



# C.H.A.I.N. REPORT

CHAIN 2015-4 Report

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## Dropping out of HIV Medical Care

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## **Introduction**

A tremendous emphasis has been placed on maximizing engagement and retention in HIV medical care in recent years since the HIV care continuum or HIV treatment cascade model was introduced in 2011. According to the US Centers for Disease Control and Prevention (CDC), only 40% of HIV-infected persons were estimated to be engaged in care in 2011 (CDC, 2014). In 2013, President Obama issued an executive order “Accelerating Improvements in HIV Prevention and Care in the United States through the HIV Care Continuum Initiative,” directing the efforts to decrease drop-offs from each stage of the continuum. Along with the National HIV/AIDS Strategy for the United States: Updated to 2020 (White House Office of National AIDS Policy, 2015), the initiative sets a goal of increasing the rate of HIV diagnosed persons retained in HIV medical care to at least 90% by 2020. This National HIV/AIDS Strategy recognizes that co-occurring conditions, such as behavioral health issues, other infectious or chronic diseases, as well as larger socioeconomic issues including housing instability, lack of transportation, and food insecurity, can be barriers to accessing or remaining in HIV care. It urges continued research to better respond to these clinical and social co-occurring conditions that impede effective HIV prevention and care.

This study examines barriers and facilitators for retention in HIV medical care using data from the Community Health Advisory & Information Network (CHAIN). CHAIN is an ongoing cohort study of a probability sample of persons with HIV (PWH) in New York City (NYC) and the suburban Tri-County region, generally representative of PWH receiving publicly funded medical or social services. The purpose of this study is to address the following questions: (1) what proportion of participants drop out of HIV medical care for one or more periods after initial entry into care? (2) who drops out? (3) what predicts dropping out compared to sustained engagement, and (4) what are the reasons participants give for dropping out of care? Understanding the factors that prevent PWH from engaging in care will inform interventions targeting the issue.

## **Key Findings**

- Twenty five-percent (25%) of NYC and 12% of Tri-County study participants reported at least one episode of dropping out of care (intentionally not going for any medical visits for six months or more) since they were diagnosed with HIV.
- There was a decreasing trend in the proportion of recent dropouts at each interview period from a high of 14-19% among PWH interviewed in 2002-2004 to 5%-6% in 2013-2014. However, PWH diagnosed in the past 5 years were no less likely to report dropout episode(s) compared to those diagnosed longer ago.
- Demographic characteristics were less strongly associated with dropout than situational considerations and receipt of supportive services. Older participants and those with higher

education were less likely to drop out. Participants in stable housing and those who received social services case management were also less likely to drop out than their counterparts.

- Participants experiencing financial hardship in the past six months (very low income, food insecurity, needing transportation services), those reporting active problem substance use, and those with lower mental health functioning had higher odds of dropping out during the same period than participants without these challenges.
- Receipt of food, transportation, and mental health services reduced the odds of dropping out to the equivalent level among individuals without these challenges.
- Receipt of alcohol and drug treatment services did not reduce the odds of dropping out.
- Health status change was associated with dropping out; participants reporting improved health compared to the prior year were more likely to drop out. Dropout was also associated with health decline, likely a result from, rather than cause of a period of no medical care.
- The reasons PWH in the study gave for dropping out include lack of perceived need for or intentional resistance to HIV treatment, substance abuse or mental health issues, competing needs and life stressors, and dissatisfaction with doctor, organization, or care. Logistical barriers were less often mentioned.

## **Methodology**

*Cohort Recruitment:* Study samples are drawn from participants in the Community Health Advisory & Information Network (CHAIN) Project, a prospective cohort study of persons living with HIV and AIDS in NYC.

The NYC CHAIN cohort was recruited in 2002 and augmented with a refresher sample that was recruited in 2009-2011, using the same sampling and recruitment protocol. Agencies with known HIV+ clients ( $n \geq 20$ ) were randomly selected from a sampling frame stratified by type of agency (medical or social service agency) and borough. Clients from each participating agency were sampled either through random selection from a listing of the agency's HIV-infected clients or through onsite sequential enrollment. To protect the privacy of agency clients, agency staff made initial contact to determine interest in the study. Contact information of interested clients was provided to CHAIN staff for formal enrollment and informed consent procedures.<sup>1</sup> For the original recruitment, we enrolled 693 clients from 43 agencies. For the refresher sample, we enrolled 319 clients from 18 agencies. The participants were interviewed every 12-18 months. The Tri-County CHAIN cohort was originally recruited in 2001 and augmented with a refresher sample that was recruited in 2004-2006, using a similar sampling and recruitment protocol to that of the NYC CHAIN.

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<sup>1</sup> For a detailed description of the recruitment of the 2002 NYC cohort, see CHAIN Report 2004-4: Field Notes: Recruiting.

For the original recruitment, we enrolled 398 clients from 32 medical or social service agencies. For the refresher sample, we enrolled 84 clients. However, starting at Round 5 in 2008, Tri-County shifted to a repeated cross-section design with little overlap in respondents between each round (or between those later rounds and the cohort interviewed for Rounds 1-4 in Tri-County).

