 86% of individuals in the overall sample (range by state 77% to nearly 100%), and usually relied on self-classification or eligibility worker assessment. We determined disease stage (i.e., absence or presence of AIDS) for ADAP enrollees based on self- or physician report at the time of enrollment in ADAP. For Medicaid enrollees, we defined the presence of AIDS based on the appearance of diagnostic codes for conditions listed in the Centers for Disease Control and Prevention (CDC) AIDS surveillance criteria[3] (e.g., opportunistic infections) and/or NDC codes for drugs used only for these conditions. We examined codes for all available years, ending on October 1, 1998. We classified as having AIDS all individuals with ICD-9-CM code 042 (no decimals), which since 1994 has designated AIDS or symptomatic HIV, both of which are indications for HAART.

We used service claims data to define program participation patterns for both ADAP and Medicaid, since we did not have detailed enrollment records. We defined the period of participation as starting with the date of first service (for Medicaid including any medical services, for ADAP just prescriptions for any covered drugs), and as ending 30 days following the last prescription or other service, to account for likely ongoing program eligibility and the typical duration of prescriptions.

Access to ARVs: program participation

To assess racial/ethnic differences in program participation, we used as comparison two AIDS epidemiologic profiles. All states conduct AIDS surveillance following standard methods specified by the Centers for Disease Control and Prevention. The surveillance cat-

egory, "persons living with AIDS" (PLWA), is an indicator of the population of persons with later-stage disease. This was an appropriate comparison for Medicaid, based on the high AIDS percent we report below.

However, AIDS prevalence statistics do not reflect recent demographic changes among individuals in earlier stages of HIV disease, since many people living with AIDS who were represented in the Medicaid and ADAP data files were diagnosed with AIDS years previously. The ideal HIV surveillance definition for this purpose, meeting U.S. Public Health Service (PHS) guidelines for HAART, is not used. Surveillance systems to estimate the number of HIV-infected individuals are at different stages of implementation in these states, and were unavailable to us. One existing surveillance category, "New AIDS cases," is likely a better reflection than PLWA of the population of individuals in earlier stages of HIV disease who are often candidates for HAART. New AIDS cases arise largely from those with symptomatic HIV disease and with decreasing CD4 counts and rising viral loads, a population eligible for HAART. Thus, for comparison of racial/ethnic differences in earlier stages of HIV disease, we looked at new AIDS cases in 1998.

HAART use

For both Medicaid and ADAP, we included in this analysis all program participants for whom claims were filed, since we were unable to determine the subset for whom HAART might not be clinically recommended (i.e., those with CD4 >500 and viral load <10,000). We analyzed pharmacy claims using NDC codes for ARVs, abstracted from the MediSource Lexicon drug database on September 28, 1999. We used three methods to characterize ARV use:

The *snapshot* method describes the prevalence of ARV use by examining drug claims in the 90 days prior to October 1, 1998, for all individuals with evidence of program participation for the full three months, based on service use before and after that period. We defined HAART as outlined in the standards of care developed by the U.S. Public Health Service[2] as three or more ARVs, including at least two reverse transcriptase inhibitors (RTIs) and at least one protease inhibitor (PI), non-nucleoside reverse transcriptase inhibitor (NNRTI), or abacavir.

The *continuity of use* method describes ARV use and gaps for each individual's full program participation during the year. Continuous HAART is defined as ≥3 ARVs plus PI, NNRTI, or abacavir present continuously (no gaps of ≥60 days).

The *refills* method quantifies ARV medication days

vs. program participation days. We defined the number of ARV and PI/NNRTI/abacavir days as the number of prescriptions times 30, on the assumption that most prescriptions are written for 30 days. We defined the duration of program participation as the number of days from first to the last date of service, plus 30 days to allow for a typical interval between services. The ratio (medication days divided by program days) indicates the mean number of all or selected ARVs received during ADAP participation. The value for consistent HAART would be about 3.0 for all ARVs and ≥1.0 for PI/NNRTI/abacavir.

Statistical analysis

We present proportions and means, as appropriate to the outcomes. We do not report measures of statistical significance, for two reasons. First, inference to a broader population is not needed since we examined the full universe of ADAP participants and all those identified as HIV-infected in Medicaid claims files, not random subsets. Second, the sample sizes are quite large, so that for all univariate comparisons even very small differences would appear to be statistically significant.

We present only univariate comparisons by race/ethnicity for three reasons. First, for some analyses (e.g., representation in programs vs. in the epidemic), we did not have access to the data required for multivariate analyses. Second, clinical guidelines for ARV therapy do not differ by gender, and children represent a very small portion of clients in these programs. Finally, when we examined differences in ARV use by HIV disease severity, we found none.

