

# Factors predicting 12-month retention in care for minority women living with HIV

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## Abstract

**Objectives:** Retention in HIV medical care is associated with improved clinical outcomes and reduced mortality. The present study was conducted to identify significant predictors of 1-year retention in care for a sample of minority women whose engagement in HIV care at baseline varied along the care continuum from newly diagnosed to lost-to-care.

**Methods:** One hundred sixty-five cisgender and transgender women living with HIV in a southern US state were offered a multicomponent retention intervention that included outreach, medical case management (MCM), patient navigation services (PN), and a group intervention for stigma. Multilevel logistic regression analysis was performed to identify baseline and intervention predictors of retention in care at 12 months following enrollment.

**Results:** Multilevel logistic regression analysis revealed that baseline characteristics such as working significantly reduced the odds of being retained as did increasing CD4 counts. However, greater amounts of patient navigation and medical case management services received increased the odds of being retained.

**Conclusion:** MCM services designed to accelerate coordination and linkage or re-linkage to primary care and PN services to help navigate the complex system of HIV offered in the present study are particularly effective for minority women who lack health insurance, have low CD4 counts, and are unemployed.

**Keywords:** HIV Care, low income women of color, medical case management, patient navigation, treatment retention

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## Introduction

Due to the efficacy of antiretroviral therapy (ART), HIV is no longer an inevitable death threat but a chronic manageable disease.<sup>1</sup> However, poor retention in care is linked to inconsistent receipt of and adherence to antiretroviral therapy and ultimately poorer health outcomes.<sup>2</sup>

Early on in the epidemic, few women were diagnosed with HIV or AIDS,<sup>3</sup> but as of 2018, they represented more than 18% of new infections.<sup>4</sup> Women tend to have worse clinical outcomes than their male counterparts.<sup>5</sup> Moreover, black and Latina women are disproportionately impacted by delayed treatment initiation and retention in care.<sup>5–7</sup>

Although the United States has set national HIV goals for 2030 including 90% of individuals

retained in care,<sup>8</sup> 62.5% of Latinas and 57.1% of black women living with HIV were retained in care in 2018.<sup>9</sup> Clearly these rates fall short of the desired 90% goal.

A number of personal and environmental factors have been identified as challenges to retention, albeit the literature specific to women, particularly those who are not pregnant or post-partum, is limited. In the United States, personal factors affecting women include being of minority race or ethnicity, younger age,<sup>10</sup> lower education,<sup>11</sup> experiencing mental health,<sup>12</sup> and substance use issues.<sup>13</sup> Similarly, having negative impressions of the health-care system<sup>11,14</sup> or health beliefs such as feeling hopeless about treatment for HIV<sup>15</sup> are also associated with poorer retention. Clinical characteristics such as higher CD4 counts<sup>16</sup> and,

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conversely, detectable viral loads or low CD4 counts<sup>17,18</sup> have also been associated with poorer retention in care.

Environmental challenges include experiencing poor social support,<sup>7,10</sup> interpersonal violence,<sup>19,20</sup> and stigma within the community.<sup>21</sup> Women who have inadequate or unstable housing,<sup>22,23</sup> transportation difficulties,<sup>24,25</sup> lack of insurance/underinsurance,<sup>6,17</sup> employment opportunities,<sup>25</sup> or fragmented or substandard HIV care<sup>14,25</sup> are also likely to experience poorer retention.

Retention strategies reported in the literature include case management, intensive outreach to re-engage patients previously known to the medical system and lost to follow-up, navigation services to help navigate the complex health and social services system, enhanced personal contact between trained project staff and patients, and practical strategies such as helping patients remember appointments.<sup>26–29</sup> One-year retention rates among adults included in studies assessing these interventions range from 64% to 91%. However, few of the studies focused specifically on women or minority women.

Most people who remain engaged in HIV care and are adherent to antiviral therapy obtain excellent clinical outcomes including reduced mortality from AIDS-related illnesses and reduced risk of transmitting HIV to others.<sup>30</sup> Nevertheless, given the limited progress in achieving widespread viral suppression, intensified efforts are needed to improve suppression rates through effective retention in care strategies, particularly among women, who experience a disproportionate burden of HIV.

