Missed Opportunities: Characteristics of People Who Received a Concurrent HIV/AIDS Diagnosis in New York State From 2016 to 2021

Mark Rosenthal, MSPH,[a] Wendy Patterson, MPH,[a] and Deepa T. Rajulu, MS[b]

Background: Late HIV diagnosis is associated with a wide range of negative outcomes. The aim of this study was to identify the characteristics of individuals who received a concurrent diagnosis (CDX) in New York State (NYS) so that more effective interventions can be developed to encourage earlier testing among these populations.

Methods: The NYS HIV registry was used to identify people who received a CDX from 2016 to 2021. A CDX was a diagnosis that met the criteria for a stage 3 HIV infection within 30 days of the initial HIV diagnosis. Sex at birth, race/ethnicity, transmission risk group, age at diagnosis, region of residence at diagnosis, urbanicity of zip code of diagnosis, and type of diagnosing facility were used as covariates. Bivariate and multivariate risk ratios were calculated to quantify associations between CDX and covariates.

Results: There were 14,866 people newly diagnosed with HIV in NYS from 2016 to 2021, of which 19.0% had a CDX. Those with female sex at birth, history of injection drug use, or history of male-to-male sexual contact/history of injection drug use risk were less likely to have a CDX. Increased age, Asian race/ethnicity, residence outside of New York City, and diagnosis at inpatient facilities or emergency rooms were associated with an increased likelihood of a CDX.

Conclusion: Populations with the highest proportions of CDX were ones that made up a small percentage of all new HIV diagnoses and may not be benefiting as much from current HIV prevention efforts. There are complex interactions between many factors including geographic and social characteristics that may lead to delayed diagnostic testing.

Key Words: HIV diagnosis, concurrent diagnosis, missed opportunities

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INTRODUCTION

HIV testing is a key component in the effort to prevent transmission in the United States.[1–3] Despite this, less than 40% of people in the United States have ever had an HIV test and less than 30% of people most at risk of acquiring HIV were tested in the past year.[4] With approximately 13% of individuals who have acquired HIV remaining undiagnosed in the United States,[5] testing is crucial. Similar patterns are observed in New York State (NYS). In 2021, 46% of NYS residents ever received an HIV test and 12% had a test in the past year.[6]

Routine testing plays a crucial role in the early diagnosis of HIV. Early diagnosis of HIV encourages early initiation of treatment, which has numerous clinical and community benefits including increased effectiveness of medications, decreased risk of early mortality, and reduced forward transmission.[7,8] People who are not afforded opportunities for earlier HIV diagnosis may have worse outcomes and greater medical expenses.[9] Late diagnosis is associated with an increased risk of clinical progression, greater risk of drug toxicity, and greater risk of death related to HIV.[10,11] Late presenters may demonstrate poor treatment adherence, exacerbated by the same factors that contribute to their late diagnoses, such as lack of knowledge about HIV and the benefits of highly active antiretroviral therapy.[10] Aside from the personal detrimental effects of late HIV diagnosis, late diagnosis also has harmful effects on the community.[12] When unaware of HIV acquisition, individuals may be unknowingly transmitting the virus, missing out on years of opportunities to prevent transmission through reducing behaviors that increase an individual's risk of HIV acquisition or by reducing an individual's viral load.[9,13]

Without treatment, HIV progresses to AIDS in approximately 10 years.[14] A concurrent diagnosis is defined as an HIV diagnosis that has progressed to stage 3 HIV (AIDS) within 30 days of diagnosis. Concurrent diagnoses are often a product of a lack of access to earlier testing opportunities. Previous research has noted that at a community level, poverty, lack of fuel, and lack of vehicle are related to concurrent diagnosis.[15] At an individual level, older patients were more likely and White female patients

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From the [a]Division of HIV/STD Epidemiology, Evaluation, and Partner Services, AIDS Institute, New York State Department of Health, Albany, NY; and [b]AIDS Institute, New York State Department of Health, Albany, NY.

