

**EXPLORING PREDICTORS OF LOSS-TO-CARE AMONG PEOPLE LIVING WITH
HIV**

by

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ABSTRACT

Retention in HIV care is an important public health issue as it improves survival and quality of life among people living with HIV (PLWH) and reduces the risk of infection spread to others. In order to increase retention in care and maintain a care continuum, it is essential to understand the factors and reasons that lead to non-retention in care. The effects of reported loss-to-care reasons on reengagement in care among a Southwestern Pennsylvania HIV program-based population of 920 individuals was examined in the present study. Participants reported 17 single primary reasons and 9 categories of multiple reasons; the most commonly reported single reasons were denial/avoidance, substance abuse, incarceration, unstable locations and mental health issues while the most reported multiple reason category was mental health and substance abuse. Multinomial regression was conducted to explore loss to care reason categories and factors associated with reengagement in care. In multinomial analysis, adjusted for race, HIV contact risk, insurance and use of antiretroviral medication, persons with single reasons related to finance and stigma were 2.5 (95% CI; 1.2, 5.5) and 3.5 (95% CI; 1.2, 10.1) times, respectively, as likely as those with multiple reasons to be reengaged in care. Enrollment in insurance and taking antiretroviral medications were also found to be strong independent predictors of reengagement in care. Participants who reported multiple reasons were less likely to be reengaged in care and those with injective drug use risk were 50% less likely to be reengaged in

care compared to those with heterosexual contact risk. Success in reengagement was lower among PLWH with higher risk reasons such as mental health issues and substance abuse; hence, while intervention approaches may be effective for those with fewer and less complicated reasons, other PLWH may benefit from program modifications in the attempt to reengage them.

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PREFACE

I would like to thank my friends and family for their continuous support and understanding throughout my time in Pittsburgh and the course of my graduate education. My sincere gratitude goes to my advisor Dr. Clareann Bunker for her guidance, patience, and reassurance for the entirety of my graduate career. I would also like to extend my appreciation to Dr. Thistle Elias for her constructive feedback and encouragement during this process. Much appreciation to the Jewish Healthcare Foundation for the invaluable experience gained through my internship which informed and provided the basis of this essay. All of your support has paved the way for my future as a Public Health professional and I am truly grateful for all of your time and effort towards my success.

1.0 BACKGROUND

According to the Centers for Disease Control and Prevention (CDC), an estimated 1.2 million persons in the United States are living with human immunodeficiency virus (HIV), a condition that can lead to debilitating illness and death when left untreated^{1, 2}. Among the persons living with HIV (PLWH), 1 in 5 are unaware of their infected status and 60% are not engaged in or linked to medical care⁴.

The *Healthy People 2020* objectives contain the National HIV/AIDS strategy, which states specific goals regarding effective HIV care including “increasing access to care and improving health outcomes for PLWH” as well as “increasing the proportion of newly diagnosed individuals who are linked to care”³. The diagnosis of HIV infection, linkage to care, retention in care, receipt of antiretroviral therapy (ART) and achievement of viral suppression are stages in the HIV Care Continuum and are important for PLWH to stay healthy, live longer and reduce chances of transmission to other people⁷. However, only 1 in 4 PLWH are successfully making it through the HIV care continuum and getting the full benefits of treatment (Figure 1)⁷.

Retention is an important component in the continuum as it bridges the gap from diagnosis to health outcomes; poorer retention clearly means poorer health outcomes for PLWH, however, it has implications for non-infected individuals as well. A CDC study published in 2015 showed that 91.5 percent of new HIV infections in 2009 were attributable to PLWH who

were not in medical care, including those who were unaware of their status, while less than six percent could be attributed to PLWH who were in care and receiving ART⁵.

As a result, retention in care of PLWH has become an increasingly important issue in the US as it allows for prophylactic treatment of opportunistic infections, prevention of mother-to-child transmission, and early initiation of antiretroviral therapy (ART) to suppress viral loads as well as possible reduction of new infections⁶.