The aim of the researchers in conducting the present study was to identify significant predictors of 1-year retention in care for a sample of minority women whose engagement in HIV care at baseline varied along the care continuum from newly diagnosed to lost-to-care. Women who took part in the study were offered a multicomponent intervention that included outreach, medical case management (MCM), patient navigation (PN), and a group behavioral intervention designed to address stigma and secondary HIV prevention. Hypothesized predictors included barriers and challenges described in the literature, as well as facilitators such as the receipt of the various intervention components. It was anticipated that the

findings could inform the development of targeted approaches to effectively retaining minority women living with HIV in medical care.

## Materials and methods

### *Participants and procedures*

Following approval from The University of Texas Health Science Center at San Antonio's Institutional Review Board (HSC20100250H), 165 adult, minority, cis, and trans women living with HIV in South Texas were consented and enrolled from a large HIV primary care medical clinic. Informed consent was written. The medical case manager and outreach worker recruited women who were identified as new to HIV care, newly diagnosed, sporadic users of care, and lost to care by doing a medical chart review or from a direct referral from the city health department. Demographics of the women are included in Table 1. At enrollment, none of the women were retained in care according to the Health Resources and Services Administration's HIV/AIDS Bureau (HRSA HAB) definition (2017). Women were considered 'New to Care' if they were living with HIV and had no previous encounter with the clinic. Women were 'Newly Diagnosed' if there was no evidence in the medical record of a prior HIV diagnosis and the patient self-reported this was the first time she had been formally identified as living with HIV. Women were considered 'Lost to Care' if they had at least one visit in the last 2 years with the clinic but no visit in the past 12 months. Women were defined as 'Sporadic Users of Care' if they only had one medical visit in the last 12 months. Four enhancements to the HIV standard of care service system available locally were offered: (1) intensive outreach; (2) PN; (3) MCM; and (4) an evidence-based psychoeducation group intervention. These are described in Table 2.

As part of their participation, the women completed a baseline survey that included variables hypothesized to predict 12-month retention. From the medical charts, we abstracted baseline CD4 values and documented HIV primary care medical visits with a provider with prescribing privileges over a 12-month period. In addition, service providers who delivered the intervention components were asked to document the types of services they provided (i.e. group, outreach, PN, MCM) as well as the duration in minutes of each service provided.

**Table 1.** Demographics of baseline sample and services received over 1 year.

Variables	Total overall (N = 165)	Retained in care (n = 118)	Not retained in care (n = 47)
	% (n)	% (n)	% (n)
Baseline medical user type			
Newly diagnosed	22.4% (37)	24.6% (29)	17.0% (8)
New to care	28.5% (47)	26.3% (31)	34.0% (16)
Sporadic users of care	16.4% (27)	17.8% (21)	12.8% (6)
Lost to care	32.7% (54)	31.4% (37)	36.2% (17)
Cisgender woman			
Transgender MTF	94.5% (156)	96.6% (114)	89.4% (42)
	5.5% (9)	3.4% (4)	10.6% (5)
Race/ethnicity			
Hispanic	58.8% (97)	61.9% (73)	51.1% (24)
African American	39.4% (65)	37.3% (44)	44.7% (21)
Other	1.8% (3)	0.8% (1)	4.3% (2)
Primary language			
English	84.8% (140)	88.4% (99)	93.2% (41)
Spanish	9.1% (15)	10.7% (12)	6.8% (3)
Employed			
Graduated high school	23.6% (39)	27.1% (32)	14.9% (7)
Graduated high school	60.0% (99)	56.8% (67)	68.1% (32)
Past 30-day drug use	35.8% (59)	29.7% (35)	51.1% (24)*
Frequent mental distress <sup>a</sup>	46.1% (76)	44.1% (52)	51.1% (24)
Experienced stigma against PLWH	32.1% (53)	28.8% (34)	40.4% (19)
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Age (years)	35.87 (11.05)	35.90 (11.29)	35.81 (10.57)
Baseline CD4 count	363.58 (251.59)	352.48 (220.83)	440.68 (233.36)*
Patient navigation (min)	1919.73 (2523.50)	2289.92 (2778.61)	990.32 (1353.56)***
Medical case management (min)	331.82 (256.55)	385.55 (267.58)	196.91 (162.93)***
Intensive outreach (min)	611.91 (1713.96)	617.67 (1910.33)	586.91 (1095.78)
MTF: Transgender Male to Female; PLWH: people living with HIV. T-tests compared participants who were retained in care to those not retained in care. <sup>a</sup> Denotes a measure from the CDC Health-Related Quality of Life-14 (CDC HRQL-14) and represents those reporting 14 or more days of mentally unhealthy days in the past 30 days. Statistically significant differences noted as * <i>p</i> ≤ .05; ** <i>p</i> ≤ .01; *** <i>p</i> ≤ .001.			

