

# Low Rates of HIV Testing Among Adults With Severe Mental Illness Receiving Care in Community Mental Health Settings

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**Objective:** This research aimed to characterize HIV testing rates among Medicaid recipients with severe mental illness who received public specialty mental health services.

**Methods:** This retrospective cohort study examined California Medicaid records from October 1, 2010, to September 30, 2011 (N=56,895). Study participants were between age 18 and 67, utilized specialty mental health care services, were prescribed antipsychotic medications, and were not dually eligible for Medicare. Adjusted Poisson regression models were used to estimate the overall effects of predictor variables on HIV testing prevalence.

**Results:** During the study period, 6.7% of people with severe mental illness received HIV testing. Men were 32% less likely

to be tested for HIV than women ( $p < .001$ ). Compared with whites, Asians/Pacific Islanders were 53% less likely and blacks were 82% more likely to be tested ( $p < .001$ ). Those with comorbid drug or alcohol use disorders were more likely to be tested than those without such disorders ( $p < .001$ ). Utilization of nonpsychiatric medical care was the strongest predictor of HIV testing ( $p < .001$ ).

**Conclusions:** Most adults with severe mental illness receiving public specialty mental health services were not tested for HIV during a one-year period. Public health administrators must prioritize HIV testing for early identification of HIV infection and prevention of HIV transmission.

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Persons with severe mental illness, such as schizophrenia, bipolar disorder, and major depression with psychosis, die 25 years earlier than the general population (1,2). Although most of this mortality is due to cardiovascular disease, two recent meta-analyses found median HIV prevalence rates ranging from 1.8% to 6% (3,4). Although studies reviewed in these analyses were limited by small sample sizes, variable time frames, and variable methods of ascertainment, the prevalence of HIV among persons with severe mental illness is consistently reported to be greater than in the general U.S. population (.5%) and contributes to the early mortality in this population. The increased HIV prevalence among persons with severe mental illness is not likely the result of a psychiatric illness-mediated biological predisposition to HIV but rather appears to be driven by higher rates of HIV-related risk behaviors. For example, people with severe mental illness report higher rates of unprotected sex, injection drug use, substance use in the context of sexual activity, and sexual violence than persons in the general population and a greater likelihood of encountering sexual partners with HIV infection (5–8).

A 2009 systematic review reported that HIV testing rates among people with severe mental illness were low (9). Unfortunately, the review was based on a series of studies with small samples, which resulted in wide ranges of recent (17%–49%) and lifetime (11%–89%) HIV testing rates (9). A recent cross-sectional study evaluated HIV testing among persons with mental illness in the 2007 National Health Interview Survey (10). This study found that those with any mental illness (including depression and anxiety) were more likely than the general population to report ever being tested for HIV (10). Although this was a study of persons with mental illness, the sample size for those with severe mental illness was quite low (N=108 for schizophrenia, and N=292 for bipolar disorder) (10). The small sample sizes in all of these studies reflect the difficulty of examining medical care received by people with severe mental illness because of the segregation of primary care and behavioral health care that is characteristic of the U.S. public health care system (11).

This study filled this gap in the literature by examining a unique data set that combined public mental health and general medical care data for Medicaid enrollees. Because

racial-ethnic minority populations have higher rates of HIV than the general population (12,13), the large size of this retrospective cohort also permitted analyses of disparities in HIV testing among racial-ethnic minority populations with severe mental illness. To our knowledge, this is the first large study examining HIV testing among people receiving specialty mental health services.

## METHODS

### Study Design

This retrospective cohort study utilized administrative, pharmacy, and billing data from California Medicaid (Medi-Cal) and the Client and Service Information (CSI) system for the period October 1, 2010, to September 30, 2011. The CSI system is an encounter-based data system that is funded by the state and county and used to track utilization of non-inpatient mental health services across California (14). The study was approved by the University of California, San Francisco, Committee of Human Research (11-06939); the State of California Committee for the Protection of Human Subjects (FWA00000681); and the Data and Research Committee of the California Department of Health Care Services (DHCS) (IRB00000552). Following approval, DHCS combined these databases, deidentified the data, and provided a unique data set. Data were made available because we were helping DHCS's public partners examine the efficacy of a separate statewide quality improvement project.