RESULTS

Study sample

We identified a total of 154,196 HIV-infected individuals enrolled in the eight state programs (Table 1), unadjusted for potential overlap. Medicaid programs generally had larger numbers of enrollees (mean 25,597, maximum 51,617) than ADAP (mean 12,952, maximum 17,891). For both programs combined, New York had the largest number of enrollees (65,662) and Texas the lowest (14,284). Of the 86% (129,955) with known race/ethnicity, 39% were identified as African American, 34% as non-Latino white, and 26% as Latino. By state, 78% to 88% of Medicaid participants had evidence of AIDS or symptomatic HIV; 53% to 75% had definitive evidence of AIDS, and the remainder had evidence of AIDS or symptomatic HIV. Of ADAP enrollees, 31% to 48% had AIDS.

Table 1. HIV-positive individuals identified in Medicaid and ADAP data, by race/ethnicity, 1998

		California		Florida		New York		Texas	
Medicaid[a]	Total	24,688	—	20,343	—	51,617	—	5,741	—
	AIDS[b]	20,738	84%	17,902	88%	40,777	79%	4,478	78%
	Non-Latino white	10,222	41%	6,257	31%	5,960	12%	1,806	31%
	African-American	5,665	23%	10,005	49%	18,450	36%	2,652	46%
	Latino	2,795	11%	1,314	6%	14,819	29%	948	17%
	Other	989	4%	21	0%	318	1%	30	1%
	Unknown	5,017	20%	2,746	13%	12,070	23%	305	5%
ADAP	Total	17,891	—	11,328	—	14,045	—	8,543	—
	AIDS	5,546	31%	4,078	36%	6,742	48%	4,101	48%
	Non-Latino white	8,374	47%	2,845	25%	4,663	33%	3,785	44%
	African-American	2,718	15%	3,870	34%	4,838	34%	2,405	28%
	Latino	5,455	30%	1,686	15%	3,952	28%	2,260	26%
	Other	498	3%	78	1%	216	2%	56	1%
	Unknown	846	5%	2,849	25%	376	3%	37	0%

[a]California Medicaid HIV data includes only fee-for-service, excluding managed care.

[b]For Medicaid, AIDS includes 13%–29% classified as "AIDS or symtomatic HIV."

Access to ARVs: program participation

We found that racial/ethnic groups exhibited distinct patterns of enrollment for both Medicaid and ADAP (see Table 2 and Figure 1). In all four states, African Americans participated in Medicaid above their representation among people living with AIDS (range 10% to 53% above), and participated in ADAP below their representation among new AIDS cases (range 17% to 31% below). Non-Latino whites exhibited the opposite pattern, participating more in ADAP (9% to 65% above) than in Medicaid (5% to 38% below). Latinos tended toward participating in ADAP (7% to 31% above), except in New York.

Table 2. Racial/ethnic distribution, Medicaid and ADAP data vs. AIDS surveillance data, 1998

		Non-Latino White	African-American	Latino
California	Medicaid	52%	29%	14%
	ADAP	49%	16%	32%
	Living with AIDS	55%	19%	23%
	New AIDS cases	44%	23%	30%
Florida	Medicaid	36%	57%	7%
	ADAP	33%	45%	20%
	Living with AIDS	36%	47%	16%
	New AIDS cases	30%	55%	15%
New York	Medicaid	15%	47%	38%
	ADAP	35%	36%	29%
	Living with AIDS	25%	43%	33%
	New AIDS cases	21%	47%	32%
Texas	Medicaid	33%	49%	17%
	ADAP	44%	28%	26%
	Living with AIDS	47%	32%	20%
	New AIDS cases	41%	37%	22%

HAART use

Our analyses indicate that for HAART use as measured by the 90–day snapshot, differences by race/ethnicity ranged from 2% to 14% (Table 3), representing relative risks of 0.75 to 1.21 (Figure 2). In California and Florida Medicaid, African Americans had lower HAART use than did non-Latino whites and Latinos. Latinos had higher HAART use than African Americans and non-Latino whites in all ADAP programs and in Texas Medicaid. HAART 90–day use also differed by program (Table 3; higher in ADAP than in Medicaid) and state (highest in New York, lowest in Texas), but these comparisons are complicated by differences in analytic and program design, as reviewed in the Discussion.