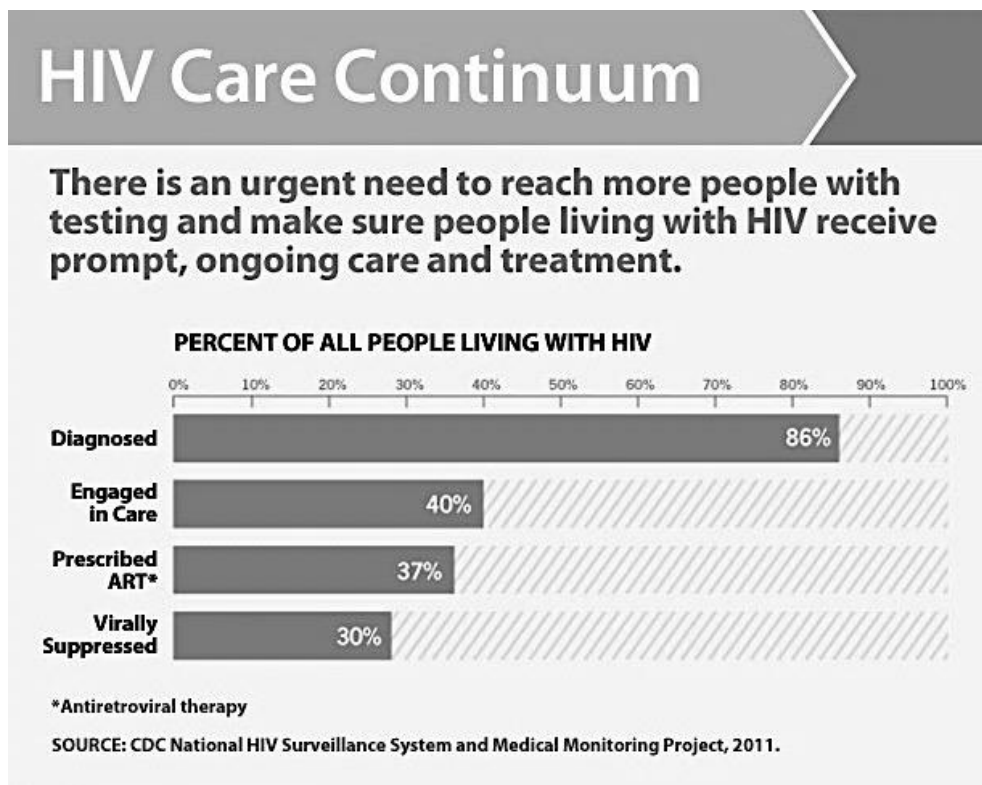


Figure 1: HIV Care Continuum for PLWH in the United States

1.1 CURRENT LITERATURE

A search of the literature revealed that numerous other studies have examined the factors that may influence PLWH retention or engagement in various aspects of healthcare, barriers and challenges that hinder retention in care, as well as health outcomes that result from retention or non-retention in care. However, limited analysis of the effect of primary and multiple reasons reported for loss-to-care on eventual reengagement in care has been done.

1.1.1 Retention in Care

Examining the literature on engagement in care starts with an understanding of commonly espoused multifarious definitions of retention or engagement in care. A study analyzing retention in care among pregnant and breastfeeding HIV-infected women alluded to the difficulty in defining retention to care, either for the purposes of monitoring and surveillance for HIV programs or for HIV clinical research; no standard interpretation exists⁸. However, implicit to the term “retention-in-care” is an expectation of continuity and access to appropriate care at pre-determined points in time; according to Messeri *et al*, “retention in care implies remaining connected to medical care, once entered”¹⁰.

Generally, HIV patients who are lost-to-follow-up are considered not to be retained in care because it is assumed that they are no longer taking any treatment, but loss-to-follow-up and retention in care are not necessarily mutually exclusive. Among patients who had been lost-to-follow-up, it was determined that a proportion of them were still on their medications; however, generally, patients who are loss-to-follow-up are considered not to be retained in care⁸.

Among HIV clients on ART, WHO defines loss-to-follow-up patients as those who are absent from the ART clinic more than 90 days after the date of their last missed appointment or drug refill and who are of a certainty alive and not transferred⁹. Patient retention is often measured by missed appointments, medical visits at defined intervals and a combination of these measures based on patient access and use of health care systems. Missed appointments are those from which the client is absent without cancelling or rescheduling¹¹.

However, this concept of retention presents an inconsistency in measures as studies differ in what types of appointments are included. Primary care visits are generally included in patient retention measures exempting other visits with nurses or laboratory clinicians, therefore, evaluation of retention requires collective decisions about which visits to include.

One group of researchers compared the ability of patient engagement in HIV care to predict their clinical outcomes using four measures of retention: annual appointments (≥ 2 appointments annually at least 60 days apart), missed appointments (missed $\geq 25\%$ of appointments), infrequent appointments (> 6 months without an appointment) and missed or infrequent appointments (missed $\geq 25\%$ of appointments or > 6 months without an appointment). All measures were associated with viral load reduction and ART initiation; annual appointments were shown to be positively correlated with increased CD4 cell counts while clients with missed appointments were more likely to have lower CD4 cell counts, higher progression to AIDS, more emergency visits and hospitalizations¹².

Overall, reengagement in care delineates a return to care after a brief or lengthened hiatus. In the current study, using data from the Minority AIDS Initiative (MAI), a program designed to reengage or link HIV clients and high-risk individuals to care, clients were considered lost to care or high-risk if they met certain criteria including;

- no HIV medical visit in the last 180 days
- only 1 HIV medical visit in the last 365 days
- no medical visit within the previous 60 days accompanied by diagnosed and untreated mental health (MH) or substance abuse (SA) issues such as homelessness or abuse in the home
- missed HIV medical appointments more than twice consecutively
- no lab values for last 180 days

All criteria are listed in Appendix 2. In the MAI, following loss to care as described above, clients were considered reengaged to care if they made it to 3 medical appointments within the program fiscal year (June 2014 to June 2015), partially reengaged if they made it to 1 or 2 appointments and not reengaged if they did not make it to any appointments.

1.1.2 Factors Influencing Retention in Care

Retention in care has previously been associated with select factors and health risk behaviors. The effect of age, gender and race on retention have been inconsistent in current literature particularly regarding age and gender; a number of cohort and survey studies examining key influencers of retention in care found that younger age, male gender, being black/African-American and injective drug use were associated with lower retention in care¹³⁻¹⁵. However, several other studies have found that compared with men, women are more likely to delay initiation of ART and return to care and also have a higher likelihood of having emergency department visits¹⁶⁻¹⁷. Also, some studies have shown no age and gender differences in relation to retention in care¹⁸⁻¹⁹.

In a study examining barriers to HIV care among women, many women reported that they failed to access care based on the belief that their family responsibilities supersede self-preservation²⁰. Other key barriers identified in the study included lack of transportation, child care issues, economic factors, lack of insurance, history of physical or sexual abuse and inability to take time of work. Distrust of healthcare systems as well as denial and disbelief about HIV diagnosis are also commonly reported reasons among PLWH who are not receiving care²⁰.

A study exploring factors associated with retention in oral health care among PLWH reported that patient experiences, especially patient-provider interactions, were significant predictors of retention in care; dissatisfaction or distrust reduces the likelihood of retention in care. Patient education and age were also found to be significantly associated with retention; patients who received education about oral health care were about 6 times more likely to be retained and older adults were 3% more likely to be retained in care for every additional year of age¹⁹.

Another major contributing factor to delays in return to care is the fear of stigma associated with the diagnosis of HIV infection.^{21,23} A literature review on adherence and retention to care among PLWH revealed that stigma and access to social and/or family support greatly impact use of healthcare services among PLWH. Psychological stressors such as depression have also been repeatedly found to have adverse influence on adherence to ART and retention in care²². HIV-infected persons with a history of substance abuse, high levels of depressive symptoms and mental health issues have been found to be twice as likely to have low levels of retention and receipt of ART²⁰.