Study Variables: The CHAIN Project collects information on multiple aspects of an individual's life, including use of social and medical services, as well as demographic, behavioral and well-being measures relevant to need for these services. Study variables for this analysis were chosen based on the theoretical and empirical evidence suggesting the variable has an effect on retention in HIV medical care.

In the CHAIN Project, an individual is classified as a "dropout" of HIV medical care when he or she answers that since last interview (for follow-up interviews) or since last year (for baseline interviews), he or she 'stopped going to the doctor or just didn't have any medical appointments for six months or more.' Interviewers are instructed to probe and not to include participants as dropouts if they report a bi-annual appointment scheduled slightly late due to schedule conflicts or availability of appointment slots. When respondents report that they had an episode of dropping out of care, a subsequent question is asked to describe the reasons and/or situations affecting not having any medical appointments during the drop out period.

Mental and physical health functioning are measured using the Medical Outcomes Study (MOS) SF-12v2 Mental Component Summary and Physical Component Summary (MCS, PCS)(Ware, 2005). The score of 42 as a cut-off point for low mental health functioning is in accordance with the Medical Outcomes Trust guidelines. For physical health functioning, the original score is used as a continuous measure in the multiple regression models.

Personal income under \$7,500 yearly is used to approximate the effect of extreme poverty on HIV primary care. This measure is used rather than the US Census poverty threshold since the majority of the CHAIN participants have incomes (60%-82% in NYC, 51%-69% in Tri-County) below this level and almost all participants (93-98% in NYC and 89%-96% of Tri-County) fall under 300% of the poverty threshold. Individual income was used since unstable housing and/or irregular household composition did not consistently or accurately represent the poverty level of the CHAIN participants. The value \$7,500 was selected since it is below the maximum Supplemental Security Income payment amount for 2016 is \$8796/year, and the average payment of \$8400/year received by study participants on for Social Security Disability Insurance.

Definitions of all study variables are listed in Table 1.

**Table 1. Study Variable Definitions**

<b>Variables</b>	
<b>Dropout:</b>	Report of going 6 months or more without going to any appointments for HIV medical care or having stopped going to the doctor
<b>Self-identified gender:</b>	Male, Female, Transgender
<b>Race/Ethnicity:</b>	Black non-Hispanic, Hispanic/Latino, White non-Hispanic or Other
<b>Current Age :</b>	Age under 40, age 40-59, age 60 and above; Continuous age for regression analyses
<b>Place of birth:</b>	U.S., Puerto Rico/Virgin Islands, Other Country
<b>Education:</b>	HS diploma/GED or less, post-secondary
<b>Married or have partner:</b>	Currently married or have a regular partner
<b>Work status:</b>	Currently working full-time or part-time
<b>Extreme poverty:</b>	Personal income less than \$7,500 in the previous year
<b>Risk exposure:</b>	Ever MSM, Ever Injection Drug Use (IDU)/Ever IDU+Ever MSM, Heterosexual/Other
<b>Years since diagnosis:</b>	5 years or less, 6-10 years, 11-20 years, over 20 years
<b>Delayed entry into HIV care</b>	Report of taking more than 3 months from diagnosis to first entry into HIV care (first evaluation for treatment).
<b>Physical health functioning:</b>	MOS SF-12v2 Physical Health Component Summary Score (PCS)
<b>Health since 6 months ago:</b>	Response of better (much better now/somewhat better now), same (about the same), or worse (somewhat worse now/much worse now), to the question: "Compared to 6 months ago, how would you rate your health in general now?"
<b>In unstable housing:</b>	"Homeless"—report of being homeless or sleeping on the street, in a shelter, or in an SRO or welfare hotel with no services in last six months, or "Unstable"—report of being in a transitional housing program, in AOD treatment housing with no other address, or temporarily doubled up with friends or family
<b>Recent incarceration:</b>	Incarceration during the past 6 months
<b>Food insecure:</b>	Report of not having enough money for food (once in a while/fairly often/very often) or report of needing help or assistance in food, groceries, or meals , or report of receiving food services (see below) in the past 6 months.
<b>Food services:</b>	Receipt of one or more of the following services in the last 6 months: (1) meals provided in a group setting, (2) prepared meals delivered to home, (3) food voucher or food from a food pantry, (4) SNP or food stamps, (4) WIC, or (5) other food, meal, groceries assistance
<b>Transportation need:</b>	(1) Report of need for transportation assistance OR (2) report that lack of transportation resulted in delayed or missed medical or social services in the past six months, OR (3) need for home care services (as defined by a report that health limits "a lot" activities like moving a table, carrying groceries, or pushing a vacuum cleaner AND health limits "a lot" climbing several flights of stairs), OR (4) report of receiving transportation services in the past 6 months
<b>Transportation services:</b>	Receipt of transportation services in the last 6 months
<b>Recent problem substance use:</b>	Use of Crack/Cocaine/Heroin or problem drinking during the past 6 months
<b>Prof. alcohol or drug treatment services:</b>	Receipt of professional alcohol or drug treatment (inpatient or outpatient treatment, detox, residential treatment, methadone maintenance, buprenorphine, employee assistance program, individual counseling), not including self-help groups (e.g., AA, NA), during the past 6 months
<b>Low mental health functioning:</b>	MOS SF-12v2 Mental Component Summary Score (MCS) <42
<b>Prof. mental health services:</b>	Receipt of mental health services from a mental health care professional, such as a psychiatrist, a psychologist, or a therapist, during the past 6 months
<b>Medial case management:</b>	Receipt of case management that referred or helped to get specific medical services during the past 6 months.
<b>Social service case management:</b>	Receipt of case management that referred or helped to get social services, revised or developed a plan for dealing with needs, or filled out forms for benefits or entitlements during the past 6 months