### Population

As of January 1, 2011, 7,505,841 people in California were enrolled in Medicaid (15). The following inclusion criteria generated the study cohort: age  $\geq 18$  years and  $< 68$ , Medi-Cal enrollee, specialty mental health care utilization during the study period, prescription of one or more antipsychotic medications during the study period, and not dually eligible for Medicare. [A list of the prescribed antipsychotic medications is available in an online supplement to this article.] Of note, prescription claims for antipsychotic medications were used to define the cohort for a parent study examining diabetes screening (16). In California eligibility for specialty mental health care is limited to individuals who meet medical necessity criteria by being diagnosed as having a "serious and disabling mental disorder" (17). The dually eligible population was excluded because Medicare laboratory billing data (which supersedes Medicaid data) were unavailable. We were not able to exclude people living with HIV; DHCS would not provide this level of data because of confidentiality concerns.

### Measures

The primary outcome measure was evidence of HIV-1 or HIV-2 antibody testing (CPT codes 86701, 86702, 86703, 87390, or S3645). The U.S. Preventive Services Task Force recommends annual HIV testing for populations at highest risk (men who have sex with men and active injection drug users) and testing every three to five years for those at increased

risk of HIV infection (having unprotected vaginal or anal intercourse; having sexual partners who are HIV infected, bisexual, or injection drug users; or exchanging sex for drugs or money) (18). Because people with severe mental illness are much more likely than the general population to fall into the categories of either highest risk or increased risk (5–8), we determined that a year-long period was a reasonable time frame to examine evidence of HIV testing. The database included additional variables: age, gender, race-ethnicity, county, antipsychotic medications, and nonpsychiatric medical office visits (new patients, CPT codes 99201–99205; established outpatients, 99211–99215; and other outpatient consultations, 99241–99245). All axis I diagnoses of mental and substance use disorders were collected from the CSI system and determined by mental health providers. Axis I diagnoses of mental disorders (not including substance use disorders) were hierarchically categorized as follows: schizophrenia spectrum disorder, bipolar disorder, major depressive disorder, anxiety disorder, and other. Counties were dichotomized into rural or urban according to 2013 National Center for Health Statistics definitions (19).

### Statistical Analysis

Adjusted Poisson regression models were used to estimate the overall effects on prevalence of HIV testing of gender, race-ethnicity, age group, county type (rural versus urban), diagnosis, and history of use of substance use disorder treatment and nonpsychiatric outpatient health care. We used a directed acyclic graph to identify confounders and mediators of each predictor. Models specific to each predictor of interest were used to estimate overall effects by adjusting for common causes of each predictor and HIV testing (confounders) but excluding factors on the causal pathway between them (mediators) (20). Models excluding confounders would provide biased estimates, whereas models including mediators would at best estimate direct effects via other pathways. Poisson regression was used as the best approximation of prevalence ratio.

Because mental health service delivery is realigned from the state to the county levels in California, we used robust standard errors to account for clustering of outcomes by county and to accommodate the use of a Poisson model for a binary outcome (Stata version 13.2) (20). Seven rural counties (12%) had few observations and were grouped with counties of similar size, region, and demographic characteristics (19). For example, we aggregated data from three rural counties: Alpine, Inyo, and Mono. We excluded data from San Mateo County, because we did not have access to the separate county pharmacy billing system that would identify the cohort taking antipsychotic medications.

## RESULTS

This study cohort represented .76% of all Medicaid recipients in California in 2011 (N=56,895 of 7,505,841). Over a year-long period, 6.7% (N=3,815) of study participants received HIV testing. Table 1 shows differences in the characteristics of participants who did and did not receive HIV testing. Table 2

**TABLE 1. Characteristics of California Medi-Cal enrollees receiving care in community mental health clinics, 2010–2011, by HIV testing status**