## Measures

### Outcome measure

The outcome variable was coded dichotomously as retained or not retained in primary HIV

medical care at 12 months. Retention in care was operationally defined as two or more HIV primary care visits, during the year following completion of the baseline interview, that were 60 or more days apart. This definition is a modification

**Table 2.** Program enhancements to standard HIV medical care.

Intervention	Services provided	Completed by
Intensive outreach	Re-engage women lost or at risk of being lost to care through street outreach, home visitation, coordination with other facilities; offer short-term resource brokering and service linkage	Female outreach worker
Patient navigation	Coordinate and accompany women to appointments; arrange transportation; help to address psychosocial barriers to care; work to enhance client-provider communication and celebrate successes (e.g. viral load suppression)	Female patient or peer navigator
Medical case management	Identify eligible patients and link these women to first medical appointment, labs, and enrollment into program; expedite and provide reminders for medical appointments; assess for barriers to medical appointments	Female social worker
Healthy relationships group	A 5-session small-group intervention focused on developing skills and building self-efficacy to make informed and safe decisions about disclosure and behaviors.	Female peer navigator & female mental health provider

of the HRSA HAB's (2017) Performance Measure for HIV Medical Visit Frequency, which focused on a 2-year period.

### Predictor measures

*Person-level* information was collected including medical user type at study entry (i.e. new to care, newly diagnosed, sporadic users of care, lost to care), baseline demographics such as gender (female/transgender), age, race/ethnicity, primary language, number of children, marital status, sexual orientation, education, income, employment status, health insurance status, past 30-day substance use, and mental health status. Several measures assessed participant's mental health status, including the Brief Symptom Inventory (BSI-18)<sup>31</sup> and the Centers for Disease Control and Prevention Health-Related Quality of Life 14-item measure (CDC HRQL-14), which provided scores such as frequent mental distress. The baseline survey also incorporated the Barriers to Care Scale<sup>32</sup> designed to address *environmental* (i.e., physical, social, and attitudinal) related barriers to care faced by persons living with HIV, including personal financial resources and perceived stigma from the community against people living with HIV (PLWH). Participants were asked to rate each of the 12 items using a four-point Likert scale (1 = 'No problem at all', 2 = 'Very

slight problem', 3 = 'Somewhat of a problem', and 4 = 'Major problem') to indicate the extent to which the item was true. We also included a number of single items adapted from a Patel et al. (2008)<sup>33</sup> and Rapkin et al.<sup>34</sup> that asked about barriers to care, including wanting to get things back on track on your own, having trouble scheduling appointments, and lack of or inability to afford health insurance. Each barrier was rated on a three-point scale ('great deal', 'somewhat', or 'not' a barrier) to obtaining medical care. All barriers to care items from the three sources were dichotomized into 'not a problem' or 'a problem' for the participant. The *clinical* predictor was baseline CD4 count. The service type (i.e. PN, MCM, outreach, group sessions) and duration in minutes of the *retention interventions* provided to the women were also measured. During preliminary analysis, CD4 count and MCM were slightly positively skewed so were given a square root transformation. PN, being positively skewed, was given a log10 transformation, before being added into the regression analysis.

### Results

Data preparation included exploring for missing data (i.e. <10%), imputing data using maximum likelihood estimations, reviewing statistical assumptions, and exploring any differences in

participant demographics for those who were retained and not retained. All statistical assumptions for logistic regression were met. All statistical analyses were conducted using SPSS version 24. A  $p$  value of  $<0.05$  was considered to be statistically significant.