Note: Gender, race/ethnicity, place of birth, education, risk exposure, years since diagnosis, delayed entry into HIV care measured at baseline interview. All other variables measured at each interview period.

*Study Sample:* The analytic sample was obtained from 4,941 interviews (3,695 in NYC and 1,246 in Tri-County) conducted between 2001 and 2015 with 1,603 individual PWH (887 in NYC and 716 in Tri-County). At each interview, study participants were asked about experiences of dropping out of care or not having an appointment for HIV medical care for more than 6 months prior to interview. The average number of interviews completed per person was 4.0 for NYC and 1.7 for Tri-County. Table 2 presents the study's sample characteristics. This table represents characteristics reported at the baseline interview used for the present analysis.

*Analysis:* Descriptive analyses were run to assess trends and subgroup differences in experiences with dropping out of care. In order to assess the possible impact of attrition on the dropout trends, trends were also evaluated by controlling for the number of interviews completed by a participant as well as the refresher status. To illustrate subgroup differences, we calculated the average percentage of dropouts across all interview periods for each subgroup (i.e. for males and females, for respondents in stable and unstable housing, etc.) for NYC and Tri-County. Table 3 presents these averages.

Random effects logit models are used to estimate the predictors of dropping out of care, adjusting for correlation among repeated observations on individuals. In the regression analyses, interactions between service need and service use are explored. Specifically, 2 by 2 interaction variables are created for food, transportation, AOD treatment, and mental health service categories. The first category serves as the reference category and includes those not needing the service (e.g. food secure) and not receiving the particular type of service (e.g. food assistance). The second category includes those not reporting need for the service in the past six months but receiving services during this time – this category most likely includes those who needed the service previously and received services that resolved their need. The third category includes those with unmet need – that is, in need but not receiving services in the service category. The last category includes those who indicated need for the service in the past six months and also received services to address the need. For the food and transportation service categories, participants who reported receiving services during the past 6 months were categorized as needing the service, thus creating a 3-category variable. This is based on the observation that these needs are ongoing and removing the services (e.g. discontinuing food assistance from persons who are food insecure) will bring them back to the “in need” category. For the AOD treatment and mental health service categories, the 4-category variables are used since it is possible that services address the need as operationally defined here (e.g. problem drug use ceases, mental health episode resolves) and/or individuals may seek AOD or mental health services for reasons not specified by our definition of need. For example,

**Table 2. Sample Characteristics at Baseline Interview**

		<b>New York City</b>	<b>Tri-County</b>
<b>Total N</b>		887	716
<b>Ever dropped out of care since HIV diagnosis:</b>		25%	12%
<b>SOCIODEMOGRAPHICS</b>			
<b>Gender</b>	<i>Male</i>	58%	49%
	<i>Female</i>	40%	50%
	<i>Transgender</i>	2%	1%
<b>Race/Ethnicity</b>	<i>Black</i>	55%	56%
	<i>Latino</i>	34%	25%
	<i>White/Other</i>	11%	19%
<b>Age</b>	<i>Mean(sd)</i>	47.2 (8.8)	46.6 (9.6)
	<i>Age under 40</i>	17%	22%
	<i>Age 40-49</i>	44%	40%
	<i>Age 50 and over</i>	39%	38%
<b>Birth place</b>	<i>US</i>	74%	74%
	<i>PR</i>	9%	6%
	<i>Other</i>	16%	21%
<b>Education high school grad</b>		59%	64%
<b>Married or have a partner</b>		38%	45%
<b>Working full- or part-time</b>		8%	19%
<b>Income &lt;\$7,500/year</b>		21%	15%
<b>HIV DIAGNOSIS AND ENTRY INTO CARE</b>			
<b>Risk exposure group</b>	<i>IDU</i>	25%	17%
	<i>IDU/IDU+MSM</i>	29%	26%
	<i>Heterosexual/ Other</i>	45%	56%
<b>Years since HIV diagnosis</b>	<i>mean</i>	11.9 (5.6)	10.9 (6.3)
	<i>5 years or less</i>	15%	24%
	<i>6-10 years</i>	27%	25%
	<i>11-20 years</i>	50%	45%
	<i>Over 20 years</i>	7%	6%
<b>Delayed initial entry into HIV care</b>		26%	20%
<b>HEALTH STATUS</b>			
<b>Physical health functioning</b>		<i>Mean(sd)</i>	44.3 (11.4)      43.4 (12.9)
<b>Health since 6 months ago</b>	<i>Better</i>	43%	40%
	<i>Same</i>	42%	46%
	<i>Worse</i>	15%	13%
<b>SERVICE NEED AND SERVICE USE*</b>			
<b>In unstable housing</b>		22%	17%
<b>Recent incarceration</b>		3%	2%
<b>Food insecure</b>		35%	44%
<b>Received food services</b>		90%	77%
<b>Need transportation services</b>		26%	33%
<b>Received transportation services</b>		6%	23%
<b>Recent problem substance use</b>		23%	19%
<b>Received professional AOD services</b>		14%	12%
<b>Low mental health functioning (MCS&lt;42)</b>		49%	54%
<b>Received professional mental health treatment</b>		36%	28%
<b>Received medical case management</b>		27%	37%
<b>Received social service case management</b>		60%	60%