Findings from the review showed that behaviorally infected individuals (including transmission by sexual behaviors and injective drug use) had better retention in care and greater

ART adherence compared to non-behaviorally infected individuals²¹. This was attributed to an increased knowledge and awareness of HIV status among behaviorally infected persons causing them to take responsibility for their health and treatment. Also, no association was found between ownership of medical insurance and initiation of ART; however, possession of medical insurance was found to increase the likelihood of PLWH usage of healthcare services. Those with publicly funded insurance coverage were more likely to discontinue treatment and be lost to care compared with those who had private insurance²¹.

1.2 PUBLIC HEALTH SIGNIFICANCE

The public health significance of exploring predictors of reengagement in care is two-fold: the impact on the individual and the impact on the community. When addressing HIV-related issues and planning programs and intervention aimed at improving retention in care, it is easy to focus on linkage to medical care, initiation and adherence to ART. However, it is essential to explore the upstream determinants that prevent PLWH from consistent retention in care. An exploration of their reasons and lived experiences may provide insight to specific issues faced by PLWH leading to targeted planning and potential retention in care. Retention in care increases the quality of life of PLWH and improves their life expectancy as it provides greater access to health management and treatments to suppress viral load. Also, retention in care strengthens the HIV care continuum and potentially reduces the risk of HIV transmission to others.

2.0 OBJECTIVE

The aim of this study is to build on previous HIV retention to care knowledge and examine the relatedness of client-reported reasons for loss-to-care with reengagement outcomes in a Southwestern Pennsylvania program-based HIV population. Such analysis will allow direct comparisons of client reengagement levels by race/ethnicity, age, medication use among other variables. Reengagement to care by client-reported reasons will also be assessed in the form of multinomial logistic regression. Results from this study will permit further understanding of factors influencing client engagement in care and allow public health agencies and HIV community welfare organizations to better address this public health issue through targeted interventions and policies.

3.1 METHODS

3.2 POPULATION & DATABASE BACKGROUND

The Jewish Healthcare Foundation (JHF) has served as the Southwestern Pennsylvania regional fiscal agent for the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act since 1992. It has also since served as fiscal agent for State 656 and Housing Opportunities for Persons with AIDS (HUD HOPWA). The Foundation works actively to improve the lives of those affected by HIV/AIDS through quality improvement training for service organizations, community support, stewardship and leadership.

In April 2012, as part of the JHF fiscal agent role, an additional \$1.2 million was awarded to JHF towards a Minority AIDS Initiative (MAI) by the Pennsylvania Department of Health Special Pharmaceutical Benefits Program (SPBP) and the Health Resources and Services Administration (HRSA) to work with AIDS Service Organizations (ASOs) across Pennsylvania. This initiative is aimed at engaging high-risk and lost-to-care HIV-positive clients in medical care. The ASO sites are located in Clarion, Williamsport, Pittsburgh, Johnstown, Harrisburg, Reading and Philadelphia. They provide targeted outreach services to identify and link clients to care with the aim of reducing community viral load (measure of the amount of HIV virus across all HIV-positive individuals in a given area).

These ASOs serve varying populations including the Lesbian, Gay, Bisexual and Transgender (LGBT) community, people with pediatric HIV, injective drug users (IDU) as well as prison inmates. Thus, their services differ and range from clinical service provision to case management, needle exchange programs and multidisciplinary care according to each organization's practices and their clients' needs and preferences.

The MAI Database was created in an effort to acquire representative health, behavioral and demographic data for HIV clients with whom AIDS Service Organizations (ASOs) were engaged. The information collected enables tracking of the project progress i.e. re-engagement in healthcare, by the Jewish Healthcare Foundation (JHF) as well as the Pennsylvania Department of Health (PADOH). The Database categories/variables were selected based on required criteria by the PADOH as well as other criteria deemed necessary for appropriate monitoring of ASO activities with clients. The ASOs report the client information to JHF who in turn convey progress reports to the initiative funders. Figure 2 shows the flow of data, reports and resources between funders, JHF, ASOs and clients.

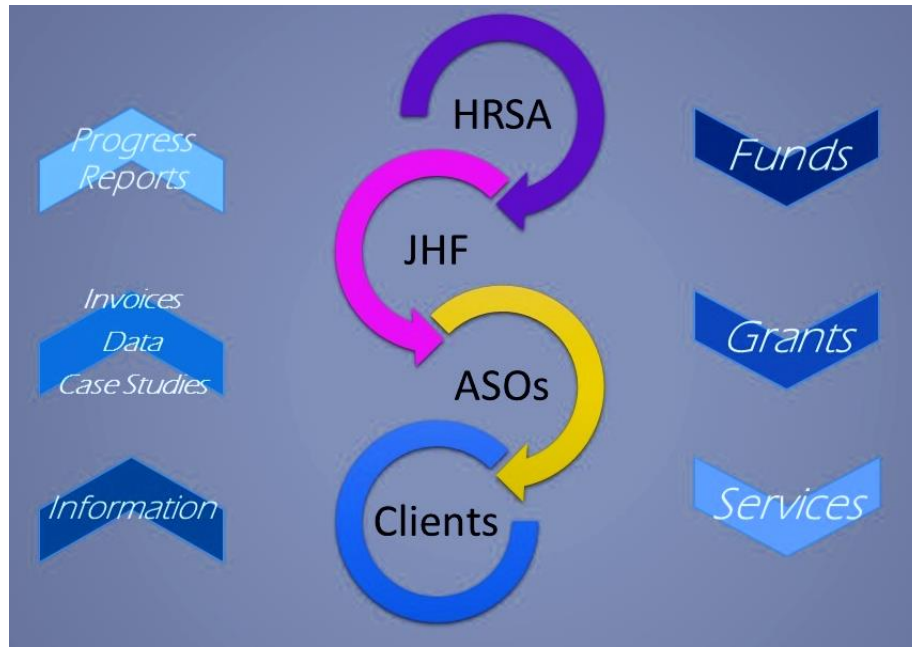


Figure 2: Flow of data and resources in the Minority AIDS Initiative

Data for every client included an encrypted unique reference number, age, gender, race, risk factor, insurance, date of last HIV appointment before MAI, date of referral and first contact, reason for loss to care, dates for subsequent medical appointments, and other data. The full list of variables can be found in Appendix 1. Data are updated on a monthly basis by ASOs who send datasheets to JHF at the beginning of each month. The data used for this study analysis are based on information collected from the beginning of the fiscal year in June 2104 till June 2015; data regarding a total of 920 HIV+ clients. The demographic composition of the study population is presented in Table 1.