Of the 165 women, 118 (71.5%) met criteria for being retained in care and 47 (28.5%) did not. There were no statistically significant differences between those two categories with respect to age, ethnicity, education level, or income level. However, there were significant differences between those retained and not retained in care with respect to other predictors (see Table 1).

### *Multilevel logistic regression model results*

Baseline predictor variables were selected that had a significant bivariate correlation with retention in care at the  $p < 0.10$  for the regression model. Any baseline predictor, such as the subscale scores from the BSI, were not included in the final regression analyses as they were not significantly correlated with retention in care in preliminary analyses. A multilevel logistic regression was used to assess the relationship between each independent variable and retention. A multilevel logistic regression was utilized to first explore baseline *personal* and *environmental level* factors, and then added in *intervention* factors such as PN and MCM in the second step of the analysis (see Table 3 for results).

The first step in the analysis was significant [ $\chi^2(12) = 40.06, p < 0.001$ ]. Three of the person-level variables were significant predictors after controlling for other variables in the model: working (dichotomized as either working full time/part time or not working), perceived affordability of their health insurance, and CD4 count. Those who reported working had 67% lower odds of being retained compared with those who reported they did not work [odds ratio (OR) = 0.33, 95% confidence interval (CI) (0.11, 1.00)]. Those who reported an inability to afford health insurance as a perceived barrier to their care were over three times more likely to be retained in care [OR = 3.49, CI (1.38, 8.81)] compared with those who reported it was not a problem. For a one-unit (1 point) increase in baseline CD4 count, there was a 13.3% decrease in the odds of being retained [OR = 0.87, CI (0.80, 0.95)].

These three variables accounted for 31% of the total variance of retention in care for Women of Color (WOC) living with HIV (Nagelkerke  $R^2 = 0.31$ ). The Hosmer and Lemeshow test showed satisfactory fit of the data [ $\chi^2(8) = 3.72, p = 0.88$ ] with 77% classification accuracy of predicting retention.

Adding in intervention variables (PN and MCM), the second step in the analysis was significant [ $\chi^2(14) = 63.93, p < 0.001$ ] and more accurately fit the data (Model 2:  $-2$  Log Likelihood = 133.24 compared with Model 1:  $-2$  Log Likelihood = 157.11). The same three person-level variables were significant in Model 2, as well as the two additional service-related variables. Those who reported working had 76% lower odds of being retained than their non-working counterparts [OR = 0.24, CI (0.06, 0.93)]. Those who self-reported an inability to afford health insurance as a perceived barrier to HIV medical care were over three times more likely to be retained [OR = 3.51, CI (1.24, 9.93)] compared with those who reported it was not a problem. For a one-unit increase in baseline CD4 count, there was a 9% decrease in the odds of being retained [OR = 0.91, CI (0.83, 0.99)]. For a one-unit (15 minute) increase in time spent with PN, individuals were 1.76 times more likely to be retained [OR = 1.76, CI (1.07, 2.87)]. For a one-unit increase in time spent with MCM, individuals were 1.13 times more likely to be retained in care [OR = 1.13, CI (1.05, 1.22)]. These five variables accounted for 46% of the total variance of retention (Nagelkerke  $R^2 = 0.46$ ). The Hosmer and Lemeshow test showed a satisfactory fit of the data [ $\chi^2(8) = 5.87, p = 0.66$ ] with 78.8% classification accuracy of predicting retention in care at 12-month follow-up.

### **Discussion**

This study sought to determine the personal and environmental-level factors as well as intervention predictors of retention in care for a sample of minority women living with HIV in South Texas. It was anticipated that knowledge of these predictors could inform the future development of interventions and strategies to increase retention in care and ultimately increased survival rates<sup>2</sup> of similar women. Contrary to expectation, for the women in our sample, being employed reduced the likelihood of being retained in care at 12 months. Although Walcott *et al.*<sup>25</sup> identified