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Correspondence to: Mark Rosenthal, MSPH, AIDS Institute, New York State Department of Health, 772 Corning Tower, Empire State Plaza, Albany, NY 12237 (e-mail: mark.rosenthal@health.ny.gov).

were less likely to have a concurrent diagnosis.[15] A study in New York City found that increasing testing coverage from 23% to 31% during 2003–2010 decreased the rate of concurrent diagnosis from 14.9 per 100,000 to 10.6 per 100,000 population.[16]

Public health initiatives that encourage testing for early diagnosis of HIV may aid in the reduction of transmission, improve health outcomes, and decrease HIV-related mortality[11] by linking people to care, treatment, and education on how to prevent transmission. On June 29, 2014, NYS announced the Ending the Epidemic Initiative, a plan to move the state closer to the end of the HIV epidemic.[17] The three-point plan aims to: (1) identify persons with HIV who remain undiagnosed and link them to health care, (2) link and retain persons diagnosed with HIV in health care to maximize virus suppression so they remain healthy and prevent further transmission, and (3) facilitate access to preexposure prophylaxis to prevent the acquisition of HIV. The Ending the Epidemic will maximize the availability of lifesaving, transmission-interrupting treatment for HIV, saving lives and improving the health of NYS residents. The plan will help NYS overcome its historical burden of the worst HIV epidemic in the country and work toward a future where new infections are rare and those living with HIV are able to live normal lifespans with minimized complications. The aim of this study was to address the characteristics of individuals who receive a concurrent diagnosis in NYS so that interventions can be developed to encourage earlier testing and address other needs among these populations.

METHODS

This study used a cross-sectional design to assess the characteristics of people who received a concurrent diagnosis (CDX) from 2016 to 2021. Records for people who were newly diagnosed with HIV from 2016 to 2021 and resided in NYS at the time of their diagnosis were extracted from the NYS HIV Registry. People who were under the age of 18 years at diagnosis, documented as having a pediatric transmission risk or missing information on the HIV disease stage at diagnosis, were excluded from the cohort. CDX was defined as a diagnosis that met the criteria for a stage 3 HIV infection (a CD4 count below 200 cells/mL or an opportunistic infection)[18] within 30 days of the initial HIV diagnosis. Sex at birth, race/ethnicity, transmission risk group, age at diagnosis, residence in New York City (NYC) or outside NYC in the rest of the state (ROS) at diagnosis, urbanicity of zip code of diagnosis, and type of facility where the diagnosis occurred were all extracted from the HIV registry to serve as covariates.

Race/ethnicity was defined as non-Hispanic Black, non-Hispanic White, Hispanic, Asian/Pacific Islander, Native American, or multirace. Transmission risk groups included individuals with a history of male-to-male sexual contact (MSM), people with a history of injection drug use (IDU), MSM/IDU, heterosexual contact, and unknown. Age at diagnosis was categorized as 18–24, 25–34, 35–44, 45–54, and 55 years and older. Urbanicity of zip codes was identified using rural–urban commuting area codes.[19] Zip codes with rural–urban commuting area values of 1–3 were classified as urban, while 4–10 were classified as rural. Diagnosing facility types were classified as outpatient; inpatient; emergency department; screening, diagnostic, and referral (SDR) organizations; other types of facilities; and unknown.

Zip code tabulation area–level measures of social determinants of health including percent below poverty, percent uninsured, percent with at least a high school education, and percent of households occupied by renters were extracted from the American Community Survey 5-year estimates for each year from 2016 to 2021. These measures were matched to individuals in this study based on their zip code of residence at diagnosis and year of diagnosis, after converting zip codes to ZIP Code Tabulation Areas (ZCTAs).[20] These community-level measures were used as a proxy for the characteristics of individuals living in each zip code.

Relative risks (RRs) and 95% confidence intervals (95% CIs) were calculated in bivariate and multivariate analyses to examine which covariates were associated with having a CDX. All variables that were significant in the bivariate analyses were included in the initial multivariate model. A backward elimination process was used to select variables to include in the final model. Adjusted RRs (aRR) were calculated using logistic regression analysis with a log-linked binomial model. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC).

The Cochran–Armitage trend test was used to identify significant trends in the count and percent of concurrent diagnoses over the 6-year study period for all diagnoses and for all levels of each variable used in the analysis.[21,22] Significance was evaluated with a two-sided *P*-value. To assess the magnitude of any trends, the slopes for the linear trend lines of the relationship between diagnosis year and percent concurrent diagnoses were calculated using linear regression.