Table 1: MAI Database Demographic Composition

	<i>N</i>	%
Total	920	100%
Gender		
Male	284	30.87%
Female	615	66.85%
Transgender M-T-F*	19	2.07%
Transgender Unknown	2	0.21%
Age		
18-24	61	6.63%
25-34	206	22.39%
35-44	225	24.46%
45-54	282	30.65%
55-64	122	13.26%
65+	15	1.63%
Race		
Black	566	61.52%
Hispanic White	176	19.13%
Non- Hispanic White	158	17.17%
Asian	4	0.44%
American Indian/AN**	2	0.22%
Other	14	1.52%

* Male-to-Female

** Alaska Native

Dependent Variable

The dependent variable in this study analysis was reengagement to care. HIV clients were considered reengaged to care if they made it to 3 medical appointments, partially reengaged if they made it to 1 or 2 appointments and not reengaged if they did not make it to any

appointments. Re-engagement to care was coded as a trichotomized variable equivalent with levels of engagement (0= not reengaged, 1=partially reengaged, 2=reengaged).

Independent Variables

Independent variables used included the following for which response alternatives are presented in brackets: age; gender (1=male, 2=female 3=transgender male-to-female 4=transgender unknown), race/ethnicity (1=Caucasian/White, 2=Black/African-American, 3=Hispanic, 4=Other, 5=Asian, 6=American Indian/Alaskan Native), risk factor (1=Heterosexual Contact, 2=Men who have sex with men (MSM), 3=Injective drug use 4=Non-behavioral transmission), insurance (0=None, 1=Medicaid, 2=Medicare, 3=Private, 4=Public, 5=Unknown), use of ART medications (0=No, 1=Yes), receiving case management (0=1, 2=Yes), receiving incentives (0=No, 1=Yes).

3.2 STATISTICAL METHODS

The population distribution was accessed by generating mean (median) and standard deviation (interquartile range) for continuous variables and proportions for categorical variables. For assessing differences by level of engagement in care and racial differences, Wilcoxon rank-sum tests and chi-square tests were used for comparing continuous and categorical variables respectively. Multinomial logistic regression models were created to analyze associations between levels of reengagement and independent variables (race, age category, loss-to-care reasons, risk factors, use of medication).

The variable for age was dichotomized (≤ 40 and $41 \geq$) and the loss-to-care reasons were categorized into 5 groups for the regression models namely; financially-related, stigma, mental health & crime, health systems & concerns, multiple reasons, no reasons provided. *PROC LOGISTIC* was used to fit the generalized logit model by specifying the *LINK=GLOGIT* option in the model statement. All variables with p-values < 0.05 were considered significant. All analyses were performed using SAS version 9.3 (SAS Corporation, Cary, North Carolina).

Table 2: Population characteristics and differences by level of reengagement

Characteristic	Not Reengaged		Partially Reengaged		Fully Reengaged		P-value
	Median	25 th , 75 th	Median	25 th , 75 th	Median	25 th , 75 th	
Age (N=911)	42	(33,50)	43	(32,51)	45	(34,51)	0.1441
	N	%	N	%	N	%	
Gender (N=899)							
Male	141	23	249	40	225	37	0.2670
Female	59	19	105	39	120	42	
Race/Ethnicity (N=920)							
Non-Hispanic White	37	23	50	32	71	45	0.0004
Black	105	19	238	42	223	39	
Hispanic White	58	31	65	39	53	30	
Other	5	25	11	55	4	20	
Risk Factor (N=920)							
Heterosexual contact	77	18	170	41	170	41	<0.0001
Men who have sex with men (MSM)	43	18	103	42	99	40	
Injective drug use (IDU)	77	34	82	36	66	30	
Non-Behavioral transmission	8	24	9	27	16	49	
Insurance (N=910)							
None	68	27	105	42	77	31	0.0082
Medicaid	106	23	169	37	187	40	
Medicare	15	16	42	42	42	42	
Private	12	12	45	46	42	42	
Currently on ART Meds (N=765)							
Yes	67	12	245	42	265	46	0.0082
No	37	20	82	44	69	36	
Receiving Case Management (N=735)							
Yes	77	17	192	42	184	41	0.0003
No	21	8	116	41	145	51	
Receiving Incentives (N=740)							
Yes	17	9	68	34	112	57	0.0003
No	80	15	243	45	220	40	

4.0 RESULTS

Of the 920 individuals included in this analysis, 205 (22%) were not reengaged, 364 (40%) were partially reengaged and 351 (38%) were fully reengaged in care. Table 2 shows the program structural features, sociodemographic and behavioral characteristics and differences by level of reengagement in care. There was no significant difference in age across the three levels; the median ages were 42(range 33-50), 43 (range 32-51) and 45 (range 34-51). Gender and age were not significantly associated with reengagement in care.

Several sociodemographic characteristics were significantly associated with reengagement in care, including race/ethnicity, risk factors for transmission, type of insurance, use of medications, receipt of case management services and incentives. People who were fully reengaged in care were more likely to be non-Hispanic whites, African-Americans were more likely to be partially reengaged and Hispanics were least likely to be reengaged in care. IDU risk exposure was significantly associated with non-reengagement in care, MSM were more likely to be partially reengaged and non-behavioral transmission was significantly associated with full reengagement in care.