**Table 3.** Baseline and intervention factors identified in logistic regression model.

Variables	$\beta^a$	SE $\beta$	Wald test	OR <sup>b</sup>	95% CI
Step 1					
Working	-1.12*	0.57	3.88	0.33	[0.11, 1.00]
Adequate health insurance	0.05	0.48	0.01	1.05	[0.41, 2.70]
Past 30-day drug use	-0.17	0.46	0.13	0.85	[0.34, 2.10]
Needed housing	-0.60	0.60	1.01	0.55	[0.17, 1.77]
Needed dental services	0.67	0.43	2.42	1.95	[0.84, 4.50]
Needed mental health services	0.85 <sup>†</sup>	0.51	2.81	2.33	[0.87, 6.28]
Personal financial resources	0.35	0.48	0.55	1.42	[0.56, 3.60]
Wanted to get things back on track on your own	-0.16	0.47	0.11	0.85	[0.34, 2.15]
Thought you would have trouble scheduling appointments	0.13	0.45	0.09	1.14	[0.47, 2.78]
Could not afford health insurance	1.25**	0.47	6.98	3.49	[1.38, 8.81]
Lack of psychological support groups for persons living with HIV/AIDS	0.27	0.55	0.24	1.31	[0.45, 3.82]
CD4 count	-0.14***	0.04	10.42	0.87	[0.80, 0.95]
Step 2					
Working	-1.43*	0.69	4.27	0.24	[0.06, 0.93]
Adequate health insurance	0.62	0.54	1.32	1.86	[0.65, 5.34]
Past 30-day drug use	-0.11	0.53	0.04	0.90	[0.32, 2.51]
Needed housing	0.43	0.71	0.37	1.54	[0.39, 6.12]
Needed dental services	0.69	0.48	2.09	1.99	[0.78, 5.03]
Needed mental health services	0.32	0.57	0.31	1.37	[0.45, 4.21]
Personal financial resources	0.05	0.54	0.01	1.05	[0.36, 3.03]
Wanted to get things back on track on your own	-0.02	0.53	1.80	0.98	[0.35, 2.75]
Thought you would have trouble scheduling appointments	0.03	0.52	0.00	1.04	[0.38, 2.85]
Could not afford health insurance	1.26*	0.53	5.63	3.51	[1.24, 9.93]
Lack of psychological support groups for persons living with HIV/AIDS	0.50	0.60	0.70	1.65	[0.51, 5.36]
CD4 count	-0.10*	0.05	4.54	0.91	[0.83, 0.99]
Patient navigation	0.56*	0.25	5.02	1.76	[1.07, 2.87]
Medical case management	0.12***	0.04	10.51	1.13	[1.05, 1.22]
SE: standard error; CI: confidence interval.					
<sup>a</sup> $\beta$ values are the estimated unstandardized regression coefficients.					
<sup>b</sup> OR = odds ratio which indicates likelihood of retention in care.					
<sup>†</sup> Nearing significance, $p < 1.0$ ; * $p \leq .05$ ; ** $p \leq .01$ ; *** $p \leq .001$ .					



limited employment opportunities as a perceived risk for sub-optimal engagement of women in care, it is possible that the employed women in the current study had difficulty taking time off to attend medical provider appointments which were typically offered during normal working hours. Although other studies have found that lack of health insurance/underinsurance is a barrier to retention,<sup>17</sup> we found that the perceived inability to afford health insurance was actually a predictor of retention. Women who perceived they were unable to afford health insurance may have been more committed to taking advantage of the mostly no- or low-cost intervention services provided by the study and therefore ultimately benefited from remaining in care. As found in some previous studies,<sup>35</sup> the lower a woman's initial CD4 count, the more likely she was to meet retention criteria at 12 months. It is possible that women with lower CD4 counts also had more health issues which increased their motivation to see a health-care provider more regularly.

Significant predictors in this study included MCM designed to accelerate coordination and linkage or re-linkage to primary care and PN services to help navigate the complex system of HIV care. Independently, the greater the amount of MCM received and the greater the amount of PN services received, the greater the likelihood of retention at 12 months. In their systematic review, Higa *et al.*<sup>28</sup> concluded that interventions that removed barriers to health-care access, including services similar to those offered through the MCM and PN components in the present study, are effective in promoting retention in care. Interestingly, our findings may be construed to suggest that PN services, delivered by paraprofessional women, rather than more costly MCM services delivered by a professional, may be the more cost-effective retention intervention, particularly in clinic settings limited by financial constraints. Nevertheless, others<sup>28,36</sup> assert that using multiple retention strategies, as occurred in the present study, rather than single interventions may be necessary to address the various barriers that prevent access to and consistent use of primary care.