\*within past six months

individuals may not be actively using drugs but be receiving AOD services as relapse prevention. Similarly, respondents who receive professional mental health services may do so because of emotional or psychological needs without necessarily having a low mental health functioning score.

In addition to quantitative analysis estimating the effect of factors predicting dropping out of care, content analysis was conducted to code qualitative data provided through open-ended questions asking dropouts to describe their reasons for gaps in HIV medical care: respondents were asked to explain why they “stopped going to the doctor or just didn’t have any appointments for six months or more.” An open coding approach was used by two separate coders to code all reasons given for dropout; differences were resolved by a third coder, and a final set of major themes was developed.

## **Results**

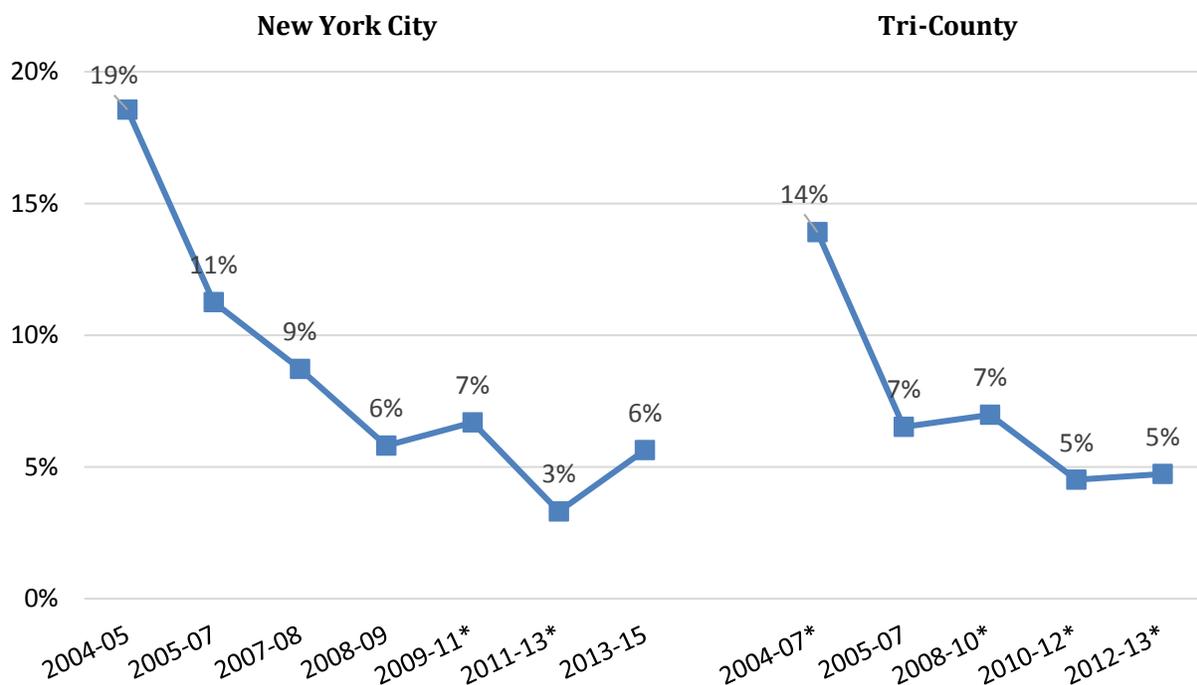
### ***Patterns of drop out***

One in four NYC CHAIN participants and one in eight Tri-County CHAIN participants have dropped out of HIV medical care for 6 months or more since their diagnosis. Considering more recent experiences of dropping out, the same proportion of participants (25% in NYC and 12% in Tri-County) reported one or more experience of dropping out during the study period. That is, at one or more follow-up interview, they reported not going to their HIV provider for six months or more at some point since the last interview (12-18 months prior). In NYC, the trend in rates of recent dropping out of care declined from the 2004-2005 period, when 19% of participants reported a recent period of dropout, to 2013-2015, when 6% reported recently dropping out. A similar trend was seen in Tri-County: 14% during 2004-2007 and 5% during 2012-2013 reported that they had a recent  $\geq 6$ -month break from seeing any HIV medical provider (Figure 1). These trends were re-assessed by controlling for the number of interviews completed by a respondent and the results did not vary from the original trend.