RESULTS

The final cohort contained 14,866 people newly diagnosed with HIV in NYS from 2016 to 2021. Among these individuals, 2824 (19.0%) had a CDX (Table 1). Female patients were slightly more likely than male patients to have a CDX (RR 1.10, 95% CI: 1.01 to 1.18). Individuals with heterosexual contact as their transmission risk had the highest percentage of CDX among people with a known transmission risk at 23.0% and were 1.45 times more likely to have a CDX than individuals with MSM risk (95% CI: 1.34 to 1.56). Individuals with MSM/IDU transmission risk were less likely (RR 0.60, 95% CI: 0.43 to 0.83) than individuals with MSM risk to have a CDX. Asian individuals had the highest percentage of CDX among racial/ethnic groups at 24.5%, while Hispanic individuals had the lowest at 17.8%. Compared with non-Hispanic White individuals, Asian individuals were slightly more likely (RR 1.19, 95% CI: 1.02 to 1.38), and non-Hispanic Black individuals were less likely to have a CDX (RR 0.86, 95% CI: 0.79 to 0.95). The percentage of

TABLE 1. Characteristics of Persons With a Concurrent HIV/AIDS Diagnosis in New York State, 2016–2021

	Total		Concurrent Diagnosis		Not Concurrent Diagnosis		Unadjusted Bivariate RR		Adjusted RR	
	N	Column%	N	Row%	N	Row%	RR	95% CI	RR	95% CI
	14,866		2824	19.0	12,042	81.0				
Sex at birth										
Male	11,938	80.3	2225	18.6	9713	81.4	Ref		Ref	
Female	2928	19.7	599	20.5	2329	79.5	1.1	1.01 to 1.2	0.74	0.66 to 0.83
Transmission risk group										
MSM	8341	56.1	1325	15.9	7016	84.1	Ref		Ref	
IDU§	350	2.4	58	16.6	292	83.4	1.04	0.82 to 1.33	0.7	0.55 to 0.88
MSM/IDU	347	2.3	33	9.5	314	90.5	0.6	0.43 to 0.83	0.52	0.38 to 0.72
Heterosexual	3418	23.0	785	23.0	2633	77.0	1.45	1.34 to 1.56	1.25	1.12 to 1.39
Unknown	2410	16.2	623	25.9	1787	74.1	1.63	1.5 to 1.77	1.11	1.02 to 1.2
Race/Ethnicity										
Non-Hispanic White	2985	20.1	615	20.6	2370	79.4	Ref		Ref	
Non-Hispanic Black	6400	43.1	1185	18.5	5215	81.5	0.9	0.82 to 0.98	0.94	0.87 to 1.02
Hispanic	4607	31.0	820	17.8	3787	82.2	0.86	0.79 to 0.95	1.02	0.93 to 1.11
Asian	687	4.6	168	24.5	519	75.5	1.19	1.02 to 1.38	1.44	1.27 to 1.64
Multirace	137	0.9	26	19.0	111	81.0	0.92	0.65 to 1.31	1.15	0.83 to 1.6
Native American, Hawaiian, or Pacific Islander	50	0.3	10	20.0	40	80.0	0.97	0.56 to 1.7	1.17	0.71 to 1.91
Age at diagnosis										
18–24	2638	17.7	219	8.3	2419	91.7	Ref		Ref	
25–34	5484	36.9	763	13.9	4721	86.1	1.68	1.45 to 1.93	1.68	1.46 to 1.94
35–44	2895	19.5	649	22.4	2246	77.6	2.7	2.34 to 3.12	2.47	2.14 to 2.84
45–54	2121	14.3	625	29.5	1496	70.5	3.55	3.08 to 4.09	3.12	2.7 to 3.6
55+	1728	11.6	568	32.9	1160	67.1	3.96	3.43 to 4.57	3.18	2.75 to 3.67
Year of diagnosis										
2016	2974	20.0	506	17.0	2468	83.0	Ref		Ref	
2017	2888	19.4	537	18.6	2351	81.4	1.09	0.98 to 1.22	1.11	1.01 to 1.23
2018	2555	17.2	507	19.8	2048	80.2	1.17	1.04 to 1.3	1.18	1.07 to 1.31
2019	2395	16.1	455	19.0	1940	81.0	1.12	0.996 to 1.25	1.09	0.98 to 1.21
2020	1964	13.2	385	19.6	1579	80.4	1.15	1.02 to 1.3	1.09	0.98 to 1.22
2021	2090	14.1	434	20.8	1656	79.2	1.22	1.09 to 1.37	1.14	1.03 to 1.27
Region of residence at diagnosis*										
NYC	11,076	74.5	1934	17.5	9142	82.5	Ref		Ref	
ROS	3790	25.5	890	23.5	2900	76.5	1.34	1.25 to 1.44	1.42	1.33 to 1.52
Urbanicity of ZCRAD										
Urban	13,739	92.4	2681	19.5	11,058	80.5	Ref		Not included	
Rural	1127	7.6	143	12.7	984	87.3	0.65	0.56 to 0.76		
Type of diagnosing facility										
Outpatient	6810	45.8	929	13.6	5881	86.4	Ref		Ref	
Inpatient	4378	29.4	1478	33.8	2900	66.2	2.47	2.3 to 2.66	2.38	2.22 to 2.55
Emergency department	131	0.9	39	29.8	92	70.2	2.18	1.67 to 2.86	2.16	1.67 to 2.79
SDR organization	1406	9.5	139	9.9	1267	90.1	0.72	0.61 to 0.86	0.85	0.72 to 1.002
Other types of facility	902	6.1	69	7.6	833	92.4	0.56	0.44 to 0.71	0.62	0.49 to 0.78
Unknown or missing	1239	8.3	170	13.7	1069	86.3	1.01	0.86 to 1.17	1.05	0.9 to 1.22
Percent in poverty by ZCRAD										
≤12.1% in poverty	3670	24.7	815	22.2	2855	77.8	Ref		Not included	
≤18.9% in poverty	3530	23.7	693	19.6	2837	80.4	0.89	0.81 to 0.993		
≤29.4% in poverty	3518	23.7	688	19.6	2830	80.4	0.89	0.81 to 0.99		
>29.4% in poverty	3361	22.6	579	17.2	2782	82.8	0.76	0.68 to 0.85		
Missing	787	5.3	49	6.2	738	93.8	—	—		
Percent uninsured in ZCRAD										
≤5.9% uninsured	3913	26.3	812	20.8	3101	79.2	Ref		Not included	
≤8.4% uninsured	3665	24.7	718	19.6	2947	80.4	0.94	0.86 to 1.03		

