Missed Opportunities for Engagement in the Prevention Continuum in a Predominantly Black and Latino Community in New York City

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Abstract

Even though over the last 25 years, the Centers for Disease Control and Prevention recommendations for HIV screening have expanded to encompass population-wide screening in all healthcare settings, and despite the availability of pre-exposure prophylaxis (PrEP), a large proportion of individuals at risk of infection are not linked to prevention care. We evaluated missed opportunities for HIV screening and linkage to PrEP from 2006 through 2017 at an urban academic medical center serving a predominantly minority community. A missed opportunity for HIV screening was a provider visit that did not include HIV testing and occurred within the 12 months before the first positive HIV test. A missed opportunity for prevention was a visit after 2012 that included a negative HIV test, no evaluation for PrEP, and was followed by a positive HIV test. Univariate analysis was performed to assess characteristics of individuals with missed opportunities for screening and prevention services. Between 2006 and 2017, 721 patients were newly diagnosed with HIV. Two hundred forty-seven diagnoses were made in the early period (2006–2010), 236 in the middle period (2010–2013), and 238 in the late period (2014–2017). Overall 60% of patients had at least one missed opportunity, 36% for HIV screening, and 42% for PrEP. There was no improvement in the rates of individuals with a missed opportunity for HIV screening over time. Ending the HIV epidemic will require concerted efforts to bolster access to testing and ensure that all individuals are offered screening, counseling, and linkage to prevention and care services.

Keywords: HIV screening, missed opportunities, HIV diagnosis, late diagnosis

Introduction

THE CENTERS FOR Disease Control (CDC) estimates that among 1.1 million HIV-infected individuals living in the United States, 15% are not aware of their diagnosis.¹ Earlier diagnosis and treatment of HIV have substantial population benefits, including reduction in transmission and a decrease in both morbidity and mortality.^{2–6} Since 2006 the CDC has recommended routine HIV screening with simplified HIV screening algorithms to reduce barriers to testing, yet gaps in testing, diagnosis, and linkage to care or prevention services for persons living with, or at risk of, HIV persist.^{7–12}

New York City (NYC) is the metropolitan area in the United States with the highest number of new HIV diagnoses.⁸

Since 2010 New York State has required that healthcare providers offer HIV testing to all persons between 13 and 64 years old receiving hospital or primary care services. However, a requirement for written consent was not removed until 2014 when it was replaced with special verbal consent. Despite these efforts an estimated 5–7% of persons living with HIV (PLWH) in New York remain undiagnosed.^{13,14} Non-Latino blacks and Latinos continue to be disproportionately affected by the HIV epidemic. Across New York State these groups have an incidence rate 4–5 times that of non-Latino whites.¹⁵ In addition, although overall HIV incidence declined from 2006 to 2014, there was an increase in incident infections among young (13–29) Latino men who have sex with men (MSM).¹⁵ Recognizing the urgent need to enhance HIV prevention and linkage to care efforts in these

groups, New York State has implemented a multi-dimensional initiative to decrease new HIV infections by the end of 2020.¹⁶ The initiative calls for identification of HIV among those who remain undiagnosed, complete linkage and retention of PLWH to maximize viral suppression (secondary HIV prevention), and facilitation of access to pre-exposure prophylaxis (PrEP) for high-risk individuals (primary HIV prevention).¹⁶

While current guidelines call for universal screening, a behavioral risk assessment is a critical part of identifying those in need of HIV rescreening and sexual health and comprehensive HIV prevention services such as PrEP. Missed opportunities for HIV testing represent a missed opportunity to engage individuals in the prevention continuum, which starts with awareness of risk, testing, and linkage to care.

We evaluated the HIV screening and linkage to PrEP from 2006 through 2017 at a large urban academic medical center serving a predominantly minority and Latino community. This period of time coincides with the approval of increasingly effective HIV prevention approaches and concerted statewide efforts to end the HIV epidemic (EtE). The impact of these initiatives on the early steps in the PrEP continuum: testing and linkage to prevention, needs to be carefully assessed to inform efficient and streamlined approaches to screening as prevention interventions are scaled up.

