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Problems paying medical bills among adults with diagnosed HIV in the United States

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Abstract

Problems paying medical bills may affect HIV outcomes among people with HIV (PWH), thus limiting progress towards achieving national HIV prevention goals. We analyzed nationally representative data from CDC's Medical Monitoring Project collected during 6/2018–5/2020. Among 8,108 PWH, we reported weighted percentages of characteristics and examined associations between problems paying medical bills and clinical outcomes using prevalence ratios with predicted marginal means, adjusting for potential confounding. Nineteen percent of PWH reported problems paying medical bills. Problems paying medical bills were more prevalent among persons who experienced homelessness (26.9% vs. 18.3%). People with problems paying medical bills were more likely to have adverse HIV outcomes and were more likely to have ≥1 emergency room visit (PR: 1.59; 95% CI: 1.51–1.68) or hospitalization (PR: 1.72; 95% CI: 1.55–1.91) in the past year. Identifying PWH experiencing financial barriers and expanding access to safety net programs could improve access to care and outcomes.

Keywords

HIV; Public Health Surveillance; Epidemiology; Social Determinants Of Health

Author Contributions

All authors on this paper meet the four criteria for authorship as identified by the International Committee of Medical Journal Editors (ICMJE); all authors have contributed to the conception and design of the study, drafted or have been involved in revising this manuscript, reviewed the final version of this manuscript before submission, and agree to be accountable for all aspects of the work. Specifically, using the CRediT taxonomy, the specific contributions of each author is as follows: Ruth E. Luna-Gierke: Conceptualization, methodology, formal analysis, and writing-original draft preparation, writing-review and editing. Yunfeng Tie: Validation, data curation, software, and writing-review and editing. Xin Yuan: Validation, writing-review and editing, software, data curation. Qingwei Luo: Software, writing-review and editing, and data curation. Linda Beer: Writing-review and editing, formal analysis, conceptualization, supervision, and methodology. Sharoda Dasgupta: Methodology, supervision, writing-review and editing, formal analysis, and conceptualization.

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Introduction

Over a quarter of people in the United States aged 18–64 years had difficulties paying their medical bills in the past 12 months (Liz Hamel, 2016). Of those, 31%- and 32% identified as Black and Hispanic, respectively. Twenty-four percent identified as White. However, race was not associated with difficulties paying medical bills when other factors were controlled for, indicating other issues, such as differences in earnings, are at play. (Liz Hamel, 2016). Problems paying medical bills are associated with socioeconomic status and access to healthcare insurance (Bennett, 2021; Liz Hamel, 2016). People with problems paying their medical bills are more likely to forego or delay necessary medical care or medications, which could exacerbate medical problems (Liz Hamel, 2016).

People with HIV (PWH) are more likely to experience socioeconomic challenges than the general population (Centers for Disease Control and Prevention, 2021; Semega, 2020). However, to our knowledge there are no studies assessing the prevalence of problems paying medical bills among PWH. Problems paying medical bills may differ among certain groups. If PWH have problems paying their medical bills, they may miss regular care visits and/or be less adherent to antiretroviral therapy (ART), which is essential for maintaining viral suppression and thus, reduces forward HIV transmission and improves health outcomes (Mugavero et al., 2013). Safety net programs, such as the Ryan White HIV/AIDS Program (RWHAP) and Medicaid, provide coverage for essential medical care services for PWH who are uninsured or underinsured. In addition, the program provides access to support services for PWH, including those for mental health, home health, and oral health.

The availability of care resources for PWH may depend on available funding, income requirements, and needs of the local population in individual jurisdictions. Estimates of problems paying medical bills among PWH could help align support programs to the needs of PWH. Financial issues related to paying medical bills could be a barrier to achieving national HIV prevention goals, and thus, ending the HIV epidemic in the United States (U.S. Department of Health and Human Services, 2021).

