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Health Insurance and AIDS Drug Assistance Program (ADAP) Increases Retention in Care among Women Living with HIV in the United States

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Abstract

Our objective was to examine the association between healthcare payer type and missed HIV care visits among 1,366 US women living with HIV (WLWH) enrolled in the prospective Women's Interagency HIV Study (WIHS). We collected secondary patient-level data (October 1, 2017-September 30, 2018) from WLWH at nine WIHS sites. We used bivariate and multivariable binary logistic regression to examine the relationship between healthcare payer type (cross-classification of patients' ADAP and health insurance enrollment) and missed visits-based retention in care, defined as no-show appointments for which patients did not reschedule. Our sample included all WLWH who self-reported having received HIV care at least once during the two consecutive biannual WIHS visits a year prior to October 1, 2017-September 30, 2018. In the bivariate model, compared to uninsured WLWH without ADAP, WLWH with private insurance +ADAP were more likely to be retained in care, as were WLWH with Medicaid only and private insurance only. In the

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adjusted model, WLWH with private insurance only were more likely to be retained in care compared to uninsured WLWH without ADAP. Private health insurance and ADAP are associated with increased odds of retention in care among WLWH.

Keywords

women living with HIV; Women's Interagency HIV Study; retention in care; AIDS Drug Assistance Program

Uninsured people living with HIV (PLWH) who are not enrolled in the Ryan White HIV/AIDS Program (RWHAP) are less likely to be virally suppressed and retained in care than insured PLWH (Kay, Batey, & Mugavero, 2018). Post-Affordable Care Act implementation, insurance options for PLWH have increased, especially in states that expanded Medicaid eligibility for adults <65 years of age to 138% of the federal poverty level (FPL). According to 2014 estimates from the Kaiser Family Foundation (KFF), approximately 42% of PLWH in HIV care reported having health insurance, compared to 36% in 2012 (Kates & Dawson, 2017). Yet, it is also estimated that an additional 60,000 PLWH could obtain health insurance coverage if all states expanded Medicaid (Snider et al., 2014), as 40% of PLWH are estimated to live in non-expansion states (KFF, 2016b).

All US states (and Washington, D.C.) and territories receive AIDS Drug Assistance Program (ADAP) funding, which is funded through Part B of the RWHAP (Health Resources and Services Administration HIV/AIDS Bureau, 2017). States use earmarked ADAP funds as the "payer of last resort" to purchase HIV antiretroviral therapy [ART] for low income, uninsured, or underinsured PLWH. Approximately one-quarter of the 1.1 million PLWH in the US rely on ADAP to help them pay for ART (NASTAD, 2019). States are allowed to set their own income eligibility requirements for receiving ADAP, which ranges from 200% (Texas, Idaho, Puerto Rico) to 550% (South Carolina) of the FPL (KFF, 2016a). Drug formularies for ART vary by state, and there are no federal requirements to cover non-HIV drugs for ADAP recipients with co-morbid conditions (McManus, Engelhard, & Dillingham, 2013). States may also set insurance-based eligibility requirements. The only federal ADAP requirements are formal documentation of HIV infection and state residency (KFF, 2017).

ADAP enrollment and insurance coverage have an impact on retention in care outcomes for PLWH (Althoff, Dwyer, Chew, & Gracely, 2018; Diepstra et al., 2017; Kay et al., 2018). Retention in care is a key step in the HIV Care Continuum (Kay, Batey, & Mugavero, 2016) and is important for achieving viral suppression (Centers for Disease Control and Prevention, 2018). The most commonly-used measure of retention in HIV care is endorsed by the Institute of Medicine (IOM) and is defined as two attended HIV primary care visits 90 days apart during a 12 month period (IOM, 2012). While the IOM measure of retention in care ("retention") is based on *attended* scheduled appointments, the missed visit retention measure is based on *unattended*, no-show appointments (Mugavero et al., 2012). Research has shown that lack of retention in care, when measured by missed HIV primary care visits, is independently associated with mortality (Horberg et al., 2013; Mugavero et al., 2014). Moreover, WLWH are more likely to miss scheduled visits than men, which places them at higher risk for mortality (Mugavero et al., 2009), and they are especially vulnerable to

inconsistently attending or dropping out of care altogether while postpartum (Momplaisir, Storm, Nkwihoreze, Jayeola, & Jemmott, 2018).

