Delayers and Dropouts: Dropping Off the Care Continuum

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Background

Timely linkage to HIV care and regular medical visits are necessary to monitor clinical status of HIV disease, to derive maximal benefit from antiretroviral therapy and other treatments, and to control the epidemic. However, surveillance data indicate that almost half of people with HIV (PWH) in New York City delay either HIV testing, delay entry into medical care, or both. An estimated one in four who are linked with care are not continuously engaged in care over time.

This study examines delayed entry to care (Delayers) and dropping out of care (Dropouts) among people diagnosed with HIV . The purpose of the Delayers study is to examine: 1) HIV testing and entry into care experiences among people with HIV in New York City and in the suburban Tri-County Region; 2) patterns of delayed vs. timely entry into HIV care after diagnosis with a focus on individual characteristics and situational factors associated with delayed entry into care; 3) the reasons that delayers give for not entering HIV care in a timely manner; and 4) a multivariate analysis of risk factors for delayed entry into care. The Dropouts study examines retention in care over time, asking similar questions: 1) Who drops out? 2) What predicts dropping out compared to sustained engagement, and 3) what are the reasons people with HIV give for dropping out of the care continuum.

Data are provided by in-person interviews with 1603 PWH recruited in 2001-2002 or 2008-2010 with follow up interviews conducted approximately yearly.

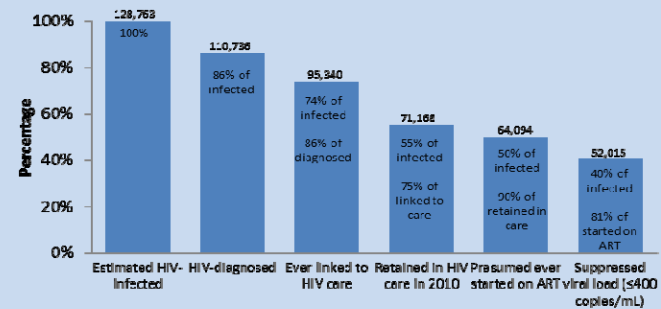**Engagement in HIV care in NYC**

Delayers Key Findings

- One-third (34%) of NYC and one-quarter (27%) of TC participants delayed testing after infection, delayed entry into HIV medical care after diagnosis, or both.
- Health problems/experiencing symptoms was the reason most often given for testing for HIV. Personal motivation based on awareness of risky behavior or simply to know one's status was mention much less often.
- The most common self-reported reasons for delayed entry into care include denial about infection, feeling fine (no symptoms), drug use, and not wanting to take HIV medications.
- In NYC, persons diagnosed with HIV who delay entry into care are more likely to be younger at diagnosis (<35 years), male, and not experiencing symptoms at time of diagnosis. They are more likely to report homelessness, actively using drugs, having no regular source of income, and not having a regular source of medical care or medical insurance at the time of diagnosis
- Among TC study participants, neither age at diagnosis nor sex were associated in delayed entry into care. MSM were less likely than PWH from other risk exposure groups to delay. Homeless experience, lack of income and active drug use during the year prior to diagnosis are associated with delayed entry into care, consistent with patterns seen in among NYC study participants.
- Test site activity, especially active referral and linkage to care, has the strongest association with timely entry into care in both NYC and TC, controlling for other factors.

Dropouts Key Findings

- 25% of NYC and 12% of Tri-Co study participants reporting at least one episode of dropping out of care (not going for any medical visits) for over 6 months since they were diagnosed with HIV
- Similarly, 25% of NYC and 12% of Tri-Co participants report one or more recent episodes of dropping out of care for over 6 months at least once during the study period.
- There is 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 are no less likely to report drop out episode(s) compared to those diagnosed longer ago.
- Demographic characteristics are less strongly associated with drop out than situational considerations and receipt of supportive services. Older PWH and PWH with higher education are less likely to drop out. PWH in stable housing and those who received social service case management are also less likely to drop out than their counterparts.
- PWH experiencing financial hardship in the past six months (very low income, food insecurity, needing transportation services), and active drug users have higher odds of drop out during the same period than PWH without these challenges.
- Health status is associated with dropping out – PWH reporting improved health compared to the prior year are more likely to drop out; qualitative answers indicate that or some, feeling better is seen to reduce the need for regular medical visits or strict adherence to regimen. Dropout is also associated with health decline, likely a result from rather than impetus to a period of no medical care.

Delayers Methods

- Data for Delayers analysis were obtained from in-person baseline interviews conducted between 2001 and 2010 for study of 863 PWH who were diagnosed on or after 1996, residing in New York City or the Tri-County suburban region north of the City.
- The sample was designed to be representative of the HIV-infected population receiving medical and/or social services in the study area. The sample is 45% female and predominantly Black and Latino. The poverty rate is high (71% in NYC and 50% in TC). Sixty-percent of participants have a history of drug use and almost half score "low" on a standardized measure of mental health functioning.
- "Delayers" are defined as participants who took over 3 months from diagnosis to first entry into HIV care (first evaluation for treatment). Respondents' report that he or she was tested because they were sick or experiencing HIV related symptoms (e.g., thrush) is used as a proxy indicator for delayed testing.
- Bivariate and Multivariate logistic regression models used to examine the risk factors of delayed entry into care. Socio-demographic variables, indicators of life at time of diagnosis, and testing experiences are included in the models.