Methods

Study population

This study was performed at a large urban academic medical center consisting of inpatient and ambulatory care services at two main sites in Upper Manhattan, in addition to a large number of ambulatory care sites. The medical center serves a community in which 72% of residents self-identify as Hispanic or Latino, 25% of households are below the federal poverty line and with a >2% HIV prevalence.^{17,18} The HIV program receives all positive HIV test results, and provides assistance with post-test counseling and linkage to care for newly diagnosed individuals at any site within the institution.¹⁹ While providers may have been prescribing PrEP since its approval, the institution-wide PrEP program has been in place since 2015.

Definition of outcomes and statistical analysis

All new HIV diagnoses between January 1, 2006 and December 31, 2017 were identified in the database maintained by the HIV program. Medical records were reviewed to collect information on demographics, inpatient and outpatient visits, sexually transmitted infection screening, and HIV-related lab tests. New diagnoses were defined as patients ≥ 18 years of age with a positive HIV test and no history of prior HIV-positive test per a review of the medical records. Study period was divided into three equal time blocks based on changes in HIV testing regulations in New York State: early (2006–2009), middle (2010–2013), and late (2014–2017).

A missed opportunity for HIV screening and potential earlier diagnosis (secondary prevention) was defined as an emergency room, inpatient, or outpatient visit at any site

within the institution in the 1 year (365 days) before the HIV diagnosis. A missed opportunity for linkage to prevention services (primary prevention) was defined as a patient with a negative HIV test after 2012 who was not started on PrEP or evaluated for PrEP services per a review of medical records and subsequently seroconverted.

Demographic and clinical characteristics of individuals diagnosed in the early, middle, and the late periods were compared. Late diagnoses were defined as $CD4 \leq 200$ at the time of, or within 90 days of, diagnosis. Univariate analysis was performed to assess characteristics of individuals with missed opportunities for screening and prevention services. Variables for those in each period were compared in a bivariate analysis using Pearson's chi squared. All statistical analyses were performed with IBM SPSS V24.

Results

A total of 721 new HIV diagnoses were identified between 2006 and 2017; of these 247 were between 2006 and 2009 ("early period"), 236 between 2010 and 2013 ("middle period"), and 238 between 2014 and 2017 ("late period"). The proportion of HIV diagnosis among males and MSM increased in the middle and late periods, whereas the proportion of patients self-identifying as "Latino," men who have sex with women (MSW), and persons who inject drugs decreased from the early to the late period. The proportion of patients diagnosed in the emergency department (ED) increased from the early to the late period (10–40%, $p \leq 0.0002$), with a concurrent decrease in the number of patients diagnosed in the inpatient setting (36–9%, $p \leq 0.0002$). The proportion of patients with a late diagnosis of HIV decreased from the early to the late period (37–29%, $p = 0.031$). There was no significant difference in age at the time of diagnosis from the early to the late period (Table 1).

Overall 258 patients (36%) had at least one missed opportunity for HIV screening in the 12 months before their diagnosis. There were a total of 1118 missed opportunities, an average of 4.3 missed opportunities per patient. There was no difference in the proportion of patients with a missed opportunity for earlier HIV diagnosis in the early compared with late periods (40–33%, $p = 0.631$). The late period demonstrated a decrease in the number of missed opportunities among MSM (4.1–2.9, $p = 0.001$) and individuals with a history of intravenous drug use (IVDU). There was no difference in the number of missed opportunities for earlier HIV screening by gender, ethnicity, age, or CD4 count at the time of diagnosis (Table 2).

From 2012 to 2017, 160 patients (42%) had at least one negative HIV test without a referral for comprehensive HIV prevention services. The majority of patients with a missed opportunity for prevention services were male (78%) and Latino (36%) or African American (27%). Thirty-four percent of patients were under the age of 25, and only 13% were over the age of 50. MSM represented 47% of the patients with missed opportunities for referral to PrEP services. Individuals over age 50 had an increased number of missed opportunities for HIV screening, whereas those under age 25 had an increased number of missed opportunities for referral to prevention services (Table 3).

Overall 60% of patients had at least one missed opportunity for primary or secondary HIV prevention.