### ***Subgroup analysis***

Table 3 presents subgroup differences, in patterns of dropping out for NYC and Tri-County study participants. There are more women than men among dropouts; transgender rates of drop out appear high, but small numbers in the sample limit interpretation. Older persons living with HIV are less likely to report a recent episode of dropping out in both NYC and Tri-County. Regarding education, in NYC, a higher proportion of drop outs have less than high school education than among drop outs in Tri-County. Very low income and unmet need for transportation characterize drop outs in both NYC and Tri-County but differences are greater among CHAIN study participants in New York.

**Figure 1. Trends in Recent Dropping Out of Care (within past year or since prior interview)**



\*include baseline interviews

***Predictors of drop out***

Estimates from the regression models indicate that recent problem substance use is the strongest predictor for dropping out of care in both NYC and Tri-County. When a participant is actively using drugs or alcohol (problem drinking or using crack, cocaine, heroin), the adjusted odds of dropping out of HIV medical care are roughly 4-5 times higher in NYC and 3-4 times higher in Tri-County than among similar participants not currently using drugs (Table 4).

*NYC:* In NYC, being older and born in a foreign country, and having higher education (more than high school diploma or GED) are associated with lower odds of dropping out of care. More recent diagnosis is associated with increased odds of dropping out; participants who were diagnosed between 6 and 20 years ago are twice as likely as those diagnosed over 20 years ago to drop out. Several situational factors, especially factors related to poverty, predict participants’ retention in care. Living in extreme poverty (personal income \$7,500 or less a year) or in unstable housing, and experiencing food insecurity and transportation service needs but not receiving related services all substantially increase the odds of not seeing an HIV primary care provider. The regression results also show that the odds of gaps in primary care are almost twice as high among working participants as among those not currently working (AOR=1.8).

**Table 3. “Dropouts” by client characteristics, service needs and utilization patterns**

		<b>NYC</b>	<b>Tri-County</b>
		<i>Dropouts</i>	<i>Dropouts</i>
<b>SOCIODEMOGRAPHICS</b>			
<b>Gender</b>			
	<i>Male</i>	7.9%	4.7%
	<i>Female</i>	9.3%	6.1%
	<i>Transgender</i>	(11.9%) <sup>1</sup>	(40.0%)
<b>Race/Ethnicity</b>			
	<i>Black</i>	8.5%	6.2%
	<i>Latino</i>	8.4%	4.6%
	<i>White/Other</i>	9.4%	5.1%
<b>Age</b>			
	<i>Age under 40</i>	10.7%	7.6%
	<i>Age 40-49</i>	10.3%	5.9%
	<i>Age 50 and over</i>	6.6%	4.8%
<b>Birth place</b>			
	<i>USA</i>	9.4%	5.6%
	<i>Puerto Rico</i>	7.1%	(6.0%)
	<i>Other</i>	5.1%	3.6%
<b>Have more than high school education</b>			
	<i>Yes</i>	5.2%	8.6%
	<i>No</i>	9.3%	5.0%
<b>Married or have a partner</b>			
	<i>Yes</i>	9.6%	4.8%
	<i>No</i>	7.7%	6.2%
<b>Working full- or part-time</b>			
	<i>Yes</i>	10.6%	6.2%
	<i>No</i>	8.4%	5.5%
<b>Income &lt;\$7,500/year</b>			
	<i>Yes</i>	13.7%	9.6%
	<i>No</i>	7.2%	5.0%
<b>HIV DIAGNOSIS AND ENTRY INTO CARE</b>			
<b>Risk exposure group</b>			
	<i>MSM</i>	8.6%	6.8%
	<i>IDU<sup>1</sup>/IDU+MSM</i>	10.2%	7.5%
	<i>Heterosexual/ Other</i>	7.5%	5.8%
<b>Years since diagnosis</b>			
	<i>5 years or less</i>	6.3%	4.9%
	<i>6-10 years</i>	8.3%	7.6%
	<i>11-20 years</i>	9.5%	5.5%
	<i>Over 20 years</i>	10.1%	(6.2%)
<b>Delayed entry into HIV care</b>			
	<i>Yes</i>	9.8%	4.6%
	<i>No</i>	8.1%	5.8%

Note: Percentages shown are the average percentage of recent dropouts within subgroup across all interview periods.