The two measures of long-term HAART use (continuity of use and refills) indicated lower consistent HAART use than 90–day use (Table 3). The "HAART without gaps" pattern occurred 65% to 90% as often as HAART by snapshot, for example 29% versus 37%. Refill rates were consistent with pattern results. For example, when HAART by "continuity of use" was at 29% (Texas Medicaid non-Latino white), there were 1.09 ARV medication-days per program-day. (HAART with three drugs at 29% generates 0.87 antiretrovirals per day [0.29 × 3], and in addition some individuals are on mono or dual therapy.) The long-term methods showed similar racial/ethnic patterns to the snapshot.
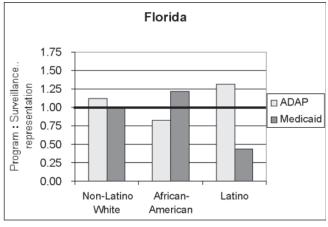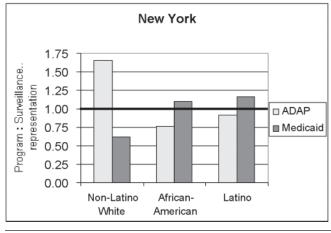
DISCUSSION

We found that in four states, African Americans participated in Medicaid above and in ADAP below their representation in the epidemic. The reverse was con-

Figure 1. Relative representation by race/ethnicity in Medicaid and ADAP data vs. in AIDS surveillance data, 1998

Each bar shows the ratio of that race/ethnicity's percent among individuals in Medicaid or ADAP, divided by the percent among Persons Living with AIDS or New AIDS cases, respectively. Equal representation is indicated by 1.00, marked with the heavy line. African Americans participated in Medicaid above their representation in the epidemic, and in ADAP below their representation. Non-Latino whites exhibited the opposite pattern, as did Latinos except in New York.
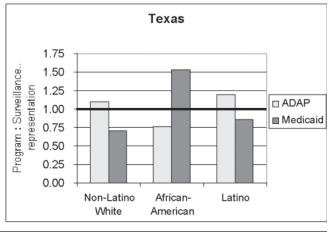
Table 3. Use of HAART by race/ethnicity in Medicaid and ADAP, 1998

		Non-Latino white	African-American	Latino
90-day snapshot[a]				
Medicaid	California	46%	40%	46%
	Florida	56%	42%	54%
	New York	56%	55%	54%
	Texas	37%	35%	44%
ADAP	California	63%	65%	74%
	Florida	61%	62%	68%
	New York	75%	76%	78%
	Texas	56%	54%	59%
Continuity of use[b]				
Medicaid	California	40%	32%	29%
	Florida	51%	35%	48%
	New York	40%	36%	34%
	Texas	29%	28%	31%
ADAP	California	60%	55%	61%
	Florida	—	—	—
	New York	69%	62%	65%
	Texas	46%	39%	45%
Refills (all ARVs)[c]				
Medicaid	California	1.63	1.35	1.25
	Florida	1.95	1.28	1.88
	New York	1.77	1.58	1.48
	Texas	1.09	1.02	1.18
ADAP	California	2.48	2.52	2.75
	Florida	1.88	1.91	1.93
	New York	2.76	2.67	2.71
	Texas	1.90	1.70	1.86

[a]90-day snapshot indicates receiving HAART medications.

[b]Continuity of use indicates receiving HAART with no gaps.

[c]Refills equals ARV medication-days per program-day.

sistently true for non-Latino whites, and was true for Latinos in three states. Within programs, differences by race/ethnicity in use of HAART were small, with African Americans using HAART at a lower rate than other groups in Medicaid, and Latinos at a higher rate than other groups in ADAP. Taken together, the findings on program participation and on HAART use within programs may suggest differences in HAART use by race/ethnicity. African Americans are more likely to be in Medicaid, with its apparently lower HAART use. However, as discussed below, program comparisons are complicated.

The differences in Medicaid and ADAP participation by race/ethnicity are consistent with program eligibility rules, especially those regarding financial status. M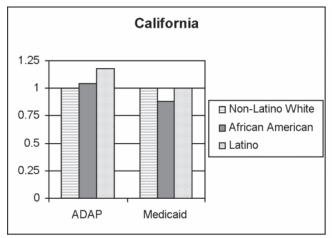edicaid is limited to those with poverty-level incomes and usually requires disability or other categorical eligibility, whereas ADAP has higher income eligibility. In general, the programs do not have overlapping enrollment except in rare circumstances such as Texas where limits on the number of drugs covered in any given month may lead to some drugs being covered under ADAP. Higher African American participation in Medicaid reflects patterns of overall Medicaid enrollment, due to higher rates of poverty. Higher ADAP enrollment by non-Latino whites similarly reflects a greater likelihood of having income above Medicaid requirements; therefore, they are more likely to participate in ADAP for access to HIV medications. However, we could not formally quantify the proportion of potential eligibles that were enrolled in each program, or determine if this proportion differed by
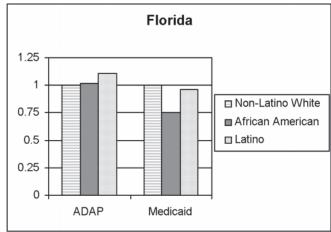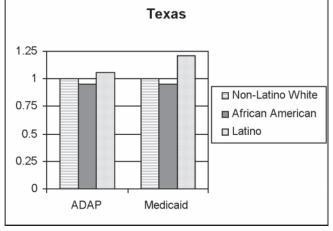
Figure 2. Relative risk of HAART use by race/ethnicity, 90-day snapshot, ADAP and Medicaid, 1998