Lack of insurance was significantly associated with non-reengagement in care and enrollment in Medicare or private insurance was associated with higher partial or full reengagement. People who reported use of medications and those who received incentives were

more likely to be fully reengaged in care compared to those who were not. Receiving of case management services was significantly associated with non-reengagement to care.

Table 3, 4 and 5 examine racial differences and differences in level of reengagement by the types of loss-to-care reasons reported by clients. Overall, clients identified 17 types of primary reasons and 9 categories of multiple reasons. Among primary reasons, the five most commonly reported were denial and avoidance (14%), substance abuse (13%), incarceration (12%), unstable location (10%) and mental health issues (9%); the frequency of reported primary reasons is shown in Figure 3.

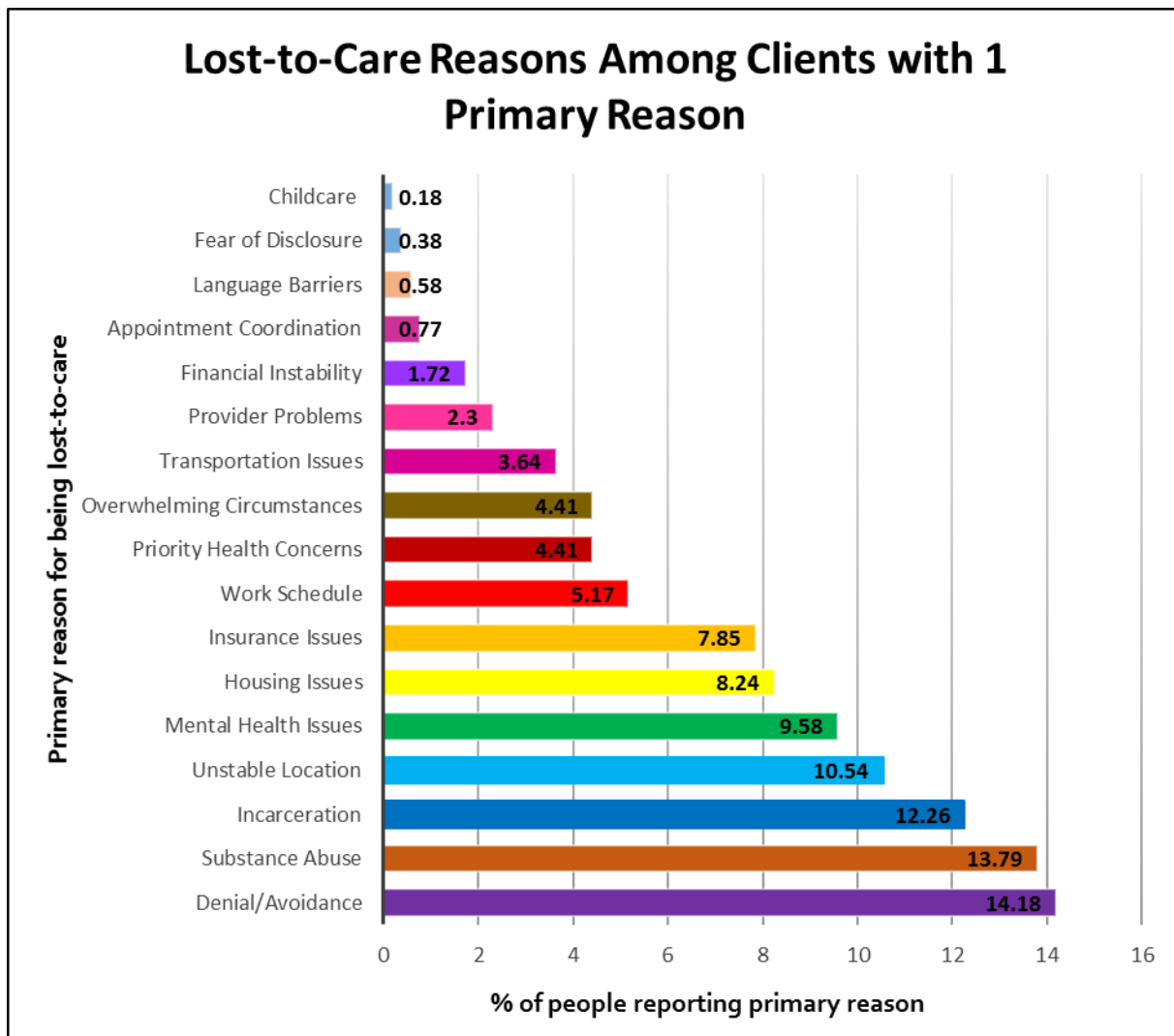


Figure 3: Loss-to-Care reasons Among Clients with 1 Primary Reason

Among 85 clients reporting multiple reasons, categories included mental health and substance abuse (34%), housing issues and substance abuse (27%), mental health, housing issues and substance abuse (18%), housing issues and mental health (5%), denial and financial instability (4%), mental health and insurance (4%), mental health and financial instability (2%), denial and substance abuse (2%), others included language barriers, insurance, substance abuse, incarceration and health concerns.