<sup>1</sup> Caution should be exercised when interpreting percentages based on small sample sizes, indicated by parentheses (N<25)

**Table 3. “Dropouts” by client characteristics, service needs and utilization patterns (cont.)**

	NYC	Tri-County
	<i>Dropouts</i>	<i>Dropouts</i>
<b>HEALTH STATUS</b>		
<b>Health since 6 months ago</b>		
<i>Better</i>	8.9%	4.3%
<i>Same</i>	6.6%	6.1%
<i>Worse</i>	13.4%	8.9%
<b>SERVICE NEED AND SERVICE USE*</b>		
<b>In unstable housing</b>		
<i>Yes</i>	15.0%	7.3%
<i>No</i>	7.6%	5.4%
<b>Recent incarceration</b>		
<i>Yes</i>	19.5%	20.8%
<i>No</i>	(8.4%)	(5.5%)
<b>Food security and service use</b>		
<i>Food secure</i>	8.1%	3.7%
<i>Food insecure and received food services</i>	8.6%	6.1%
<i>Food insecure and no food services</i>	(10.2%)	(3.9%)
<b>Transportation need and service use</b>		
<i>Did not need transportation services</i>	7.9%	5.4%
<i>Needed transportation and received services</i>	8.8%	3.8%
<i>Needed transportation and no transportation services</i>	12.1%	9.8%
<b>Problem substance use and service use</b>		
<i>No recent problem substance use and no AOD services<sup>1</sup></i>	5.8%	4.6%
<i>No recent problem substance use and received AOD</i>	8.3%	(3.1%)
<i>Recent problem substance use and no AOD services</i>	18.5%	11.1%
<i>Recent problem substance use and received AOD</i>	15.2%	(15.5%)
<b>Mental health functioning and service use</b>		
<i>Higher MH functioning and no MH services<sup>2</sup></i>	6.3%	6.0%
<i>Higher MH functioning and received MH services</i>	6.8%	3.6%
<i>Low MH functioning and no MH services</i>	12.8%	6.6%
<i>Low MH functioning and received MH services</i>	8.3%	4.8%
<b>Received medical case management</b>		
<i>Yes</i>	8.8%	5.5%
<i>No</i>	8.7%	6.1%
<b>Received social service case management</b>		
<i>Yes</i>	9.7%	6.1%
<i>No</i>	7.8%	5.7%

Note: Percentages shown are the average percentage of dropouts within subgroup across all interview periods.

<sup>1</sup> Caution should be exercised when interpreting percentages based on small sample sizes, indicated by parentheses (N<25)

\*within past six months

Factors related to health, behavioral health, and related services appear to be strong predictors. Changes in general health status, whether a change for the better or the worse, increase the participant's odds of dropping out of care compared to those whose health status remains constant (AOR=1.6). Participants with recent problem substance use are significantly more likely to have dropout episodes, even after receipt of AOD treatment services (AOR=3.2 without treatment compared to AOR 2.3 with treatment). Participants with lower mental health functioning have increased odds of dropping out of care when they have not received professional mental health services (AOR=1.8). Social service case management decreases the odds of dropping out of care by 30%.

*Tri-County:* As in NYC, recent problem substance use (with or without AOD treatment), food insecurity and transportation needs, without receipt of services to address these needs, increase the odds of dropping out of care in Tri-County. Transgender women in Tri-County are 20 times more likely to drop out of care than male participants; however, caution should be exercised when interpreting this finding, since it is based on only 8 observations provided by four individuals of transgender experience. Among participants with lower mental health functioning, receipt of professional mental health services reduced the odds of dropping out of care by 60%.

### ***Qualitative Analysis***

A total of 220 New York and 67 Tri-County study participants who experienced one or more recent episodes of dropping out of care were asked to report their reasons. Narrative answers were coded, and results for NYC are shown in Table 5. Multiple answers were possible per interview.

While reasons were diverse, several themes emerged from narrative descriptions of reasons for episodes of non-engagement in HIV medical care. The most common response was a version of “I just stopped, didn't feel like going, didn't care about treatment” (25%). In the NYC cohort, the most common response appeared to convey what might be considered ‘treatment fatigue.’ One-fourth (25%) of those who had no medical visits for over six months said they just stopped, didn't feel like going, or didn't care about treatment. Eight percent specifically mentioned wanting to avoid or stop taking HIV medications and another 5% said they were “tired of it, was fed up, wanting a break” without specifically mentioning medications. Substance abuse issues were reported as a reason for dropout by 21% of respondents, and 12% reported depression or other mental health challenges. One in eight (12%) claimed that they didn't need to have any appointments for HIV medical care because they felt fine, didn't have symptoms, or were not sick; and another 8% said they didn't