Contrary to expectation, intensive outreach did not predict retention in care. Perhaps, this intervention component was more effective in engaging or helping re-engage women but not necessarily in retaining them in care. Likewise,

despite stigma being a reported barrier in the literature, the evidence-based psychoeducational group intervention component designed to address HIV-related stigma in the present study was not associated with retention. A possible reason may be that women in the present study received inadequate exposure to this evidence-based intervention component with the median session attendance being three out of five sessions for the 100 women who participated in at least one session. Only 30 women completed all five sessions. Furthermore, not all women in the study participated in the evidence-based group intervention due to barriers such as lack of evening or weekend hours which could have helped those who worked, or an absence of childcare for those with younger children. Stigma itself was also not found to be predictor of retention in care. In addition, where it is common to find that substance use and mental health issues may predict decreased retention in HIV care,<sup>13,37</sup> our study did not find these associations.

A strength of the study was that it used a prospective rather than retrospective design, thereby reducing the likelihood of errors related to estimating or reporting on past events. Another strength is that it incorporated an objective measure of retention in care rather than relying on patient self-report, as have a number of earlier studies.<sup>28</sup> A limitation of the study is that it focused on minority women living in one particular region of the United States so the results may have limited generalizability to the United States as a whole. Despite efforts to include transgendered minority women who are representative of the HIV clinic in which the study was conducted, our small sample size prevented us from comparing retention predictors for the two gender subgroups. Although there is no gold standard retention measure,<sup>38</sup> the design could have been strengthened by incorporating multiple measures of retention in order to facilitate comparisons across studies. Another relative weakness is the short time frame, namely 12 months, during which to measure retention, given that individuals living with HIV are expected to remain in care for many years in order to reap the survival benefits. Finally, as with any study with a non-randomized design, there is a potential bias introduced in terms of generalizability based on the population of those who agree to participate. Although this may be a possible limitation of the study, we

had to use intensive outreach to bring those who were out of care back into care through the program. The women did not choose which intervention to be a part of, rather they were offered all services and they choose which services benefited them the most.

Future studies may test the multicomponent intervention in a more rigorous manner by using an appropriate control group, following the women for longer than 12 months, using multiple measures of retention, and assessing the relationship between retention and viral suppression at the study endpoint. Additional research focused specifically on disenfranchised women living with HIV is needed to assess the efficacy of intervention strategies designed to remove structural barriers to retention in care. For instance, this could include expanding clinic hours to offer evening and weekend hours for working women, providing free or low-cost childcare services for those with children, offering affordable PN and MCM services, and increasing access to HIV medical providers with the ability to prescribe. Given that about one in five transgendered women in the United States are living with HIV,<sup>39</sup> and that they are less likely to be engaged, retained, and adherent to HIV care than other vulnerable subgroups,<sup>40,41</sup> there is a pressing need to develop interventions specific to this important but understudied subgroup as well.

### Conclusion

Retention in HIV care is associated with improved clinical outcomes and reduced mortality. This study added support to a growing body of literature that interventions that remove barriers to health-care access and use are effective in promoting retention in care, particularly for minority women living with HIV. Furthermore, the MCM services designed to accelerate coordination and linkage or re-linkage to primary care and PN services to help navigate the complex system of HIV offered in the present study are particularly effective for minority women who perceive they have inadequate health insurance, have low CD4 counts, and are unemployed.

### Author contributions

**Mercedes V. Ingram:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Validation; Writing – original draft; Writing – review & editing.

**Nancy Amodei:** Conceptualization; Funding acquisition; Investigation; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing.

**Veronica Villela Perez:** Conceptualization; Funding acquisition; Investigation; Methodology; Project administration; Supervision; Writing – review & editing.

**Victor German:** Conceptualization; Funding acquisition; Investigation; Project administration; Supervision; Writing – review & editing.

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