TABLE 1. DEMOGRAPHICS OF NEW HIV INFECTIONS FROM 2006 TO 2017

	<i>Early (E) period</i> 2006–2009	<i>Middle (M) period</i> 2010–2013	<i>Late (L) period</i> 2014–2017	<i>Early to late</i>
	N (%)	N (%)	N (%)	p Value
New HIV diagnosis	247 (34.26%)	236 (32.73%)	238 (33.01%)	
Sex at birth				
Males	165 (66.80%)	182 (77.12%)	185 (77.73%)	0.009
Females	82 (33.20%)	54 (22.88%)	53 (22.27%)	0.009
Race/ethnicity				
Latino	117 (47.37%)	101 (42.80%)	78 (32.77%)	0.004
Black	88 (35.63%)	76 (32.20%)	73 (30.67%)	0.492
White	28 (11.34%)	19 (8.05%)	27 (11.34%)	0.394
Other	14 (5.67%)	40 (16.95%)	19 (7.98%)	<0.0002
Age				
<25	53 (21.46%)	54 (22.88%)	65 (27.31%)	0.291
26–49	145 (58.70%)	141 (59.75%)	130 (54.62%)	0.630
≥50	49 (19.84%)	41 (17.37%)	43 (18.07%)	0.781
Risk factors				
Women who have sex with men	55 (22.27%)	44 (18.64%)	40 (16.81%)	0.299
Men who have sex with women	67 (27.13%)	53 (22.46%)	32 (13.45%)	0.001
Men who have sex with men	78 (31.58%)	106 (44.92%)	115 (48.32%)	<0.0002
History or active intravenous drug use	13 (5.26%)	5 (2.12%)	2 (0.84%)	0.009
Other	3 (1.21%)	2 (0.85%)	4 (1.68%)	0.715
Unknown	43 (17.41%)	31 (13.14%)	52 (21.85%)	0.044
Location of diagnosis				
Outpatient	110 (44.53%)	123 (52.12%)	120 (50.42%)	0.214
Inpatient	90 (36.44%)	66 (27.97%)	22 (9.24%)	<0.0002
ED	25 (10.12%)	47 (19.92%)	96 (40.34%)	<0.0002
CD4 at diagnosis				
Early diagnosis (CD4 > 200)	116 (46.96%)	123 (52.12%)	139 (58.40%)	0.031
Late diagnosis (CD4 < 200)	92 (37.25%)	78 (33.05%)	68 (28.57%)	0.031

Bold indicates *p* values ≤ 0.05.

TABLE 2. CHARACTERISTICS OF INDIVIDUALS WITH MISSED OPPORTUNITIES FOR HIV SCREENING WITHIN 12 MONTHS OF DIAGNOSIS

	<i>Early (E) period</i> 2006–2009	<i>Middle (M) period</i> 2010–2013	<i>Late (L) period</i> 2014–2017	<i>Total</i>	<i>Early to late</i>
	N (% , MO/person)	N (% , MO/person)	N (% , MO/person)	N	p-value
Missed opportunities					
Patients	104 (40.31%, 4.2)	70 (27.13%, 5.1)	84 (32.56%, 3.9)	258	0.631
Visits	433	356	329	1118	
Sex at birth					
Males	63 (60.58%, 4.4)	51 (72.86%, 4.5)	60 (71.43%, 3.8)	174	0.160
Females	41 (39.42%, 3.8)	19 (27.14%, 6.7)	24 (28.57%, 0.2)	84	0.160
Race/ethnicity					
Latino	59 (56.73%, 4.7)	32 (45.71%, 4.5)	33 (39.29%, 3.4)	124	0.207
Black	26 (25.00%, 3.4)	28 (40.00%, 4.9)	25 (29.76%, 5.4)	79	0.871
White	13 (12.50%, 4.5)	2 (2.86%, 2.0)	7 (8.33%, 2.6)	22	0.795
Other	6 (5.77%, 1.0)	8 (11.43%, 8.8)	3 (3.57%, 1.0)	17	0.270
Age					
<25	23 (22.12%, 4.5)	18 (25.71%, 2.8)	14 (16.67%, 5.9)	55	0.638
26–49	54 (51.92%, 3.4)	36 (51.43%, 5.3)	47 (55.95%, 3.1)	137	0.472
≥50	27 (25.96%, 5.4)	16 (22.86%, 7.3)	23 (27.38%, 4.3)	66	0.591
Risk factors					
Women who have sex with men	28 (26.92%, 4.0)	17 (24.29%, 7.1)	18 (21.43%, 4.6)	63	0.721
Men who have sex with women	26 (25.00%, 4.8)	17 (24.29%, 4.1)	15 (17.86%, 5.9)	58	0.275
Men who have sex with men	33 (31.73%, 4.1)	25 (35.71%, 5.0)	41 (48.81%, 2.9)	99	0.001
History of active intravenous drug use	5 (4.81%, 5.2)	4 (5.71%, 6.3)	0 (0%, 0)	9	0.041
Other	1 (0.96%, 6.0)	1 (1.43%, 2.0)	2 (2.38%, 1.5)	4	0.463
Unknown	15 (14.42%, 3.3)	8 (11.43%, 2.8)	14 (16.67%, 3.8)	37	0.716
CD4 at diagnosis					
Early diagnosis (CD4 > 200)	50 (48.08%, 4.0)	41 (58.57%, 6.3)	50 (59.52%, 4.0)	141	0.472
Late diagnosis (CD4 < 200)	40 (38.46%, 4.9)	22 (31.43%, 3.9)	24 (28.57%, 4.5)	86	0.472