**Table 4. Predictors of Dropping Out of HIV Medical Care**

	New York City		Tri-County	
	OR	AOR	OR	AOR
<b>Male</b>	1			
<b>Female</b>	1.06	1.39	1.25	1.61
<b>Transgender<sup>1</sup></b>	1.88	1.58	11.70*	19.92**
<b>White/Other</b>	1			
<b>Black</b>	0.92	0.86	1.17	1.08
<b>Latino</b>	0.98	0.84	0.85	1.26
<b>Age</b>	0.93***	0.95***	0.98	1.00
<b>Birth place</b>				
	<i>US</i>	1		
	<i>PR</i>	0.79	1.04	0.75
	<i>Other</i>	0.39**	0.69	0.68
<b>Have more than HS/GED</b>	0.49*	0.56*	1.58	1.56
<b>Married or have partner</b>	1.05	1.12	0.84	0.80
<b>Work FT or PT</b>	1.19	1.76*	1.02	1.41
<b>Income &lt;\$7,500/year</b>	2.25***	1.84**	2.03*	1.84
<b>Risk exposure group</b>				
	<i>MSM</i>	1		
	<i>IDU<sup>1</sup>/IDU+MSM</i>	1.53#	1.31	0.57
	<i>Heterosexual/ Other</i>	0.78	0.72	0.84
<b>Years since diagnosis</b>				
	<i>5 years or less</i>	2.62*	1.32	1.05
	<i>6-10 years</i>	2.93***	2.12*	1.86
	<i>11-20 years</i>	2.51***	2.28**	1.28
	<i>over 20 years</i>	1		1.05
<b>Delayed entry into HIV care</b>	1.48#	1.14	0.74	0.79
<b>Physical health functioning</b>	1.00	1.00	1.00	1.02
<b>Health since 6 months ago</b>				
	<i>better</i>	1.55**	1.55*	0.64
	<i>same</i>	1		0.62
	<i>worse</i>	2.21***	1.66*	1.35
<b>In unstable housing</b>	2.07***	1.75*	1.19	0.81
<b>Recent incarceration</b>	1.49	0.68	3.37#	0.62
<b>Food secure</b>	1			
<b>Food insecure and received food services</b>	1.09	0.94	1.79	1.93
<b>Food insecure and did not receive food services</b>	1.89	2.23	1.34	1.48
<b>Did not need transportation services</b>	1			
<b>Needed transp. services and received transp. services</b>	1.07	1.34	0.73	1.10
<b>Needed transp. services and did not receive transp. services</b>	1.78***	1.88**	1.66	2.21#
<b>No recent problem AOD use and did not receive AOD services</b>	1			
<b>No recent problem AOD use and received AOD services</b>	1.82#	1.28	0.71	0.61
<b>Recent problem AOD use and did not receive AOD services</b>	4.33***	3.23***	2.51**	2.17#
<b>Recent problem AOD use and received AOD services</b>	4.93***	2.28*	3.54**	3.21#
<b>Higher MH functioning and did not receive MH services</b>	1			
<b>Higher MH functioning and received MH services</b>	1.21	1.01	0.47	0.50
<b>Low MH functioning and did not receive MH services</b>	2.33***	1.76**	1.28	1.07
<b>Low MH functioning and received MH services</b>	1.45#	1.14	0.62	0.39#
<b>Received medical case management</b>	0.93	0.92	1.07	1.07
<b>Received social service case management</b>	0.67**	0.70*	0.91	0.79

# p<.10, \* p<.05, \*\* p<.01, \*\*\* p<.001

AOR = adjusted odds ratio from random effects logit models which adjust for the dependency among multiple observations contribute by the same individual. Analysis based on 820 NYC respondents with 3,153 observation points and 609 Tri-County respondents with 1,046 observation points.

<sup>1</sup> 16 transgender respondents with 74 observations in NYC. 4 transgender respondents with 6 observations in Tri-County.

think they needed to go for visits for other reasons. Situational considerations were often important; respondents described difficulties with competing needs and life stressors (e.g. family needs), as well as incarceration, and homelessness /unstable housing, as explanations for dropping out of medical care. Dissatisfaction with doctors or organization of care (e.g. wait times) and logistical barriers (e.g. lack of transportation) were less often mentioned.

Reasons for dropping out of care were very similar in the Tri-County sample, except insurance issues were mentioned by twice as many (11%) and active drug use was mentioned by significantly fewer respondents (6%) than among New York City dropouts. Similar to NYC, competing needs and life stressors, and 'treatment fatigue' or just not going for appointments, wanting a break, etc. were relatively high on the list of reasons, mentioned by 11-12% of dropouts. Only 4% of Tri-County respondents said that feeling fine/not experiencing symptoms was a reason not to follow through with HIV medical care visits.

## **Discussion**

Twenty-five percent (25%) of NYC CHAIN participants and of 12% Tri-County CHAIN participants have dropped out of HIV primary care for 6 months or more at least once since their diagnosis as HIV positive. Although trends of dropout appear to be decreasing over time, at each round of interviews with CHAIN study participants, 5%-6% report not seeing any primary care provider during the prior six months or longer.

Regarding predictors of dropping out of care, this study found dropping out to be significantly associated with recent problem substance use, low mental health functioning, poverty, housing instability, transportation service needs, and food insecurity. This is consistent with the co-occurring conditions recognized in the National HIV/AIDS Strategy as barriers to accessing and remaining in HIV care. Conforming to other studies' findings (Kerr et al., 2005; Olatosi, Probst, Stoskopf, Martin, & Duffus, 2009; Rana et al., 2015), we found that the likelihood of dropping out of care decreases with increasing age.