Using representative data from CDC's Medical Monitoring Project (MMP), we assessed differences in problems paying medical bills by selected sociodemographic characteristics and social determinants of health, as well as associations between problems paying medical bills and clinical outcomes, among adults with diagnosed HIV in the United States.

Methods

Data source

MMP is an annual, cross-sectional survey that is designed to produce nationally representative estimates of behavioral and clinical characteristics of adults with diagnosed HIV in the United States. MMP demographics for the data cycles used in this analysis have been described elsewhere (Centers for Disease Control and Prevention, 2021; Centers for Disease Control and Prevention, 2020). MMP data collection is a part of routine public health surveillance, and thus, determined to be non-research. Participating states or

territories obtained local institutional review board approval to collect data, when required. Informed consent was obtained from all participants.

Briefly, MMP uses a two-stage sampling method, in which during the first stage, 16 states and 1 territory were sampled from all U.S. states, the District of Columbia, and Puerto Rico. During the second stage, simple random samples of persons with diagnosed HIV aged 18 years and older were drawn for each participating jurisdiction from the National HIV Surveillance System (NHSS), a census of persons with diagnosed HIV in the United States. We included data from PWH that participated in the 2018–2019 MMP data collection cycles, and data were collected via phone or in-person interviews and medical record abstractions. Data used in our analysis were collected beginning in June 2018 through May 2020.

All sampled areas participated in MMP; the response rate among sampled persons for each cycle year was 45%. Data were weighted based on known probabilities of selection at state or territory and person levels. In addition, data were weighted to adjust for person nonresponse and post-stratified to known population totals by age, race/ethnicity, and sex at birth from the NHSS. More details on MMP methodology have been described elsewhere (Beer, Johnson, et al., 2019; Centers for Disease Control and Prevention, 2021).

All measures were based on the 12 months before interview, unless otherwise indicated. All respondents were asked “During the past 12 months, did you have problems paying or were you unable to pay any medical bills for your own care?” Of the 8,150 total respondents, 8,108 responded to the question. Household poverty was calculated using guidelines defined by the United States Department of Health and Human Services, and categorized as <100%, 100%–138%, 139%–399%, and ≥400% of the federal poverty limit (FPL) (U.S. Department of Health and Human Services, 2018). Homelessness was defined as living on the street, in a shelter, in a single-room occupancy hotel, or in a car. Incarceration was defined as being in jail or prison for more than 24 hours. Health care coverage type was categorized as: any private, public only (including Medicare, Medicaid, TRICARE/CHAMPUS, and VA coverage), and receipt of coverage only through the Ryan White HIV/AIDS Program (RWHAP). Uninsured persons were excluded from the health insurance analysis because of small sample size.

Retention in HIV care was defined as having ≥2 elements of outpatient HIV care ≥90 days apart in the 12 months prior to interview. These elements include a self-reported visit to an HIV provider or any of the following from the medical record abstraction: in-person visit with an HIV provider, CD4 or viral load test, or resistance test or tropism assay. Antiretroviral therapy (ART) adherence was defined as not missing any ART doses during the past 30 days. PWH not taking ART were classified as non-adherent. Sustained viral suppression was defined as having all viral load measurements in the past 12 months as undetectable or <200 viral RNA copies/mL. Missing or unknown values for viral load measurements were classified as not suppressed.

Analytic methods

First, differences in problems paying medical bills were assessed by selected demographic characteristics and social determinants of health. Next, we investigated associations between problems paying medical bills and clinical outcomes, including retention in HIV care, missed HIV care visits, ART adherence, sustained viral suppression, and report of emergency room visits and hospitalizations. Weighted percentages with 95% confidence intervals were reported for all characteristics. In addition, prevalence ratios with marginal means were calculated to quantify associations between problems paying medical bills and clinical outcomes. Associations were adjusted for age and race/ethnicity, which were a priori assumed to be potential confounders. All analyses were conducted using SAS v.9.4 (SAS Institute, Cary, NC), and SAS-callable SUDAAN, version 11.0.3 (RTI International, Research Triangle Park, NC).