Non-reengagement to care was higher among people who reported incarceration as their primary reason and among those who reported multiple reasons. People who reported priority health issues and insurance issues were more likely to be partially reengaged. Full reengagement was higher among people who had reported financial instability, overwhelming circumstances, work schedule issues and transportation issues. (Table 3)

Table 3: Loss-to-Care Reasons by levels of reengagement

	Not Reengaged		Partially Reengaged		Fully Reengaged		P-value
	N	%	N	%	N	%	
Loss-to-Care Reasons							
Appointment Coordination	0	0	4	100	0	0	<0.0001
Child Care	0	0	0	0	1	100	
Denial/Avoidance	7	10	29	39	38	51	
Fear of Disclosure	0	0	2	100	0	0	
Financial Instability	0	0	1	11	8	89	
Housing Issues	10	23	17	40	16	37	
Incarceration	16	25	32	50	16	25	
Insurance Issues	1	3	21	51	19	46	
Language Barriers	0	0	1	33	2	67	
Mental Health Issues	6	12	20	40	24	48	
Overwhelming Circumstances	1	4	7	31	15	65	
Priority Health Concerns	3	13	13	57	7	30	
Provider Problems	1	8	6	50	5	42	
Substance Abuse	17	24	22	30	33	46	
Transportation Issues	0	0	9	47	10	53	
Unstable Location	13	24	26	47	16	29	
Work Schedule	1	4	10	37	16	59	
Multiple Reasons	22	26	24	28	39	46	
Newly Diagnosed	14	12	49	44	50	44	
No reason provided	93	47	71	35	36	18	

Race/ethnicity was associated with loss-to-care reasons. African-Americans were most likely to report denial and avoidance and housing issues. Insurance issues and substance abuse were reported more by non-Hispanic Whites compared to Hispanic Whites and African-Americans. Incarceration and unstable location were more likely to be reported by Hispanics than non-Hispanic Whites and African-Americans (Table 4).

Table 4: Racial Differences in Single Primary Loss-to-Care Reasons

Loss-to-Care Reasons	N	Non-Hispanic White (N=103)		Black (N=310)		Hispanic White (103)	
		N	%	N	%	N	%
Appointment Coordination	4	0	0	4	1	0	0
Child Care	1	0	0	1	1	0	0
Denial/Avoidance	73	8	8	53	17	12	12
Fear of Disclosure	2	0	0	2	1	0	0
Financial Instability	9	1	1	7	2	1	1
Housing Issues	43	5	5	33	11	5	5
Incarceration	63	14	13	28	9	21	20
Insurance Issues	41	15	15	23	7	3	3
Language Barriers	2	0	0	2	1	0	0
Mental Health Issues	50	9	9	32	10	9	9
Overwhelming Circumstances	23	2	2	18	6	3	3
Priority Health Concerns	23	6	6	16	5	1	1
Provider Problems	12	3	3	7	2	2	2
Substance Abuse	70	18	17	35	11	17	16
Transportation Issues	19	9	9	7	2	3	3
Unstable Location	54	7	6	24	8	23	22
Work Schedule	27	6	6	18	6	3	3

Multiple reasons were most commonly reported among African-Americans and Non-Hispanic Whites. Mental health and crime-related primary reasons were significantly higher among Hispanic and non-Hispanic Whites compared to African-Americans (Table 5).

Table 5: Racial Differences in Loss-to-Care Reasons by Categories

Reason Categories	Non-Hispanic White (N=158)		Black (N=566)		Hispanic White (N=176)		P-value
	N	%	N	%	N	%	
No Reason Provided							
Yes	21	13	121	21	51	29	0.0023
No	137	87	445	79	125	71	
Financially-related Reasons							
Yes	45	29	131	23	41	23	0.3676
No	113	71	435	77	135	77	
Stigma-Related Reasons							
Yes	8	5	55	10	12	7	0.1249
No	150	95	511	90	164	93	
Mental Health & Crime-Related Reasons							
Yes	41	26	95	17	47	27	0.0026
No	117	74	471	83	129	73	
Health Systems & Concerns							
Yes	9	6	29	5	3	2	0.0973
No	149	94	537	95	173	98	
Multiple Reasons							
Yes	18	11	55	10	10	6	0.1580
No	140	89	511	90	166	94	
Loss to care categories: Financial (Child Care, Housing Issues, Financial Instability, Insurance Issues, Overwhelming circumstances, Transportation Issues, Unstable Location, Work Schedule); Stigma (Denial/Avoidance, Fear of Disclosure); Mental Health & Crime (Incarceration, Mental Health Issues, Substance Abuse); Health Systems & Concerns (Appointment Coordination, Provider problems, Language barriers, Priority Health Concerns); Multiple reasons							

In the unadjusted regression models, loss-to-care reasons were significantly associated with partial and full reengagement to care (Table 6). Clients who had reported financial and stigma related reasons were about 3 and 4 times respectively more likely to be reengaged in care compared with those who reported multiple reasons; those reporting health systems and concerns were 5 times more likely to be partially reengaged in care. Those who did not report loss-to-care reasons were 20% less likely to be reengaged in care compared to those who provided multiple reasons. Compared to Non-Hispanic Whites, African Americans were 1.7 times more likely to be partially reengaged in care and Hispanics were 50% less likely to be fully reengaged in care.

Table 6: Factors Associated With Reengagement in Care Using Unadjusted Multinomial

Logistic Regression Models

Independent Variables		Partially Reengaged		Fully Reengaged	
		OR ^a (95% C.I.)	P-value	OR ^a (95% C.I.)	P-value
**Loss-to-Care Reasons	Multiple Reasons	Reference	–	Reference	–
	No Reasons	0.7 (0.4-1.4)	NS	0.2 (0.1-0.4)	S
	Financial	3.2 (1.6-6.6)	S	2.2 (1.1-4.3)	S
	Stigma	4.1 (1.5-11.1)	S	3.1 (1.2-8.0)	S
	Mental Health & Crime	1.7 (0.9-3.5)	NS	1.1 (0.5-2.0)	NS
	Health Systems & Concerns	5.5 (1.6-18.3)	S	2.0 (0.6-6.7)	NS
Race/Ethnicity	NHW	Reference	–	Reference	–
	Black	1.7 (1.0-2.7)	S	1.1 (0.7-1.8)	NS
	Hispanic	0.8 (0.5-1.4)	NS	0.5 (0.3-0.8)	S
	Other	1.6 (0.5-5.1)	NS	0.4 (0.1-1.6)	NS
Insurance	No Insurance	Reference	–	Reference	–
	Medicaid	1.0 (0.7-1.5)	NS	1.6 (1.0-2.3)	S
	Medicare	1.8 (0.9-3.5)	NS	2.5 (1.3-4.9)	S
	Private	2.4 (1.2-4.9)	S	3.0 (1.5-6.3)	S
Risk factors	Heterosexual Contact	Reference	–	Reference	–
	MSM	1.0 (0.7-1.7)	NS	1.0 (0.7-1.6)	NS
	IDU	0.5 (0.3-0.7)	S	0.4 (0.3-0.6)	S
	NBT	0.5 (0.2-1.4)	NS	0.9 (0.4-2.2)	NS
Uses Medications	No	Reference	–	Reference	–
	Yes	1.7 (1.0-2.7)	S	2.1 (1.3-3.4)	S