We also found that working full-time or part-time increases the odds of disengagement in care. This may reflect competing priorities, especially when the work does not provide paid time off and/or there are disclosure concerns associated with attending medical appointments. Changes in general health status were also a significant factor. PWH who reported their health being better than 6 months ago were more likely to drop out, possibly feeling it unnecessary to see their HIV provider. PWH who reported worse health were also more likely to drop out; however, we cannot evaluate

**Table 5. Self-Reported Reasons for Dropping Out of HIV Medical Care**

	<i>Total Sample</i>	<b>New York City</b>	
		<b>(n=220)</b>	<b>100%</b>
Just stopped, didn't feel like going, didn't care about treatment	54	25%	
Doing drugs, relapsed	46	21%	
Felt fine, wasn't sick, no symptoms	27	12%	
Mental Health (depression, mind was a mess, emotional issues)	27	12%	
Disruption in care (program closed, doctor left, I moved or was moved)	26	12%	
Competing needs, life stressors (work, family issues, parole requirements)	21	10%	
Did not want HIV medications/ wanted to discontinue meds/ use alternative practices	18	8%	
Did not like the doctor	17	8%	
Didn't think I needed to go, had enough pills, doctor did not require	17	8%	
Was overwhelmed, too stressful or frightening to deal with	14	6%	
Forgot/just missed appointments	13	6%	
Tired of it, was fed up, wanted a break	11	5%	
Insurance issue, no insurance, coverage issue	9	4%	
Don't care for doctors/hospitals in general	8	4%	
Fear/avoidance of what doctor would say (e.g about non-adherence, drug use)	8	4%	
Other health issues, physical health limitation	6	3%	
Service was poor, dissatisfied with outcomes	6	3%	
Fatalism, wanted to give up, nothing could be done	9	4%	
In denial about HIV - couldn't/didn't want to believe was infected	5	2%	
I was incarcerated, didn't want to get care in jail/prison	5	2%	
Logistical barriers (clinic too far, no transportation, child care complications)	5	2%	
Was homeless, unstably housed	4	2%	
Characteristics of the clinic or services (no single doctor, no choice of doctor, wait times)	4	2%	
Stigma, did not want to be associated with HIV/PLWH	2	1%	
Other personal or structural reason	10	5%	

Note: Multiple responses possible.

whether their health was worse due to dropping out of care or they stopped going to see their provider because their health had gotten worse (e.g., avoiding bad news or a doctor's reprimand for medication non-adherence or substance use relapse).

Since the introduction of antiretroviral therapy (ART), mortality from HIV has dramatically declined and the quality of life for PWH has improved substantially. HIV is now considered a chronic illness rather than a terminal illness. Nevertheless, delaying or avoiding disease progression requires maintaining HIV care and adhering to prescribed treatments. The risk factors for dropping out of care, in this study as well as in other studies, direct our attention to promising points of intervention: clearly communicating the importance of consistent engagement in medical care, addressing feelings about the need and value of medical care even when feeling well, addressing substance use and mental health challenges, and providing the supportive services necessary to sustain engagement (for recent review see, [Bulsara, Wainberg & Newton-John, 2016](#)). Only when service needs and health beliefs have been addressed will we see individual and public health outcomes that approach the collective goal of ending the epidemic.

## References

- Bulsara, S.M., Wainberg, M. L., Newton-John. T.R. O. (2016). Predictors of Adult Retention in HIV Care: A Systematic Review. *AIDS & Behavior*, epub. doi 10.1007/s10461-016-1644-y
- Centers for Disease Control and Prevention. (2014). *Vital Signs: HIV Diagnosis, Care, and Treatment Among Persons Living with HIV — United States, 2011*.
- Kerr, T., Marshall, A., Walsh, J., Palepu, A., Tyndall, M., Montaner, J., . . . Wood, E. (2005). Determinants of HAART discontinuation among injection drug users. *AIDS Care*, 17(5), 539-549. doi: 10.1080/09540120412331319778
- Olatosi, B. A., Probst, J. C., Stoskopf, C. H., Martin, A. B., & Duffus, W. A. (2009). Patterns of engagement in care by HIV-infected adults: South Carolina, 2004-2006. *AIDS*, 23(6), 725-730. doi: 10.1097/QAD.0b013e328326f546
- Rana, A. I., Liu, T., Gillani, F. S., Reece, R., Kojic, E. M., Zlotnick, C., & Wilson, I. B. (2015). Multiple gaps in care common among newly diagnosed HIV patients. *AIDS Care*, 27(6), 679-687. doi: 10.1080/09540121.2015.1005002
- Sayles J.N., Wong M.D., Kinsler J.J., Martins D., Cunningham W.E.. (2009). The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *J Gen Intern Med*, 24(10):1101-8.
- Ware, J. E. (2005). *How to score version 2 of the SF-12 health survey (with a supplement documenting version 1)*. Lincoln, R. I.; Boston, MA: QualityMetric Inc.; Health Assesment Lab.
- White House Office of National AIDS Policy. (2015). *National HIV/AIDS Stragety for the United States: Updated to 2020*. Washington D. C.