Results

Nearly one in five adults with diagnosed HIV had problems paying their medical bills during the past 12 months. Problems paying medical bills varied by certain demographic characteristics and social determinants of health. Persons who lived in households <400% of the FPL were more likely to have problems paying their medical bills than those who lived in households ≥400% of the FPL (<100% FPL: 16.8%; 100%–138% FPL: 26.4%; 139%–399% FPL: 22.8%; ≥400% FPL: 8.1%; Table 1). The prevalence of problems paying medical bills were 1.47 times as high in persons that experienced homelessness as those that did not (95% CI: 1.24–1.75). Differences in problems paying medical bills were also seen by health care coverage. Compared with persons with any private health care coverage, those whose only source of coverage was Ryan White were more likely to have problems paying their medical bills (PR: 1.55; 95% CI: 1.35–1.78). However, persons that only had public insurance were less likely than those with private health care coverage to have problems paying their medical bills (PR: 0.78; 95% CI: 0.70–0.87). Problems paying medical bills were also associated with suboptimal clinical outcomes. After adjusting for age and race/ethnicity, persons who had problems paying their medical bills were less likely to be retained in HIV care (PR: 0.93; 95% CI: 0.90–0.97), be 100% ART dose adherent (PR: 0.82; 95% CI: 0.76–0.87) and have sustained viral suppression (PR: 0.88; PR: 0.83–0.93; Table 2). Persons who had problems paying their medical bills were also more likely to miss ≥1 HIV care appointment (PR: 1.35; 95% CI: 1.22–1.50), have ≥1 emergency room visit (PR:1.59; 95% CI: 1.51–1.68) or be hospitalized (PR: 1.72; 95% CI 1.55–1.91).

Discussion

Nearly one in five adults with diagnosed HIV report problems paying their medical bills during the previous 12 months. Persons with certain demographic characteristics and social determinants of health—including those who experienced homelessness, lived in households at <400% of the FPL, and relying solely on the RWAP for health coverage—were more likely to report having problems paying their medical bills. Our results are consistent with those of the total United States population, among which over a quarter of adults have problems paying their medical bills and those most affected were people with lower

household incomes (Liz Hamel, 2016). PWH who had problems paying their medical bills were more likely to have adverse clinical outcomes, including lower prevalence of sustained viral suppression, retention in care and 100% ART dose adherence.

Although the prevalence of problems paying medical bills were high across all health care coverage types, people who received coverage only through the RWHAP were more likely than those with any private insurance to report problems paying their medical bills, likely reflecting lower socio-economic status (SES) in this population. Persons with lower SES are more likely to make difficult decisions regarding their health and health care (e.g., medication rationing), which can be detrimental to a person's health (Beer, Tie, et al., 2019; Liz Hamel, 2016). This is consistent with our study's finding that PWH living in households at <100% of the FPL and those between 100%–399% of the FPL were more likely to have problems paying their medical bills than those living at ≥400% of the FPL. For context, a family of four living 100%–399% of the FPL might have an annual household income between $25,100–$100,399 (U.S. Department of Health and Human Services, 2018). Being unable to pay medical bills is not isolated to PWH living below the FPL. The wide range in household income indicates that many other PWH can experience financial barriers, even if they live above the FPL.

Compared with those with any private healthcare coverage, persons with public insurance were less likely to have problems paying their medical bills. This finding indicates that publicly funded programs, such as Medicaid and Medicare, for which many people qualify based on low income, robustly cover essential medical care services for PWH, and are essential for their health and well-being. However, eligibility criteria for these programs may preclude those who may not qualify for services but still need financial support, given their medical needs. For instance, PWH that live in states that did not expand Medicaid under the Affordable Care Act, generally qualify for Medicaid if their household income is <=138% of the FPL and they meet criteria for living with a disability. Although many PWH qualify for disability benefits, not all do. PWH that live in states that expanded Medicaid must meet the low-income requirement but are not required to meet the criteria for living with a disability. This results in increased access to benefits for PWH. Most states that did not expand Medicaid are in the Southern region of the United States (Kaiser Family Foundation, 2022). This region is also disproportionately affected by HIV (Centers for Disease Control and Prevention, 2022). It is important to also note that RWHAP will cover medical and support services for people with HIV, but it is a payer of last resort. However, expanding public programs like Medicaid, could help address some financial barriers experienced by PWH in the South.