Bold indicates *p* values ≤ 0.05.

Discussion

The HIV care continuum traditionally has focused on testing, linkage to care, and achieving virological suppression among HIV-positive individuals. The same paradigm has been expanded to the concept of the prevention continuum to include linkage of HIV-negative individuals to sexual health and prevention services.²⁰ In both the HIV care and prevention continuums, the first step includes an assessment of risk, HIV testing, and referral of negatives to prevention.

We show that despite recommendations for universal HIV testing, the overall proportion of patients with a missed opportunity for earlier HIV diagnosis remained unchanged from the early to the late period. Our findings are similar to those of other investigators that demonstrated high rates of missed opportunities in a variety of care settings; however, this study extends these findings over a longer duration of time.²¹

Women and older individuals have previously been shown to be at higher risk for late diagnosis, and have more missed opportunities for HIV testing.^{19,22} In our study we saw a significant and encouraging decrease in the number of missed opportunities per woman from the early to the late period (3.8–0.2). This may reflect the more recent emphasis of screening women for HIV in the first trimester of pregnancy.

We did not see any change in the proportion of individuals 50 years and older with a missed opportunity for HIV testing.¹⁹ Individuals 50 and older have a disproportionate number of missed opportunities, representing 18% of new diagnosis but 27% of missed opportunities in the late period.¹⁹ Consistent with that, individuals over age 50 had few missed opportunities

for prevention services, which may be due to the low numbers of individuals tested for HIV. Others have shown that older individuals are less likely to have comprehensive review of sexual history and risk reduction during healthcare encounters,^{23,24} which may result in improper characterization of risk and account for such a low proportion of individuals with recent negative HIV tests and missed opportunities for PrEP.

Nationwide MSM represent 2% of the population but account for 70% of new HIV infections making them an important target of prevention interventions.²⁵ Over 12 years we saw a decrease in the number of missed opportunities for earlier HIV screening per person, likely reflecting multi-pronged efforts to engage MSM in PrEP care and more frequent HIV testing in this context. Yet, the increase in the proportion of MSM newly diagnosed with HIV (32–48%, $p \leq 0.002$), with the highest increase after 2014, underscores what national data show that this group bears a high burden of new infections.

Blacks and Latinos, women as well as MSM, bear the greatest burden of new infections. In our cohort, 47% and 36% of new diagnoses in the early period were Latinos and blacks, respectively.^{26,27} This decreased over time (33% Latinos in late period, $p = 0.004$), and there were fewer missed opportunities for HIV testing over time for both groups. However, assessment of missed opportunities for linkage to PrEP services reveals that majority (62.5%) of individuals who were not engaged in the PrEP prevention cascade were blacks or Latinos.