* Unadjusted regression models

** **Loss to care categories:** Financial (Child Care, Housing Issues, Financial Instability, Insurance Issues, Overwhelming circumstances, Transportation Issues, Unstable Location, Work Schedule); Stigma (Denial/Avoidance, Fear of Disclosure); Mental Health & Crime (Incarceration, Mental Health Issues, Substance Abuse); Health Systems & Concerns (Appointment Coordination, Provider problems, Language barriers, Priority Health Concerns); Multiple reasons

NHW = Non-Hispanic White || **MSM** = Men who have sex with Men || **IDU** = Injective drug use || **NBT** = Non-behavioral transmission

S: Significant (p < 0.05)

NS: Not significant (p > 0.05)

Compared to persons without insurance, those enrolled in Medicaid, Medicare and private insurance were 1.6, 2.5 and 3 times more likely to be reengaged in care, respectively.

Clients who were exposed to IDU risk were about 50% less likely to be partially or fully reengaged in care compared to those with heterosexual contact risk.

Table 7: Factors associated with reengagement in care based on fully adjusted multinomial logistic regression models

Independent Variables		Partially Reengaged		Fully Reengaged	
		OR ^a (95% C.I.)	P-value	OR ^a (95% C.I.)	P-value
**Loss-to-Care Reasons	Multiple Reasons	Reference	–	Reference	–
	No Reasons	4.0 (1.5-11.4)	S	1.4 (0.5-3.9)	NS
	Financial	4.0 (1.8-9.1)	S	2.5 (1.2-5.5)	S
	Stigma	4.8 (1.6-14.4)	S	3.5 (1.2-10.1)	S
	Mental Health & Crime	2.2 (1.0-4.7)	S	1.3 (0.6-2.7)	NS
	Health Systems & Concerns	4.1 (1.2-14.8)	S	1.3 (0.4-4.7)	NS
Race/Ethnicity	NHW	Reference	–	Reference	–
	Black	1.4 (0.7-2.9)	NS	0.8 (0.4-1.7)	NS
	Hispanic	0.7 (0.3-1.6)	NS	0.5 (0.2-1.1)	NS
	Other	1.8 (0.3-10.9)	NS	0.3 (0.04-2.9)	NS
Insurance	No Insurance	Reference	–	Reference	–
	Medicaid	1.6 (0.9-2.8)	NS	2.8 (1.6-4.8)	S
	Medicare	2.6 (0.9-6.9)	**S	3.7 (1.4-9.9)	S
	Private	1.5 (0.6-4.4)	NS	2.5 (0.9-7.1)	NS
Risk factors	Heterosexual Contact	Reference	–	Reference	–
	MSM	0.9 (0.5-1.8)	NS	1.1 (0.6-2.1)	NS
	IDU	1.2 (0.6-2.3)	NS	1.1 (0.5-2.0)	NS
	NBT	0.3 (0.1-0.9)	S	0.5 (0.2-1.6)	NS
Uses Medications	No	Reference	–	Reference	–
	Yes	1.8 (1.1-3.3)	S	1.9 (1.1-3.6)	S

* Model fully adjusted for insurance, race, risk factors, and use of medications

** **Loss to care categories:** Financial (Child Care, Housing Issues, Financial Instability, Insurance Issues, Overwhelming circumstances, Transportation Issues, Unstable Location, Work Schedule); Stigma (Denial/Avoidance, Fear of Disclosure); Mental Health & Crime (Incarceration, Mental Health Issues, Substance Abuse); Health Systems & Concerns (Appointment Coordination, Provider problems, Language barriers, Priority Health Concerns); Multiple reasons

NHW = Non-Hispanic White || **MSM** = Men who have sex with Men || **IDU** = Injective drug use || **NBT** = Non-behavioral transmission

S: Significant (p < 0.05) || **NS:** Not significant (p > 0.05) || ******Borderline Significant

The use of ART medications was significantly associated with reengagement; clients who reported use of medication were twice as likely to be reengaged in care compared to those who did not. None of the other variables were significant at the $p < 0.05$ level.

After adjusting for race, insurance, risk factors and medication use, all reason categories were significantly associated with higher partial reengagement in care compared to the multiple reasons category. Clients who reported financial and stigma-related reasons were 2.5 to 4 more likely to be fully reengaged in care compared with those who had multiple reasons; those reporting health systems and concerns were 4 times more likely to be partially reengaged in care. Compared with other loss-to-care categories, persons with mental health and crime related reasons had the lowest likelihood of reengagement.

Enrollment in Medicaid or Medicare was associated with 2.8 to 3.7 times higher likelihood of reengagement in care compared to a lack of insurance. Clients with non-behavioral transmission were 20% less likely than those with heterosexual risk to be partially reengaged in care. Clients who reported use of medications remained twice as likely to be partially and fully reengaged in care. All other variables were insignificant at the $p < 0.05$ level. After adjusting for ethnic differences in loss-to-care reasons and other factors, reengagement in care did not differ significantly by ethnicity.

5.0 DISCUSSION

Engagement in care is an important component of the HIV care continuum and is essential for successful suppression of community viral load, management of health and improvement of quality of life for PLWH. This study adds to existing literature by evaluating the differences in reengagement to care based on PLWH-reported reasons for initial loss-to-care as well as other sociodemographic information.