These findings indicate that although people relying on publicly funded insurance may be less likely to experience financial obstacles in paying for medical bills, there may be other lower income PWH who do not qualify for these safety net programs that may be falling through the gaps. It is also important to note that not all health care plans are created equal. Persons with private health insurance qualify for health care services in different ways, with variable deductibles and coverage costs

People who have problems paying their medical bills might experience greater challenges in having their medical needs met, which for PWH, may lead to adverse HIV clinical outcomes (Dasgupta et al., 2021). Because problems paying medical bills is associated with adverse HIV outcomes, expansion of safety net programs could help PWH receive the care they need to live long, healthy lives, and achieve national HIV prevention and care goals. For instance, expansion of Medicaid could increase the number of PWH who qualify for Medicaid benefits, which could help address financial burdens related to paying medical bills and improve clinical outcomes among PWH (Dawson, 2020).

Our analysis is subject to limitations. Our data are self-reported and may result in misclassification (e.g., recall bias) of variables included in this study, including problems paying for medical bills. In addition, our response rates were 45%. However, results were adjusted for nonresponse and post-stratified to known population totals by age, race/ethnicity, and sex from NHSS using established, standard methodology. People with HIV may also have comorbidities that increase their need to seek medical care, and thus, increase their medical bills and lead to suboptimal outcomes. Our analysis does not describe specific mechanisms through which problems paying medical bills affects HIV outcomes. The purpose of analysis was to examine bivariate associations between problems paying medical bills and clinical outcomes. Lastly, we did not assess differences by jurisdiction, region or with respect to Medicaid expansion or differences in local public health care programs. Assessing these differences in the future might help direct efforts where PWH need the most support.

Conclusions

One in five PWH reported problems paying their medical bills, with a disproportionate impact among those with lower SES, including those living in households at <400% of the FPL and homeless persons. People who have problems paying their medical bills were more likely to have adverse HIV outcomes, which could deter progress in achieving national HIV prevention and care goals. State and local health departments may engage with stakeholders to identify and provide additional assistance to PWH experiencing financial burden. In addition, increasing access to safety net programs, including through Medicaid expansion, would help a larger percentage of PWH and allow them to receive the care they need to achieve viral suppression, live a healthy life, and allow the nation to reach its HIV prevention goals.

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Key Considerations

- Nearly one in five people with HIV (PWH) reported problems paying their medical bills.
- Social determinants of health, such as experiences with homelessness and having a household income <400% of the federal poverty level, are associated with PWH having problems paying their medical bills.
- PWH with problems playing medical bills were more likely to have adverse HIV outcomes as well as ≥1 hospitalization or emergency room visit.
- Increasing access to safety net programs, including Medicaid expansion, could help increase access to services among PWH, thus improving their outcomes.

Table 1.

Problems paying medical bills during the past 12 months among adults with diagnosed HIV, by selected characteristics—United States, 2018–2019