Having private health insurance, as opposed to having Medicaid or being uninsured, has also been shown to be associated with retention in care, when defined with either the attended visit-based IOM measure (Kay et al., 2018; Yehia, Stephens-Shields, et al., 2015) or missed visit-based measure (Althoff et al., 2018; Kay et al., 2018) of retention. Medicare coverage has been shown to be associated with greater odds of retention in care (based on attended appointments) than private insurance coverage (Yehia et al., 2012). Research also suggests that PLWH who have ADAP along with RWHAP core and support services have a 20.6 (95% CI= 16.6–25.5) times greater odds of retention in care than PLWH without any RWHAP services (Diepstra et al., 2017). Yet, according to 2016 national estimates, just half of PLWH are retained in care (49%) (Centers for Disease Control and Prevention, 2018). Because PLWH who are not retained in care are at increased risk of transmitting HIV to others and are more likely to experience adverse health outcomes (e.g., virologic failure) (Thompson et al., 2012; Zinski et al., 2015), it is important to identify factors associated with retention in care.

Though past research has separately explored the relationships between health insurance coverage and ADAP enrollment and retention in care, the combination of insurance and ADAP and its association with retention in care has not been explored. Thus, it is unclear whether particular combinations of health insurance and ADAP enrollment are differentially associated with retention in care, an HIV health outcome that women are less likely to achieve than men. The objective of this study was to examine the association between healthcare payer type (insurance type plus ADAP enrollment status) and retention in care, as measured by missed HIV care visits, among a cohort of US women living with HIV (WLWH) enrolled in the Women's Interagency HIV Study (WIHS).

Methods

Data source and sample

We analyzed patient-level data from WLWH at nine WIHS sites: Brooklyn, NY; Bronx, NY; Atlanta, GA; Washington, D.C.; San Francisco, CA; Chicago, IL; Miami, FL; Chapel Hill, NC; and Birmingham, AL/Jackson, MS. The WIHS, established in 1993, is an ongoing prospective cohort study of both WLWH and women at risk for HIV (Adimora et al., 2018). Clinical, behavioral, and socioeconomic data are currently collected biannually for over 1500 WLWH and over 500 HIV-at risk women (Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2017).

Our sample included all WLWH who self-reported having received HIV care at least once during the two consecutive biannual WIHS visits a year prior to the 12-month analytic period of interest (October 1, 2017-September 30, 2018) and who had a WIHS visit during the analytic period of interest. There were 111 WLWH who reported having received HIV care at least once during the year prior to the analytic period but who did not attend a WIHS visit between October 1, 2017 and September 30, 2018; these women were excluded from

the sample due to not having a WIHS visit during the analytic period. With these inclusion criteria, we established a sample of 1,366 WLWH who were in HIV care at baseline.

Outcome

Our primary outcome was retention in care as measured by *missed HIV care appointments*, which were defined as no-show appointments for which patients did not reschedule. This information was self-reported and was determined from the following question: “In the last six months, did you miss any scheduled regular HIV care appointments? By this, I mean you did not go for a scheduled appointment and did not re-schedule.”

WLWH who reported that they had missed 1 scheduled regular HIV care appointments over the 12-month analytic period were considered *not retained* (Mugavero et al., 2012). WLWH who did *not* report missing any scheduled HIV care appointments over the 12-month analytic period were considered *retained*; this also included women who did not have any visits scheduled and, therefore, did not have any visits to miss, as is customary for analyses using the missed visit-based measure of retention in care (Mugavero et al., 2014).

Predictors

The primary predictor of interest was *healthcare payer type*, which was a cross-classification of patients’ ADAP enrollment and health insurance enrollment (both self-reported at the visit six months prior to the start of the analytic period). ADAP enrollment was determined by the following question, “Since your last study visit, have you received assistance from ADAP (AIDS Drug Assistance Program)?” Health insurance, which included all insurance coverage WLWH had received since their last visit, was categorized into four mutually exclusive groups similar to those used by the Kaiser Family Foundation (Kates et al., 2014): Medicaid, private insurance, other insurance (including Medicare, Tricare/CHAMPUS, Veteran’s Administration, and city or county coverage), and no health insurance. Possible categories for healthcare payer type included: uninsured only; Medicaid only; private only; other only; uninsured/ADAP; Medicaid/ADAP; private/ADAP; and other/ADAP.