Over 12 years we noted a significant increase in the number of diagnoses made in the ED (10–40%, $p < 0.0002$) and a concurrent decrease in diagnosis in the inpatient unit (36–9%, $p < 0.0002$). The improvement seen in the ED from the early to the late period may relate to a change in New York State Law in 2010 shifting from risk-factor-based screening to a mandated universal one-time HIV screen, or to changes in EMR systems that increasingly encouraged HIV screening in the ED. These data support the importance of routinized testing in the ED, but warrant further evaluation to determine if this represents a shift in diagnosis from the inpatient to the ED setting. The ED often represents a critically important point of access for testing and linkage to prevention services for many individuals without access to routine medical care.²⁸

The current opt-out approach to HIV screening with targeted rescreening of those at risk is not well implemented, and, as shown here and by others, continues to result in missed opportunities for HIV diagnosis.^{9,11,12} Our data highlight the need for better comprehensive risk assessment tools, not just to identify who to test but for who to link to prevention services. In this setting, information technology (IT) may be a cost-effective and efficient tool leveraged to identify individuals without a recent HIV test, to find candidates for targeted repeat screening, and to assist providers in identifying individuals in need of referral to HIV prevention services. In one study a prompt for patients with no previous HIV test or a high-risk diagnosis code resulted in an increase in inpatient screening from 9.5% to 21.8%, and led to an increase in new HIV diagnoses.²⁹ In the future automated risk assessment methods that leverage longitudinal electronic health records and natural language processing could be used to identify those at risk to enhance implementation of screening programs.³⁰

TABLE 3. CHARACTERISTICS OF INDIVIDUALS WITH MISSED OPPORTUNITIES FOR HIV SCREENING AND PREVENTION SERVICES FROM 2012 TO 2017

	<i>MO for linkage to prevention services</i>	<i>MO for HIV screening</i>	<i>p Value</i>
	N (%)		
Missed opportunities			
Patients	160 (41.78%)	118 (30.81%)	0.002
Sex at birth			
Males	125 (78.13%)	88 (74.58%)	0.49
Females	35 (21.88%)	30 (25.42%)	
Race/ethnicity			
Latino	59 (35.54%)	46 (44.23%)	0.15
Black	45 (27.11%)	39 (37.50%)	0.07
White	16 (9.64%)	9 (8.65%)	0.79
Other	8 (4.82%)	8 (7.69%)	0.33
Age			
<25	55 (34.38%)	24 (20.34%)	0.01
26–49	85 (53.13%)	64 (54.24%)	0.85
≥ 50	20 (12.50%)	30 (25.42%)	0.006
Risk factors			
WSM	27 (16.17%)	24 (19.20%)	0.5
MSW	23 (13.77%)	22 (17.60%)	0.37
MSM	78 (46.71%)	58 (46.40%)	0.96
IVDU	3 (1.80%)	1 (0.80%)	
Other	1 (0.60%)	2 (1.60%)	
Unknown	35 (20.96%)	18 (14.40%)	0.15

MO, missed opportunities; MSW, men who have sex with women; MSM, men who have sex with men; IVDU, intravenous drug use.

Bold indicates p values ≤ 0.05 .

One major limitation of this study is that we were unable to track individuals who were offered and declined screening or referral to prevention services if not documented in the chart. Further, New York has a large number of health facilities, and we were unable to account for individuals who may have been screened at other institutions. In the future, programs identifying gaps in screening and linkage to prevention services may benefit from regional health information systems, so that patients can be tracked across hospital systems. Finally, in this study, we only identified missed opportunities among HIV-positive individuals. However, this represents the leading edge of the problem, and excludes missed opportunities for HIV screening among high-risk individuals whose HIV status is negative or unknown and have not yet been screened or referred for comprehensive prevention services.

Reducing the number of missed opportunities for HIV screening can contribute to an incremental reduction in HIV incidence. Evaluating both primary and secondary prevention together is an important first step in improving the HIV prevention continuum. However, this requires education of patients and providers about testing and availability of PrEP, timely identification of individuals at risk, provider engagement in screening initiatives, and linkage to HIV care and sexual health services. Our results illustrate a modest improvement in missed opportunities in certain groups and the ED over the past 12 years. They also identify a large number of MSM in whom HIV testing was performed but linkage to comprehensive prevention services not provided. Ending the epidemic will require a multi-pronged approach to minimize missed opportunities for HIV screening and linkage to care or comprehensive prevention services.

Author Disclosure Statement

Dr. Zucker is supported by the training grant “Training in Pediatric Infectious Diseases” (National Institute of Allergy and Infectious Diseases T32AI007531).

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