	Problems paying medical bills					
	Yes		No			
	n[a]	Row% (95% CI)[b, c]	n[a]	Row% (95% CI)[b, c]	PR (95% CI)	p value
Total	1,495	19.1 (17.2–21.0)	6,613	80.9 (79.0–82.8)		
Age at time of interview (years)						**<0.001**
18–29	154	23.2 (19.3–27.2)	525	76.8 (72.8–80.7)	1.48 (1.28–1.70)	<0.001
30–39	306	26.3 (23.5–29.1)	940	73.7 (70.9–76.5)	1.67 (1.47–1.90)	<0.001
40–49	308	19.8 (16.7–23.0)	1,369	80.2 (77.0–83.3)	1.26 (1.10–1.45)	0.001
>=50	727	15.7 (13.9–17.6)	3,779	84.3 (82.4–86.1)	Reference	
Gender [d]						**0.841**
Male	1,063	18.8 (17.0–20.6)	4,795	81.2 (79.4–83.0)	Reference	
Female	386	19.0 (16.2–21.9)	1,692	81.0 (78.1–83.8)	1.01 (0.89–1.15)	0.841
Race/Ethnicity						**0.020**
Non-Hispanic White	404	18.2 (15.8–20.7)	1,907	81.8 (79.3–84.2)	Reference	
Non-Hispanic Black/African American	697	20.6 (18.5–22.7)	2,746	79.4 (77.3–81.5)	1.13 (0.97–1.31)	0.117
Hispanic/Latino[e]	276	16.2 (12.8–19.7)	1,526	83.8 (80.3–87.2)	0.89 (0.71–1.11)	0.300
Other[f]	118	22.7 (16.8–28.5)	434	77.3 (71.5–83.2)	1.24 (0.96–1.61)	0.109
Educational attainment						**0.046**
<High School	212	16.1 (13.2–19.0)	1,185	83.9 (81.0–86.8)	0.80 (0.67–0.96)	0.013
High School diploma or equivalent	400	18.6 (15.6–21.6)	1,783	81.4 (78.4–84.4)	0.92 (0.79–1.07)	0.280
>High School	883	20.2 (18.1–22.2)	3,641	79.8 (77.8–81.9)	Reference	
Employment Status [g]						**0.003**
Employed	728	19.7 (17.2–22.1)	3,107	80.3 (77.9–82.8)	Reference	
Unemployed	642	19.8 (18.0–21.7)	2,754	80.2 (78.3–82.0)	1.01 (0.90–1.13)	0.877
Student	18	16.0 (8.5–23.4)	88	84.0 (76.6–91.5)	0.81 (0.52–1.27)	0.350
Retired	106	13.3 (10.0–16.6)	651	86.7 (83.4–90.0)	0.68 (0.54–0.85)	0.001
Household poverty level [h]						**<0.001**
<100% FPL	519	16.8 (14.3–19.2)	2,718	83.2 (80.8–85.7)	2.06 (1.52 – 2.77)	<0.001
>=100% - <139% FPL	219	26.4 (22.5–30.3)	657	73.6 (69.7–77.5)	3.24 (2.35 – 4.47)	<0.001
>=139% - <400% FPL	556	22.8 (20.1–25.5)	1,864	77.2 (74.5–79.9)	2.80 (2.10 – 3.73)	<0.001
>=400% FPL	72	8.1 (6.0–10.3)	830	91.9 (89.7–94.0)	Reference	
Experienced homelessness [i]						**<0.001**
Yes	192	26.9 (23.4–30.4)	573	73.1 (69.6–76.6)	1.47 (1.24–1.75)	<0.001
No	1,303	18.3 (16.2–20.3)	6,040	81.7 (79.7–83.8)	Reference	
Incarcerated >24 hours						**0.016**

	Problems paying medical bills					
	Yes		No			
	n[a]	Row% (95% CI)[b, c]	n[a]	Row% (95% CI)[b, c]	PR (95% CI)	p value
Yes	80	25.1 (19.4–30.8)	247	74.9 (69.2–80.6)	1.34 (1.06–1.68)	0.016
No	1,413	18.8 (16.9–20.7)	6,360	81.2 (79.3–83.1)	Reference	
Healthcare coverage type						**<0.001**
Any private	535	20.1 (17.6–22.7)	2,231	79.9 (77.3–82.4)	Reference	
Public only	702	15.8 (14.1–17.5)	3,800	84.2 (82.5–85.9)	0.78 (0.70–0.87)	<0.001
RWHAP only	238	31.2 (27.6–34.8)	528	68.8 (65.2–72.4)	1.55 (1.35–1.78)	<0.001

Note: All measures are reported based on the past 12 months. Overall p values are based on Wald F tests. Numbers may not add to total due to missing data.