Covariates for education level (less than high school, high school diploma, more than high school), ethnicity (Hispanic/Latinx or non-Hispanic/Latinx), and race (White, Black or African American, or other) were taken from women’s first WIHS visit. Other covariates were from six months prior to the start of the analytic period. These included age (continuous), employment status (yes/ no), WIHS site, viral load (suppressed: yes/no), and annual household income (four categories ranging from \$6,000 to >\$75,000). Information about annual household income was combined with information about women’s total household size over the past year (nine categories ranging from 1 to >8 household members) to create a variable for FPL based on 2018 federal poverty guidelines (U.S. Department of Health and Human Services, 2018) (living at or below the FPL: yes/no). Women were also asked about barriers to their regular HIV care: “In the last six months, have any of the following happened in terms of your regular HIV care?” Women could choose one or more options among possible barriers to care, including not being able to pay, not knowing where to go, not having anyone else to care for children/others, no need for care/HIV under control,

not having time/work conflicts, not going due to fear others might see you getting HIV care, and not going because feeling too sick.

Analysis

We computed descriptive statistics, including frequencies, percentages, medians, interquartile ranges (IQRs) and ranges, for the primary exposure, covariates, and the outcome. We then examined the relationship between healthcare payer type and missed visits-based retention in care using bivariate and multivariable binary logistic regression. We dropped records missing covariate data for household size ($n=64$) and income ($n=43$); no other variables had missing data. Unadjusted odds ratios (ORs) and adjusted odds ratios (AORs) with 95% confidence intervals (CIs) are shown in Table 2. We controlled for age, race, and study site due to their hypothesized association with both exposure (e.g., (Berchick, Hood, & Barnett, 2018; Sohn, 2017)) and outcome (e.g., (Horberg et al., 2013; Yehia, Rebeiro, et al., 2015)). To account for state-level differences in Medicaid eligibility, we conducted a separate sensitivity analysis in which we also included a state-level variable for Medicaid expansion status during the analytic period; however, the inclusion of this variable did not affect the multivariable model and, therefore, was dropped from analysis. We did not control for income given that the majority of WLWH had Medicaid coverage, and there are income thresholds for Medicaid eligibility. Instead, in a separate analysis including only Medicaid-insured WLWH, we examined the bivariate and multivariable relationship between healthcare payer type and missed visits-based retention while controlling for income as a measure of FPL, age, race, and study site (Table 3).

Results

Approximately three-quarters of WLWH were Black or African American (75.3%) and had a median age of 51 (IQR=13, [44, 57]). Annual household income of \$18,000 was reported by 64.8% of WLWH; 65.3% had a high school diploma or less, while 35.6% were employed. Seventy-one percent were living at or below the FPL. About half of WLWH reported Medicaid only (53.4%), followed by private insurance only (14.9%) and Medicaid/ADAP coverage (9.8%). Just 2.7% of WLWH were uninsured and did not have ADAP coverage, while 8.6% were uninsured but had ADAP. Among women's reported barriers to regular HIV care, the most commonly reported barrier was "no need for care/HIV under control" (5.3% of women), followed by "not going due to fear others might see you" (4.0%) and "not going because feeling too sick" (3.9%). About three-fourths were virally suppressed (73.4%).

In unadjusted regression analyses (Table 2), compared to uninsured WLWH without ADAP, WLWH with *private insurance and ADAP* had a significantly higher odds of being retained in care (OR=2.43, 95% CI=1.01–5.88), as did WLWH with *Medicaid only* (OR=2.11, 95% CI=1.04–4.32) and WLWH with *private insurance only* (OR=3.95, 95% CI=1.74–8.95). In the adjusted model (Table 2), WLWH who had *private insurance only* were three times more likely to be retained in care compared to uninsured WLWH without ADAP (AOR= 3.15, 95% CI=1.36–7.30). Though they did not reach statistical significance in the adjusted model, all healthcare payer combinations (with the exception of *other only*) were associated with

higher odds of retention in care than *uninsured only (no ADAP)*. Among WLWH with Medicaid, there was no statistically significant difference in retention in care between WLWH who had *Medicaid only* and WLWH who had *Medicaid and ADAP*, in either unadjusted or adjusted analyses that controlled for income, age, race, and study site (Table 3).