Characteristic	Total (N=56,895)		HIV testing <sup>a</sup> (N=3,815)		No HIV testing (N=53,080)		p
	N	%	N	%	N	%	
Sex							<.001
Male	25,587	44.9	1,405	5.5	24,182	94.5	
Female	31,308	55.0	2,410	7.7	28,898	92.3	
Race-ethnicity							<.001
Asian/Pacific Islander	7,197	12.6	195	2.7	7,002	97.3	
Black	11,038	19.4	1,197	10.8	9,841	89.2	
Hispanic	11,248	19.8	812	7.2	10,436	92.8	
Other	5,913	10.4	321	5.4	5,592	94.6	
White	21,499	37.8	1,290	6.0	20,209	94.0	
Age <sup>b</sup>							<.001
18–27	8,911	15.7	705	7.9	8,206	92.1	
28–47	24,021	42.2	1,879	7.8	22,142	92.2	
48–67	23,963	42.1	1,231	5.1	22,732	94.9	
County type							.541
Rural	1,611	2.8	123	7.6	1,488	92.4	
Urban	55,284	97.2	3,692	6.7	51,592	93.3	
Diagnosis <sup>c</sup>							<.001
Anxiety disorder	2,128	3.7	116	5.4	2,012	94.6	
Bipolar disorder	8,126	14.3	694	8.5	7,432	91.5	
Major depressive disorder	12,927	22.7	851	6.5	12,076	93.5	
Other	3,967	7.0	219	5.5	3,748	94.5	
Schizophrenia spectrum disorder	29,747	52.3	1,935	6.5	27,812	93.5	
Comorbid drug or alcohol use disorder	10,127	17.8	971	9.6	9,153	90.4	<.001
Evidence of use of general medical care	37,374	65.7	3,065	8.2	34,309	91.8	<.001

<sup>a</sup> Evidence of receipt of HIV test in the past year

<sup>b</sup> Categories were those provided by the California Department of Health Care Services.

<sup>c</sup> Axis I diagnoses were hierarchically categorized as follows: schizophrenia spectrum disorder, bipolar disorder, major depressive disorder, anxiety disorder, and other.

shows the unadjusted and adjusted relative risk of HIV testing in relation to various predictor variables.

After adjustment for potential confounders for each predictor variable (see footnotes in Table 2), men were less likely than women to be tested for HIV (adjusted risk ratio [ARR]=.68  $p<.001$ ). In addition, older adults were dramatically less likely than adults ages 18–27 to receive HIV testing (ARR=.63). Compared with rates among whites, HIV testing rates were significantly lower among Asians/Pacific Islanders (ARR=.47,  $p<.001$ ) but higher among blacks (ARR=1.82,  $p<.001$ ). No other racial-ethnic disparities in HIV testing were found. There was some variability in HIV testing by psychiatric diagnosis ( $p<.001$ ).

In contrast, participants with comorbid drug or alcohol use disorders were somewhat more likely than those without such disorders to be tested for HIV (adjusted RR=1.47,  $p<.001$ ). Participants with evidence of use of nonpsychiatric outpatient medical care were more than twice as likely to be tested for HIV than those who did not use such care (adjusted RR=2.29,  $p<.001$ ).

## DISCUSSION

This large retrospective cohort study of adults with severe mental illness served within California's public mental health care system generated three main findings that have important

public health implications. First, only 6.7% of individuals in this sample received HIV testing during a one-year period—clearly a missed prevention opportunity. This low testing rate is concerning given the high prevalence of HIV risk factors and HIV infection in this population. Best estimates find HIV prevalence among those with severe mental illness to be as much as tenfold higher than in the general U.S. population (3). In addition, despite the high prevalence of HIV risk behaviors among persons with severe mental illness, this testing rate is not much higher than the 2011 self-reported HIV testing rate among California's general population (5.2%) (21). Because effective treatments for HIV are widely available in the United States and people with severe mental illness appear to adhere to antiretroviral therapy at rates similar to rates in other groups (22), this lack of

testing is a missed prevention opportunity to detect HIV early in the course of illness, thus reducing the risk of disease progression to AIDS and preventing its spread to others.

HIV testing is central to national efforts to reduce infection rates, with the hope of eventually eradicating HIV. In 2010, it was estimated that nearly 76% of HIV-positive individuals in the United States knew their HIV status—likely because of 2006 efforts by the Centers for Disease Control and Prevention to increase routine HIV testing (23,24). Because individuals with severe mental illness are much more likely to be at high risk or increased risk of HIV infection compared with the general population (5–8,18) and evidence suggests that there is room to improve regarding obtaining sexual risk histories (25,26), we believe that annual HIV testing should be strongly considered by public mental health administrators. Yearly HIV testing among persons with severe mental illness could fit naturally with guideline-recommended metabolic screening for individuals taking antipsychotic medications.