[a] Numbers are unweighted.

[b] Percentages are weighted percentages.

[c] CIs incorporate weighted percentages.

[d] Transgender persons were excluded because of small sample size

[e] Hispanics or Latinos can be of any race. Persons are classified in only 1 race/ethnicity category.

[f] Other race defined as persons who were American Indian/Alaska Native, Asian, Native Hawaiian/Other Pacific Islander, or multiracial

[g] Employed includes employed for wages, self-employed, or homemaker.

[h] Poverty guidelines as defined by HHS; poverty was assessed based on the person's reported household income for the calendar year prior to the year they were interviewed (i.e., 2016 guidelines were used for persons interviewed in 2017). More information regarding HHS poverty guidelines can be found at https://aspe.hhs.gov/frequently-asked-questionsrelated-poverty-guidelines-and-poverty

[i] Living on the street, in a shelter, in a single-room-occupancy hotel, or in a car.

Table 2.

Problems paying medical bills during the past 12 months among adults with diagnosed HIV, by HIV clinical outcomes, hospitalizations, and emergency room visits—United States, 2018–2019

	Problems paying medical bills					
	Yes		No			
Characteristics	n[a]	Col % (95% CI)[b, c]	n[a]	Col % (95% CI)[b, c]	aPR (95% CI)[d,e]	p value
Total	**1,495**	**19.1 (17.2–21.0)**	**6,613**	**80.9 (79.0–82.8)**		
Retention in care, past 12 months						
Yes	1,124	73.1 (70.3–75.8)	5,330	80.1 (78.3–82.0)	0.93 (0.90–0.97)	<0.001
No	298	26.9 (24.2–29.7)	897	19.9 (18.0–21.7)	--	
Missed ≥1 HIV care appointment, past 12 months						
Yes	483	31.9 (29.2–34.7)	1,437	22.4 (21.2–23.6)	1.35 (1.22–1.50)	<0.001
No	1,000	68.1 (65.3–70.8)	5,111	77.6 (76.4–78.8)	--	
100% dose adherence, past 30 days [f]						
Yes	713	46.1 (42.9–49.3)	3,943	58.9 (57.1–60.6)	0.82 (0.76–0.87)	<0.001
No	773	53.9 (50.7–57.1)	2,618	41.1 (39.4–42.9)	--	
Sustained viral suppression,past 12 months [g]						
Yes	897	54.1 (49.8–58.4)	4,486	63.3 (60.9–65.8)	0.88 (0.83–0.93)	<0.001
No	598	45.9 (41.6–50.2)	2,127	36.7 (34.2–39.1)	--	
≥1 emergency room visit, past 12 months						
Yes	889	60.4 (57.5–63.2)	2,539	37.4 (35.7–39.0)	1.59 (1.51–1.68)	<0.001
No	603	39.6 (36.8–42.5)	4,064	62.6 (61.0–64.3)	--	
≥1 hospitalization, past 12 months						
Yes	445	28.7 (26.6–30.8)	1,179	17.0 (15.8–18.3)	1.72 (1.55–1.91)	<0.001
No	1,044	71.3 (69.2–73.4)	5,423	83.0 (81.7–84.2)	--	

Note: Numbers may not add to total due to missing data.

[a] Numbers are unweighted.

[b] Percentages are weighted percentages.

[c] CIs incorporate weighted percentages.

[d] Adjusted Prevalence Ratio.

[e] Adjusted for age and race/ethnicity

[f] Persons not taking ART were classified as non-adherent

[g] Missing or unknown values for viral load were classified as not virally suppressed