Prevalence of use for non-Latino whites is defined as 1.0, and relative prevalence of use in the other groups is indicated.

race/ethnicity. These differences may take on clinical importance given apparent lower ARV use in Medicaid than in ADAP.

In order to compare the ethnic/racial mix of program participants to that of the epidemic, we compared Persons Living with AIDS to Medicaid and new AIDS cases to ADAP. The former comparison is obvious because the large majority of individuals in Medicaid have evidence of AIDS. The latter comparison was chosen for a program that serves individuals with earlier HIV disease in the absence of HIV reporting data, on the theory that new AIDS cases arise from HIV-infected populations. Recent HIV reporting data in Texas and Florida support the suitability of this comparison. These data indicate that the racial/ethnic mix of new AIDS cases lies between that of PLWA and HIV reports. For example, in Texas African-Americans represent 47% of PLWA, 41% of new AIDS cases, and 36% of recent HIV diagnoses. Since ADAP is a mix of AIDS and HIV (non-AIDS), comparing to new AIDS cases is appropriate; had we used HIV reporting data, ADAP would have appeared to even more sharply overrepresent whites and underrepresent African-Americans.

These findings are consistent with other components of our state case studies. State policies play a significant role in determining access to HIV drugs. The Medicaid requirement of being at or below 75% of the federal poverty level ($6,180/year) in all four states restricts participation to the poorest individuals, and poverty is unequally distributed by race/ethnicity. Three state Medicaid programs require meeting HIV disability criteria; in the exception (New York), we found enrollment notably shifted toward Medicaid instead of ADAP. Legal immigration status is also re-

quired in all four Medicaid programs, which may help explain lower Latino participation. Drug coverage in Medicaid programs varies in the four states, e.g., with limits on the number of prescriptions per month in Texas,[18] perhaps contributing to lower HAART use. ADAP eligibility requirements are much more lenient, with higher income cut-offs, no disability requirement, and no immigration status assessment. Our qualitative study of providers and patients found that, regardless of eligibility rules, minority populations often lack trust in government and are frequently suspicious of HIV drugs, perhaps leading to delays in HIV testing and in care.[17] In addition, respondents reported that the many challenges of living in poverty could compete with HAART use.

Analysis of pharmaceutical claims is a valid technique to compare participants within programs, but not a definitive measure of actual medication use. Indices of HAART use, such as the three-month snapshot, are blunt instruments for examining complex real-life medication patterns. However, they are likely to reflect underlying realities, as seen in prior analyses of HIV and chronic illness.[19,20] Group differences in the prevalence of HAART in a three-month period would be worrisome, since they would reflect differences in quality of care, and the observed group similarity is reassuring. Yet, claims review remains inferior to detailed clinical assessments for several reasons. First, we could not limit the analysis to individuals meeting guidelines for offering ARV therapy, since data on CD4 count and viral load were absent or sketchy (CD4 is reported for some ADAP programs). We did infer from the high prevalence of AIDS, symptomatic HIV disease, or CD4 <500 that the vast majority of program participants met HAART guidelines via clinical or laboratory criteria, with evidence of no substantial differences by race/ethnicity. Still, assessment of HAART utilization as measured from claims is not meaningful for individuals, but only for group comparisons. Second, participants may use medications obtained from sources outside the programs, such as the Veterans Administration, clinical trials, and pharmaceutical company expanded access programs. We could not quantify this phenomenon, but believe it to be of small magnitude. Third, we did not examine sequential enrollment in ADAP and Medicaid (e.g., for those with Medicaid monthly spend-down requirements). If there is medication splitting between programs, this could decrease estimates of HAART use for both. Conversely, we may have overstated HAART use in the "snapshot" by requiring only one occurrence of each HAART drug in 90 days instead of regu-

lar prescription fills, and by including only individuals with service use over the full 90 days.