TABLE 1. (*Continued*) Characteristics of Persons With a Concurrent HIV/AIDS Diagnosis in New York State, 2016–2021

	Total		Concurrent Diagnosis		Not Concurrent Diagnosis		Unadjusted Bivariate RR		Adjusted RR	
	N	Column%	N	Row%	N	Row%	RR	95% CI	RR	95% CI
≤11.3% uninsured	3462	23.3	649	18.7	2813	81.3	0.9	0.8 to 1.01		
>11.3% uninsured	3043	20.5	597	19.6	2446	80.4	0.92	0.82 to 1.04		
Missing	783	5.3	48	6.1	735	93.9	—	—		
Percent with at least high school education in ZCRAD										
≤11.9%	3661	24.6	766	20.9	2895	79.1	Ref		Not included	
≤18.9%	3646	24.5	734	20.1	2912	79.9	0.96	0.86 to 1.06		
≤26.1%	3484	23.4	684	19.6	2800	80.4	0.92	0.83 to 1.02		
>26.1%	3292	22.1	592	18.0	2700	82.0	0.83	0.72 to 0.96		
Missing	783	5.3	48	6.1	735	93.9	—	—		
Percent of renter-occupied households in ZCRAD										
≤49.9%	3488	23.5	853	24.5	2635	75.5	Ref		Not included	
≤70.6%	3600	24.2	693	19.3	2907	80.8	0.78	0.71 to 0.86		
≤86.4%	3600	24.2	695	19.3	2905	80.7	0.78	0.7 to 0.86		
>86.4%	3388	22.8	533	15.7	2855	84.3	0.62	0.55 to 0.71		
Missing	790	5.3	50	6.3	740	93.7	—	—		

*While NYC includes the 5 boroughs in New York City only, ROS includes all counties in New York State outside of the 5 boroughs of NYC.
ZCRAD, zip code of residence at diagnosis.