Second, it is notable that use of nonpsychiatric outpatient medical care was the only modifiable factor that was associated with higher rates of HIV testing among adults with severe mental illness. This finding supports the importance of national efforts to integrate behavioral health and primary care, although we do not know whether increased

**TABLE 2. Relative risk (RR) of HIV testing among California Medi-Cal enrollees with severe mental illness (N=56,895) and receiving care in community mental health clinics, 2010–2011**

Characteristic	Unadjusted RR				Adjusted RR (ARR) <sup>a</sup>			
	RR	95% CI	Pairwise p	p	ARR	95% CI	Pairwise p	p
Male (reference: female) <sup>b</sup>	.71	.62–.82	<.001	<.001	.68	.58–.80	<.001	<.001
Race-ethnicity (reference: white) <sup>b</sup>				<.001				<.001
Asian/Pacific Islander	.45	.38–.54	<.001		.47	.40–.55	<.001	
Black	1.81	1.39–2.35	<.001		1.82	1.41–2.35	<.001	
Hispanic	1.20	1.08–1.34	.001		1.15	1.03–1.29	.017	
Other	.91	.77–1.07	.238		.93	.81–1.08	.361	
Age (reference: 18–27) <sup>b,c</sup>				<.001				<.001
28–47	.99	.87–1.13	.866		.95	.82–1.09	.459	
48–67	.65	.51–.82	<.001		.63	.50–.80	<.001	
Rural county type (reference: urban) <sup>b</sup>	1.14	.74–1.76	.541	.541	1.23	.85–1.78	.276	.276
Diagnosis (reference: schizophrenia spectrum disorder) <sup>d</sup>				<.001				<.001
Anxiety disorder	.84	.69–1.02	.076		.90	.76–1.08	.269	
Bipolar disorder	1.32	1.21–1.43	<.001		1.16	1.05–1.29	.003	
Major depressive disorder	1.01	.92–1.11	.797		1.02	.94–1.11	.610	
Other	.85	.69–1.04	.105		.85	.72–.99	.038	
Comorbid drug or alcohol use disorder (reference: no) <sup>e</sup>	1.59	1.43–1.74	<.001	<.001	1.47	1.37–1.58	<.001	<.001
Evidence of health care use (reference: no) <sup>f</sup>	2.13	1.73–2.63	<.001	<.001	2.29	1.87–2.80	<.001	<.001

<sup>a</sup> A directed acyclic graph was used to summarize the a priori hypotheses for the causal relationships among the variables in the analysis and then used to identify the confounders and mediators of the relationship of each variable to HIV testing. The model for each relationship included the identified confounders and excluded the mediators.

<sup>b</sup> Controlled for three main demographic variables (sex, race-ethnicity, and age) and county type, unless the variable was the predictor variable of interest

<sup>c</sup> Categories were those provided by the California Department of Health Care Services.

<sup>d</sup> Controlled for main demographic variables, county type, and comorbid substance use disorder

<sup>e</sup> Controlled for main demographic variables, county type, and axis I diagnosis

<sup>f</sup> Controlled for main demographic variables, county type, axis I diagnosis, and comorbid substance use disorder

comorbidity drove these nonpsychiatric medical care visits. Notably, many of the large primary and behavioral health care integration pilot programs funded by the Substance Abuse and Mental Health Services Administration found that access to primary care alone was not sufficient to improve general medical outcomes, and many of these programs were fiscally unsustainable (27). In addition, most of these programs narrowly focused on cardiovascular risk reduction (27,28). Given the high prevalence of HIV and other blood-borne infections among people with severe mental illness (3), we strongly suggest expanding the focus of efforts to integrate care beyond cardiovascular risk reduction to include HIV testing and expanding approaches to reducing high-risk sexual and drug use behaviors.

Individuals with severe mental illness have low rates of primary care utilization overall (29), but they do use community mental health clinics (30). Therefore, we believe that there is an opportunity to expand the scope of practice of community psychiatrists to take more responsibility for certain aspects of their patients’ medical care. We found that primary care providers and psychiatrists are at odds regarding who is responsible for conducting medical screening and treatment of this patient population, even when it comes to guideline-recommended metabolic testing (31,32). Because HIV testing is potentially more complicated and

stigmatizing than metabolic testing, we believe that public mental health care system leaders should prioritize educating psychiatrists about the importance of HIV testing to reduce disease progression and transmission in this vulnerable population.