Individuals who were reengaged were more likely to be Non-Hispanic White, owners of insurance, users of medication and people who reported only one primary reason for loss-to-care. Gender and age were not associated with reengagement in care, even when age was dichotomized. 21 transgender individuals were accounted for in the study population and they were reengaged at a slightly lower level compared to non-transgender clients, however, this difference was not significant. These results are consistent with the results from prior studies and confirm the importance of insurance as a supportive factor for retention to care^{13-15, 18-19}. Also, the use of medication which remained a strong predictor of reengagement to care in unadjusted and adjusted regression models, buttresses the literature which suggests that loss-to-follow-up may not encapsulate retention in care as use of medications during the loss-to-follow-up period signifies some level of self-management of health.

After adjustment for loss-to-care reasons and other factors, no difference was observed in reengagement across race/ethnicity categories; this suggests that the initial difference observed in

descriptive analyses was as a result of underlying differences in loss-to-care reasons and situation experienced by the race groups. Findings also showed that clients with reasons related to finance, stigma and health systems and concerns were more successfully reengaged than clients with mental health issues and multiple reasons which also included substance abuse, housing issues and mental health issues.

A surprising finding from the analyses in relation to case management services showed that clients receiving case management services were less likely to be reengaged in care. This finding contradicts prior study findings indicating that people receiving intensive case management services were more likely to consistently engage in care¹⁸. However, a second look at the data showed that not all agencies provided case management services; these were provided as organization specialties or on needs basis. Therefore, the finding suggests that clients being provided with case management services had more unmet needs which may delay their likelihood of being reengaged in care.

Consistent with other studies²¹, clients who had non-behavioral transmission were less likely to be reengaged in care compared to those with behavioral risk factors. This is suggestive of greater awareness among the latter about HIV status and management compared to people upon whom HIV status was conferred perinatally or through blood transfusion. However, injective drug use was a strongly significant predictor of non-reengagement to care (50% less likely), a consistent finding among several studies^{13-15, 20}. People who were not reengaged were more likely to report incarceration and substance abuse as primary loss-to-care reasons as well as multiple reasons for loss-to-care.

As the paradigm of HIV care and prevention increasingly focuses on establishing a continuum of care among PLWH, it becomes essential to highlight factors that influence

retention in care. This study provides understanding of PLWH situations which are important in program and intervention planning for PLWH. The study findings show that approaches to reduce HIV transmission must be multifaceted and include medical care provision as structural and supportive services that can assuage some of the common unmet needs that constitute barriers to linkage and retention in health care.

Interventions designed for people living with HIV must take into consideration the multiple health and social problems such as mental health issues, substance abuse, socioeconomic inequalities, and lack of stable housing among others and adapt the outreach programs to meet the needs of the target population.

6.0 LIMITATIONS

Several important limitations to this study should not be overlooked. A program-based convenience sample of PLWH in Southwestern Pennsylvania was used, and thus the results may not be generalizable to the national population of PLWH. Also, some of the individuals in the study were not in the program long enough to have a full fiscal year of data; thus, there is a possibility that some of those who were considered “not reengaged” may have returned to care in the next fiscal year.

Furthermore, health outcomes such as CD4 counts and HIV viral loads were not compared with levels of engagement to assess the import of reengagement in care in this program; this was due to the fact that a great proportion of participant laboratory reports were incomplete or awaiting receipt. Therefore, the study was limited to exploring client reasons and reengagement. In addition, information regarding length of time between follow-up appointments, appointments cancelled and strategies used by ASOs to reengage clients in care were not available for exploration in the analyses. Despite these limitations, the data analyses provides an appropriate overview and highlights possible areas to focus on or improve in future interventions.

7.0 CONCLUSION

Based on the analysis in this study, it appears that the MAI program approach to reengagement is relatively successful for clients who gave single reasons for loss to care, particularly reasons related to financial concerns, stigma and health systems and concerns. However, the approach is ineffective for persons with mental health issues, incarceration and substance abuse or who reported multiple reasons for loss to care. Consideration should be given to program modifications related to reengagement of such individuals. Also, while ethnicity, per se, is not associated with reengagement after adjusting for reasons for loss and other factors, the program focus on minorities should continue because the data showed that the minorities experienced more high risk reasons for loss to care.

APPENDIX A

VARIABLES IN MAI DATABASE

- Encrypted Unique Reference Number (EURN)
- Age
- Gender
- Race/Ethnicity
- Risk Factor
- Insurance
- Date of last HIV appointment in community
- Date of Referral
- Date of First Contact
- Reason the client was lost to care
- Prescriptions
- SPBP Eligibility & Enrollment
- Medical Case management provided
- Incentives provided
- Comments regarding client
- Dates of medical appointments
- Viral load results
- CD4 count results

APPENDIX B

LOSS-TO-CARE AND HIGH RISK CRITERIA

- No HIV medical visits in the last 180 days
- Only 1 HIV medical visit in the last 365 days
- No medical visit within the previous 60 days accompanied by diagnosed and untreated mental health or substance abuse issues such as homelessness or abuse in the home
- Missed HIV medical appointment more than twice consecutively
- Decrease in the CD4 count of >100 absolute cells since the last specimen
- Viral load >20 copies while on HIV medications
- No lab values for last 180 days
- Medication non-adherence (or missed >3 doses in one week)
- Missed OB/GYN appointment for >2 years
- No ART with a CD4 < 350
- Pregnant woman who missed one or more HIV specialty appointments
- Pregnant woman not taking ART
- Pregnant woman whose viral load is >20
- Missed ancillary referral appointments

- Removed from active case management services while residing in the service region (i.e. discharged from medical case management services due to not meeting re-certification criteria)
- Two or more missed medical case management appointments
- 340B Pharmacy program unable to reach patient by phone for refills
- Unable to contact (i.e. phone disconnected, mail returned) for > 1 month
- Loss of medical insurance
- Loss of employment or income source or denial of benefits (i.e. disability)
- Loss of transportation or support services
- New or recurring mental health or substance abuse issues
- Change in relationship status (i.e.: partner leaves, serious illness or death of partner or other significant person or trauma)

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