CDX by age at diagnosis followed a clear trend of increasing CDX as age at diagnosis increased: starting at 8.3% for individuals aged 18–24 and reaching 32.9% for individuals aged 55 years and older. Compared with individuals aged 18–24 years, individuals aged 25–34 years were 1.68 (95% CI: 1.45 to 1.93) times more likely to have a CDX and those aged 55 and older were 3.96 (95% CI: 3.43 to 4.57) times more likely.

Compared with individuals living in NYC, people living outside of NYC at the time of diagnosis were 1.34 (95% CI: 1.25 to 1.44) times more likely to have a CDX. People living in a rural zip code at diagnosis were 1.51 (95% CI: 1.26 to 1.81) times more likely to have CDX. People living in zip codes with higher levels of poverty had lower percentages of people with a CDX (22.2% CDX at below 12% poverty and 17.2% CDX at above 29% poverty). Compared with individuals living in zip codes with 12.1% or less living in poverty, individuals living in zip codes with more than 29.4% poverty were 0.78 times (95% CI: 0.70 to 0.85) less likely to have a CDX. People living in zip codes with higher levels of renter-occupied households (ROHs) had lower percentages of people with a CDX (24.5% CDX at below 50% ROH and 15.7% CDX at above 86% ROH). People living in zip codes with 49.9% or less ROH were 0.64 times (95% CI: 0.58 to 0.71) as likely to have CDX than those living in zip codes with greater than 86.4% ROH. Approximately one-third of people diagnosed at inpatient facilities (33.8%) or emergency rooms (29.8%) were diagnosed concurrently, compared with only 13.6% of people diagnosed at outpatient facilities. Compared with individuals diagnosed in an outpatient facility, people diagnosed at an inpatient medical facility were 2.47 (95% CI: 2.30 to 2.66) times more likely to have a CDX and individuals diagnosed in an emergency department were 2.18 times more likely (95% CI: 1.67 to 2.86).

The final multivariable model included sex at birth, transmission risk group, race/ethnicity, age at diagnosis, year of diagnosis, region of residence at diagnosis, and type of diagnosing facility. In this model, female patients were less likely than male patients to have a CDX (aRR 0.75, 95% CI: 0.67 to 0.84). This reversal is due to an uneven distribution of birth sex across transmission risk groups, with female patients only in the IDU or heterosexual risk categories, and differences by birth sex within those 2 risk categories. Individuals with IDU or MSM/IDU risk were less likely than those with MSM transmission risk to have a CDX (aRR 0.71, 95% CI: 0.56 to 0.89 and aRR 0.53, 95% CI: 0.38 to 0.73, respectively). Asian individuals were 1.44 times more likely (95% CI: 1.26 to 1.63) to have a CDX than non-Hispanic White individuals. Increased age was still associated with a higher likelihood of a CDX, with individuals aged 25–34 years were 1.67 times as likely (95% CI: 1.45 to 1.92) as those aged 18–24 to have a CDX and those aged 55 and older were 3.14 times as likely (95% CI: 2.71 to 3.62). Residence at diagnosis in any region of the state outside of NYC increased the likelihood of a CDX by 1.45 times (95% CI: 1.35 to 1.54). People diagnosed at either inpatient facilities or emergency rooms remained more than twice as likely to have a CDX as those diagnosed in outpatient facilities (aRR 2.33, 95% CI: 2.17 to 2.50, and aRR 2.16, 95% CI: 1.67 to 2.79, respectively).

Based on the results of the Cochran–Armitage trend test, there was a significant increasing trend in CDX over the six-year period among the following groups: non-Hispanic White individuals, Hispanic individuals, individuals with male sex at birth, those with MSM transmission

risk, those living in urban zip codes, and those diagnosed at SDR organizations, other facility types, or unknown facility types. In contrast to the increasing trend in the percentage of individuals with a CDX, the numbers of individuals with a CDX tended to trend downward for most categories as the total number of new diagnoses decreased over the years.