Finally, we found that rates of HIV testing differed among subgroups with severe mental illness; older adults, in particular, were much less likely to be tested for HIV. Eleven percent of new HIV infections occur among adults ages 50 and older, and older individuals are more likely to receive a diagnosis of HIV infection later in the course of the disease (29–31). These late diagnoses lead to impaired quality of life and reduced life expectancy in this population. Because 42% of our study participants were between age 48 and 67, a lack of prioritization of HIV testing in this age group constitutes another missed opportunity for prevention.

We also found low rates of HIV testing among Asians/Pacific Islanders, a finding consistent with other reports (33). Because Asians/Pacific Islanders are the only racial-ethnic group to experience an increase in HIV/AIDS diagnosis in recent years and studies indicate that testing rates increase if testing sites are culturally appropriate and testing is provided in a safe environment (34), this appears to be another missed prevention opportunity. Our findings that black participants and persons with comorbid substance use disorders were more likely to be tested for HIV suggest that

clinicians are appropriately targeting screening efforts to some subpopulations at highest risk of HIV infection. However, the fact that HIV testing rates for blacks and persons with comorbid substance use disorders were only 10.8% and 9.6%, respectively, suggests that there is still significant room for improvement among these high-risk populations.

The major limitation of this study was our reliance on a large administrative database, including the CSI data submitted by counties to track mental health service utilization (14). Because dually eligible (Medicaid and Medicare) patients were not included, HIV testing rates may not reflect the population with severe mental illness as a whole, especially those over age 65. Extrapolation to newly enrolled patients may also be limited. In addition, HIV testing that was not billed to Medicaid (for example, bundled with other services during an inpatient hospital admission) was not captured, which could have led to an underestimation of screening rates.

Generalizability is a concern with use of databases with claims from a single state. In addition, the lack of a control group made direct comparisons challenging. We could not determine whether HIV testing was performed for people with a preexisting HIV infection, because we were not provided with HIV-related ICD-9 diagnosis codes. This decision was made by the Data and Research Committee of the California DHCS in an effort to avoid threatening the confidentiality of persons in rural counties. In addition, prescription claims for antipsychotic medications were used to define the cohort for a parent study examining diabetes screening (16). Therefore, we were unable to examine HIV testing of people with severe mental illness who received services at specialty mental health facilities and who were not taking these medications. Finally, although we were able to explore the role that substance use plays in driving HIV testing, this data set did not include sexual orientation, making it impossible to evaluate subpopulations that might most benefit from HIV testing (for example, men who have sex with men).

## CONCLUSIONS

Our findings suggest that even after three decades of efforts to increase HIV testing in the United States, primary care physicians and psychiatrists are in need of more comprehensive education about the importance of HIV testing among persons with severe mental illness. Future research should be conducted to evaluate patient-, provider-, and system-level factors that might influence HIV testing. For example, these studies could explore factors that may contribute to this quality gap, such as patient refusal, stigma around HIV testing (both at patient and provider levels), and lack of psychiatrist education about HIV prevalence in populations with severe mental illness. Furthermore, mental health care teams' practice of prioritizing psychosocial problems over medical screening and the lack of systemic

infrastructure to facilitate HIV testing should be addressed. Policies or practices that might exempt mental health facilities from following guidelines recommended for all health care facilities should be discouraged. In addition, it is important to investigate whether HIV testing is more frequently ordered by psychiatrists or primary care providers.

Future studies must also focus on evidence-based efforts to increase HIV testing and linkage to care for people with severe mental illness. Although a recent systematic review found equivalent adherence to HIV/AIDS treatment guidelines among adults with severe mental illness and the general population, the results were limited by the paucity of such data (22). Although we recognize that longitudinal examination of HIV treatment among individuals with comorbid severe mental illness and HIV has been challenging because of the segregation of mental health and general medical care records in the public health system, we believe that evaluating the HIV care that this population receives—or does not receive—is another important area for future research.

In summary, we found a highly concerning lack of HIV testing among people with severe mental illness served in the public specialty mental health care system. Lack of HIV testing is a missed prevention opportunity and ultimately increases the risk of HIV transmission and delays treatment for those who have been infected, resulting in increased morbidity and mortality. The high-risk population of people with severe mental illness must be prioritized for any HIV testing initiative. Because most people with severe mental illness in the United States receive care in public specialty mental health clinics (30,35), we encourage public mental health administrators to expand their current efforts to integrate care beyond cardiovascular risk reduction to develop multilevel interventions to improve HIV testing in their systems of care.

## AUTHOR AND ARTICLE INFORMATION

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