Discussion

WLWH who had private insurance and ADAP, private insurance only, or Medicaid only were more likely to be retained in care than uninsured WLWH without ADAP. After adjusting for age, race, and study site, women who had private insurance only were more likely to be retained in care than uninsured WLWH without ADAP. These results speak to the significance of healthcare payers (particularly, private insurance and ADAP) in improving HIV primary care visit attendance among WLWH. Women who are unable to afford ART or who are unaware of assistance programs like ADAP may miss HIV primary care appointments or even drop out of care altogether, which increases risk of viral non-suppression. It is also important to consider pregnancy-related outcomes among WLWH, who are more likely to attain viral suppression and prevent perinatal HIV transmission if ART is started prior to pregnancy (Woldesenbet et al., 2020). Provision of affordable ART for WLWH through ADAP and insurance is crucial in ensuring that WLWH are able to link to and remain retained in care, including during health events like the perinatal period and menopause.

Future research should consider the role of health insurance in impacting HIV health outcomes outside of the US, which has a unique healthcare system not readily comparable to other countries'. For example, in many African countries, donor funding, rather than health insurance, is the primary source of ART (Were, Hogan, Galárraga, & Wamai, 2020). A recent analysis of nearly 14,000 pregnant WLWH in Kenya found that only 7%–16% were enrolled in Kenya's social health insurance system, and that WLRH with health insurance were actually less likely to be on ART than uninsured WLWH (Were et al., 2020). The authors speculated that this may have been due to women enrolling in insurance only if they felt sick; however, outcomes such as viral suppression and retention were not examined.

Our findings complement prior research, which demonstrated that WLWH with private health insurance were more likely to be virally suppressed than WLWH with Medicaid, and, among uninsured WLWH, those with ADAP were more likely to be virally suppressed than those without ADAP (Ludema et al., 2016). Our findings also expand on prior research which found that PLWH who receive RWHAP support services were more likely to be both retained in care (as defined by both the IOM and missed visit measures) and virally suppressed than PLWH who did not receive RWHAP support services, even when controlling for primary payer type (Kay et al., 2018). Since all uninsured PLWH should be able to enroll in ADAP, it is important that providers work with their patients to ensure that they are enrolled in the health insurance and RWHAP programs for which they are eligible.

Given the strict ADAP eligibility requirements in many states, it is not surprising that just a quarter of WLWH in the sample (26.7%) were enrolled in ADAP, even though the majority

(71.0%) had annual incomes at or below the FPL and would have otherwise qualified for ADAP enrollment based on income level. Since many states (e.g., North Carolina, (Directory of ADAPs, 2019) Virginia, (Virginia Department of Health, 2019) New York (New York State Department of Health, 2015)) do not allow PLWH who are eligible for or enrolled in Medicaid to enroll in ADAP, it is likely that this ADAP eligibility restriction explains the small proportion of WLWH in our sample who had both Medicaid and ADAP (10% with Medicaid/ADAP vs. 53% with Medicaid only). The small proportion of Medicaid-insured WLWH in the sample who were enrolled in ADAP may account for similar retention in care outcomes between WLWH with Medicaid only and WLWH with Medicaid/ADAP. Yet, ADAP may still be important for Medicaid-insured WLWH in ways not captured in our study. Besides paying for ART, some state ADAPs also cover the cost of treating co-occurring infections like hepatitis C virus infection (National Alliance of State and Territorial AIDS Directors, 2017) and co-morbid conditions, such as hypertension and diabetes (Blackstock, Wang, & Fiellin, 2011).

This study has several limitations. Women enrolled in WIHS are not representative of all WLWH. All questions asked of WLWH during WIHS study visits reflect coverage at some point during the past six months, so it is possible that some WLWH may have experienced a change in coverage during that time that was not reflected in the analysis. In addition, given the variability of state-level ADAP requirements, results may not be generalizable across states. Finally, it is important to note that women's appointment adherence data was self-reported.

In conclusion, being enrolled in both private health insurance and ADAP was associated with increased odds of being retained in care as measured by no missed scheduled HIV care appointments during a 12-month period among WLWH. Since missed HIV care appointments are associated with increased mortality risk (Horberg et al., 2013; Mugavero et al., 2014), it is important to identify factors associated with retention in care. Based on our findings, we recommend that HIV providers work with their patients to ensure they are covered by the health insurance programs and RWHAP services (e.g., ADAP) for which they are eligible.

The Ryan White HIV/AIDS Program continues to be crucial for the overall health of PLWH in the US, many of whom rely on RWHAP to pay for wraparound services that Medicaid does not cover, such as transportation assistance and childcare (Arnold, Fuller, Kirby, & Steward, 2018). Given that PLWH in the US are increasingly in older age groups, coverage of medication costs for treating common comorbid conditions, such as hypertension, will become increasingly important. Thus, we recommend that policymakers continue to fund RWHAP services, which depend on annual appropriations from Congress (KFF, 2019), so that all WLWH can afford life-saving medical care.