DISCUSSION

Early diagnosis of HIV is 1 of the 3 pillars of the NYS Ending the Epidemic Initiative. Early diagnosis and linkage to care can prevent long-term complications and forward transmission of HIV. The benefits of active antiretroviral therapy can only be realized when people get tested and are aware of their status. It was anticipated that with the advent of active antiretroviral therapy in the mid-1990s, earlier testing would increase. However, this has not been the trend, especially in Europe where stagnant or even increasing rates of late diagnoses are observed.[23]

The number of people concurrently diagnosed has been decreasing over time alongside the decrease in the number of people newly diagnosed with HIV. This decrease was particularly large in 2020 because of the reduced availability of services and testing during the COVID-19 pandemic. While the number of new diagnoses rebounded in 2021, HIV testing remained lower than pre-pandemic levels. Despite attempts to encourage earlier diagnosis, the proporton of individuals who receive a CDX has remained relatively stable over the past decade, even as the number of new diagnoses has declined.[13] In NYS, the proportion of CDX among new HIV diagnoses trended slightly upward over the six-year period from 17.0% in 2016 to 20.8% in 2021. This could indicate the effectiveness of widespread testing—reaching more people who had not received testing in the past. In addition, this could also indicate that there were many missed opportunities for earlier diagnosis.

In NYS, we identified that CDX were most strongly associated with increasing age at diagnosis. CDX were also more likely among those with residence outside of NYC, and rural areas in particular; individuals of Asian race/ethnicity; and those with heterosexual or unknown HIV[5] transmission risk—further investigation showed this transmission risk association was exclusive to male patients and that female patients with heterosexual risk had no increased likelihood of a CDX compared with those with MSM risk. Since most individuals newly diagnosed from 2016 to 2021 were of non-Hispanic Black or Hispanic race/ethnicity, age 18–34 at diagnosis, or reported MSM transmission risk, HIV prevention efforts often seek to engage these populations. However, our analysis showed that smaller populations are proportionately higher for CDX indicating that they may not be benefiting as much from the same interventions. These populations may need more focused and culturally appropriate HIV prevention messaging and education about HIV testing opportunities. Routine testing should be encouraged for all individuals, regardless of perceived risk, to allow for early diagnosis of HIV, so treatment can be started earlier to prevent long-term health effects. Continued research is needed to determine whether older adults, in particular, have many years of missed opportunities for earlier HIV testing and diagnosis. Further analysis showed that all groups with higher proportions of CDX were more often diagnosed at inpatient facilities or ERs, driving the strong associations seen between diagnosing facility type and CDX. This could be a sign of a lack of access to regular health care and HIV prevention education and again suggests missed opportunities for earlier diagnosis. It is also possible people presenting at these types of facilities may be in overall poor health leading to hospitalization or seeking emergency care.

By contrast, the fact that CDX were less likely among those living in areas with higher poverty or a higher proportion of renter-occupied housing and those with IDU or MSM/IDU transmission risks may indicate that these populations are being effectively reached with HIV prevention education and testing opportunities in NYS.

Limitations of this study include that social determinants of health metrics were assigned based on the zip code of residence and do not reflect the characteristics of the specific individual. This assumes that the characteristics of a zip code are reflective of an individual's characteristics. In addition, the data used in this study do not allow us to confirm whether individuals sought care due to symptoms related to HIV or whether HIV testing was offered while seeking treatment for other symptoms or comorbidities.

Future studies could focus on the effectiveness of interventions to improve testing and prevention outreach and especially effectiveness in reducing the time to diagnosis for the populations most likely to have a CDX. In addition, the long-term health outcomes of people concurrently diagnosed, such as HIV viral suppression, should be investigated. Analyzing these data by region within the state would help expand our understanding of regional demographics and inform program planning and interventions tailored to local needs. A better understanding of healthcare access before HIV diagnosis would help identify missed opportunities for earlier diagnosis, such as records of STI diagnoses before a person's HIV diagnosis.

CONCLUSION

This study indicates that the populations with the highest proportions of CDX are those that make up a small percentage of all new HIV diagnoses and therefore may not be benefiting as much from HIV prevention efforts. By understanding the characteristics of those most likely to have CDX, intervention and prevention strategies can be honed to ensure that population subgroups are not missing the benefit of specialized outreach and routine, accessible HIV testing. While individual characteristics are helpful, there are complex interactions between many factors, including geographic and social characteristics, which may lead to delayed diagnostic testing. Intervention and prevention programs should focus on individual and community characteristics when developing prevention and testing initiatives.

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