Table 1. Predictors of Delayed Entry into HIV Medical Care		New		Tri-	
		OR	AOR	OR	AOR
Socio-demographics					
Sex at Birth	Male	1			
	Female	0.54*	0.63	1.15	0.75
Race/Ethnicity	White/Other	1			
	Black	0.68	0.87	0.87	0.98
	Hispanic	1.52	1.24	1.26	0.69
Age at Diagnosis	36-49yrs	2.28**	2.58**	0.77	1.17
	≤35years	1			
	50+ years	0.61	1.06	0.59	0.45
Birth Place	US	1			
	PR	0.95	0.65	2.73	6.30*
	Other	0.94	0.78	0.81	0.80
Education	HS grad	1			
	Less than HS/GED	0.87	0.91	1.11	1.06
Risk Exposure Group	MSM	1			
	IDU/IDU+MSM	1.37	1.61	13.22***	4.46
	Heterosexual/ Other	0.58	0.88	7.11**	6.17*
Life at Time of Diagnosis					
Drinking a lot		1.17	0.74	1.46	1.19
Using drugs regularly		2.38***	2.90**	1.72	1.07
In jail or prison during the past year		1.64	2.34	2.32	3.30
No or limited social support		1.66	1.12	0.90	0.61
Housing during the past year	Stable	1			
	Unstable	1.19	0.62	0.96	0.44#
	Homeless	1.63	0.86	1.78	0.97
Did not have health insurance		1.92*	1.76	1.24	1.48
Did not have regular source of medical care		1.94*	2.01#	1.47	1.07
Testing experience					
Year of Diagnosis	Prior to 2002	1			
	2002 or later	0.76	0.69	0.77	0.74
Illness or symptoms reason for testing		1.37	1.77	1.22	0.87
Diagnosed at medical site		1.01	2.03	--	--

Table 2. Predictors of Dropped out of HIV Care		New York City		Tri-County	
		OR	AOR	OR	AOR
Female		1.06	1.42	1.01	1.47
Black		0.92	0.91	0.74	0.77
Latino		0.98	0.92	1.41	0.93
Age		0.93***	0.95***	0.98	0.98
Birth Place	US	1			
	PR	0.79	0.75	3.23*	3.06#
	Other	0.39**	0.45*	0.56	0.49
Risk Exposure Group	MSM	1			
	IDU/IDU+MSM	1.53#	1.39	1.05	1.03
	Heterosexual/ Other	0.78	0.69	0.78	0.59
Married or Have Partner		1.05	1.12	0.63#	0.55*
Have More than HS/GED		0.49*	0.60#	1.39	1.15
Work FT or PT		1.19	1.81*	0.81	0.99
Income <$7.5K/year		2.25***	1.65*	1.26	0.98
Food Insecure		1.70***	1.52*	1.93**	2.60**
Transportation Need		1.97***	1.58*	2.30**	2.52**
In Stable Housing		0.48***	0.59*	0.76	1.82
Recent Incarceration		1.49	0.76	5.46*	6.19#
Recent Drug Use		4.18***	2.96***	3.30***	3.94***
Low Mental Health Functioning		1.85***	1.57**	1.25	0.95
Physical Hhealth Functioning		1.00	0.99	1.00	1.02
Health since 6 Months ago	better	1.55**	1.54*	0.64	0.55#
	same	1			
	worse	2.21***	1.58*	1.33	1.31
Years since Diagnosis	5 years or less	2.52**	1.31	0.77	0.64
	6-20 years	2.57***	2.13**	1.46	1.41
	over 20 years	1			
Received Prof. MH Services		0.86	0.74	0.63	0.49*
Received Prof. AOD Services		1.96**	1.16	1.23	0.49
Received Medical Case Mgmt		0.93	1.04	1.03	1.13
Received Social Service Case Mgmt		0.67**	0.64*	0.85	0.83
Delayers		1.48#	1.12	0.89	0.77

Dropouts Methods

- Data for Dropouts analysis were obtained from 4,941 interviews conducted between 2001 and 2015 for study of 1,603 NYC and Tri-County PWH who were asked about recent dropping out of care or not having an appointment. An average number of interviews completed per person is 4.0 for NYC and 1.7 for Tri-County.
- Random effects logit models with clustered sandwich estimator to allow for correlation among repeated observations on individuals were used to estimate the predictors of dropping out of care.
- Predictors in the model are: sex at birth, race/ethnicity, age at interview, birth place, risk exposure group, Married or have partner, higher education, work status, very low income, food insecurity, transportation need, in stable housing, recent incarceration, recent drug use, low mental health functioning, physical health functioning, change in health status since last year, years since diagnosis, delayed entry into care upon diagnosis.

<.10 * p < .05 **p <.01 *** p<.001

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