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Table 1.

Demographic and Clinic Characteristics of Study Participants (N=1,366)

Characteristic	N (%)
Age, Median (Interquartile Range) [with bounds]; Range	50.4, 51(13) [44, 57]; 28–82
Hispanic/Latinx ethnicity	198 (14.5)
Race	
White	199 (14.6)
Black or African American	1029 (75.3)
Other	138 (10.1)
WIHS Site	
Bronx, NY	187 (13.7)
Brooklyn, NY	202 (14.8)
Washington, D.C.	146 (10.7)
San Francisco, CA	154 (11.3)
Chicago, IL	161 (11.7)
Miami, FL	84 (6.2)
Chapel Hill, NC	128 (9.4)
Atlanta, GA	163 (11.9)
Birmingham, AL/Jackson, MS	141 (10.3)
Employed	486 (35.6)
Annual household income	
\$6,000	159 (12.0)
\$6,001–\$12,000	493 (37.3)
\$12,001–18,000	205 (15.5)
> \$18,000	466 (32.2)
Total household size	
1–2	765 (58.7)
3–4	379 (29.1)
5–6	120 (9.2)
7–8+	38 (1.4)
Living at or below federal poverty level	925 (71.0)
Educational level	
< High school	457 (33.5)
High school diploma	434 (31.8)
> High school	474 (34.7)
Virally suppressed (HIV viral load <200 copies/mL)	968 (73.4)
Health insurance type	
Medicaid	864 (63.3)
Private	294 (21.5)
Uninsured	154 (11.3)
Other	54 (4.0)
ADAP enrollment	364 (26.7)

Characteristic	N (%)
Healthcare Payer Type	
Uninsured only	37 (2.7)
Uninsured /ADAP	117 (8.6)
Medicaid only	730 (53.4)
Medicaid /ADAP	134 (9.8)
Private only	203 (14.9)
Private /ADAP	91 (6.7)
Other only	32 (2.3)
Other /ADAP	22 (1.6)
Reported barrier to HIV Care	
No need for care/HIV under control	72 (5.3)
Not going due to fear others might see you getting HIV care	54 (4.0)
Not going because feeling too sick	52 (3.9)
Not having time/work conflicts	51 (3.7)
Not being able to pay	27 (2.0)
Not having anyone else to care for children/others	18 (1.3)
Not knowing where to go	13 (1.0)

Note. N=64 missing for total household size

N=43 missing for income

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Table 2.

Bivariate and Multivariable Logistic Regression Analyses of Healthcare Payer Type and Retention in Care among Study Participants

Healthcare Payer Type	Retention in Care OR (95% CI)	Retention in Care AOR (95% CI)*
Uninsured only (no ADAP)	<i>Referent</i>	<i>Referent</i>
Uninsured + ADAP	1.86 (0.82–4.23)	1.89 (0.81–4.41)
Medicaid only	2.11 (1.04–4.32)	1.61 (0.76–3.41)
Medicaid + ADAP	1.59 (0.72–3.54)	1.26 (0.54–2.91)
Private only	3.95 (1.74–8.95)	3.15 (1.36–7.30)
Private + ADAP	2.43 (1.01–5.88)	1.95 (0.78–4.86)
Other only	1.23 (0.44–3.45)	0.89 (0.31–2.60)
Other + ADAP	4.80 (0.96–23.97)	3.38 (0.66–17.30)

* Controlling for age, race, and study site

Statistically significant results ($p < 0.05$) are bolded

Definitions and abbreviations.

Not retained: Missed 1 scheduled HIV primary care appointment during the 12-month analytic period

OR: odds ratio

AOR: adjusted odds ratio

ADAP: AIDS Drug Assistance Program

Table 3.

Bivariate and Multivariable Logistic Regression Analyses of ADAP and Retention in Care among Study Participants with Medicaid Coverage

Healthcare Payer Type	Retention in Care OR (95% CI)	Retention in Care AOR (95% CI) *
Medicaid/ADAP	<i>Referent</i>	<i>Referent</i>
Medicaid only	1.33 (0.85–2.07)	1.37 (0.84–2.24)

* Controlling for income, age, race, and study site

Definitions and abbreviations.

Not retained: Missed 1 scheduled HIV primary care appointment during the 12-month analytic period

OR: odds ratio

AOR: adjusted odds ratio

ADAP: AIDS Drug Assistance Program

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