More broadly, prescriptions filled do not necessarily translate to medications taken properly, or at all. Importantly, prescription fills are only a single step in the clinical sequence of events leading to excellent ARV therapy: assessment of need, offering and acceptance of ARVs, writing and filling of prescriptions, and proper use and adjustment of medications. There are numerous legitimate reasons to decline ARVs despite meeting treatment guidelines, including side effects, drug failure, viral resistance, competing health or survival needs, and a preference to delay to later in disease.

We observed that more ADAP than Medicaid participants were on HAART (Table 3). This finding must be considered in light of analytic methods not optimal for program comparison, as well as dissimilar program characteristics. One analytic issue is the relative comprehensiveness of pharmacy claims. Though we believe claims data from both programs are very complete, it is possible that occasional long delays in claims resolution (i.e., more than two years) preclude claims entry into our data. Subject inclusion procedures differed by program: we included all ADAP participants (since HIV is a prerequisite) versus Medicaid participants with evidence of HIV. To minimize this discrepancy, we erred toward specificity in searching for HIV-infected persons in Medicaid. Still, it is possible that individuals without HIV appear in the study sample (which would lower the HAART indices), and that individuals with HIV are missing (which would raise the indices). The severity of HIV disease could also differ by program, and it is impossible to compare them precisely due to nonequivalent clinical data. Further, each of the uncertainties enumerated earlier, such as use of medications from other sources, could differ by program. Finally, there may be sampling bias for individuals in Medicaid managed care because pharmacy claims (including ARV claims) are generated for these individuals, but clinic visit claims are not.

Another possible explanation for unequal HAART levels in ADAP and Medicaid is the wide discrepancy in program eligibility and benefits, potentially attracting patients and even providers with different behaviors. ADAP pays for HIV drugs for individuals with inadequate or absent medication coverage. Thus, most enrollees want to use these drugs, or anticipate doing so. In contrast, Medicaid pays for comprehensive health care, so individuals may enroll to obtain care other than medications. Also, ADAP is used primarily by people with income or assets above Medicaid levels

and who may be working, and thus, on average, lead more structured lives. Medicaid is a safety net program for people who are likely to be disabled (less so in New York due to broader eligibility rules) and who, by definition, live below 75% of the federal poverty level. Poverty, coexisting medical conditions, and survival priorities may partly explain Medicaid users' lower use of HAART. Seeking participation in ADAP may be analogous to seeking care in a network of HIV care research clinics, in which ARV use has been documented as very high.[1] The Medicaid and ADAP databases contained no information on behavioral risks (e.g., substance use) or on predictors of adherence, which could affect the decision to start and continue HAART.

Provider issues may play a role as well. In late 1999, the federal Medicaid program sent a letter to state Medicaid directors highlighting existing HIV treatment guidelines and calling on state programs to ensure patient access to experienced HIV providers. Even with overlap between ADAP and Medicaid providers, there may be structural and/or reimbursement factors affecting how the same providers participate in each program.

Comparisons among states are uncertain for similar reasons, and thus should be undertaken with caution. There are known differences in the structure of claims data (e.g., diagnostic and/or service variables), and probably differences in coding practices. In addition, we used slightly different HIV search algorithms for Medicaid, due to differences in data availability and states' own algorithms; we estimate less than 10% effect of the algorithm on the 90-day snapshot for ARV use. We cannot fully characterize the combined effects of these differences, so caution in state comparisons is indicated.

Our study began because of a concern that African Americans may be underrepresented in the AIDS Drug Assistance Program. We wanted to find out if this was at least in part due to higher levels of participation in state Medicaid programs. Our results did find that African Americans participated in Medicaid programs at higher rates than their proportion of the epidemic in each of the four states studied. But this raised as many questions as it answered. Clearly, many African Americans would screen into Medicaid and thus not be eligible for ADAP because of having Medicaid insurance coverage. However, three of the four states also required disability or other federal program eligibility in order to qualify for Medicaid. This suggests that, as a group, African Americans were being treated for more advanced HIV disease,

which is the basis for an AIDS diagnosis and a finding of medical disability.

Our finding of only small differences by race/ethnicity in the use of HAART within programs must be assessed in context. Medicaid income requirements are such that the lower use of HAART among Medicaid enrollees may reflect the reality of survival priorities associated with poverty. The small differences by race/ethnicity with ADAP may reflect the high motivation of individuals applying for a program designed to provide AIDS drugs; differences in attitudes toward drugs might affect enrollment patterns more than ARV utilization once in the program. Within-program patterns may miss important differences in early detection and early treatment that may exist across racial/ethnic communities. We hope that these findings and our project as a whole will assist in responding to the challenges posed by the disproportionate burden of HIV in communities of color.

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