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Economic Burden Among Gay, Bisexual, and Other Men Who Have Sex With Men Living With HIV or Living Without HIV in the Multicenter AIDS Cohort Study

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Background: With HIV now considered a chronic disease, economic burden for people living with HIV (LWH) may threaten long-term disease outcomes. We studied associations between economic burden (employment, income, insurance, and financial difficulty) and HIV status for gay, bisexual, and other men who have sex with men (GBMSM) and how economic burden relates to disease progression.

Setting: We analyzed data collected every 6 months through 2015 from GBMSM LWH and GBMSM living without HIV from 2 waves (2001–2003 cohort and 2010+ new recruit cohort) of the Multicenter AIDS Cohort Study.

Methods: Using generalized estimating equations, we first assessed the association between HIV status (exposure) and economic burden indicators since the last study visit (outcomes) of employment (working/student/retired versus not currently working), personal annual income of ≥$10,000, insurance (public/private versus none), and financial difficulty meeting basic expenses. Then among people LWH, we assessed the relationships between economic burden indicators (exposures), risk of progressive immune suppression (CD4 ≤500 cells/uL), and progression to AIDS (CD4 ≤200; outcomes).

Results: Of 1721 participants, 59.5% were LWH (n = 1024). GBMSM LWH were 12% less likely to be employed, 16% more likely to have health insurance, and 9% more likely to experience financial difficulty than GBMSM living without HIV. Among GBMSM LWH, employment was associated with a 6% and 32% lower likelihood of immune suppression or progression to AIDS, respectively, and the income was associated with a 15% lower likelihood of progression to AIDS.

Conclusions: Interventions that stabilize employment, income, and offer insurance support may enrich GBMSM LWH's ability to prevent disease progression.

Key Words: HIV, employment, income, insurance, economic burden, United States

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INTRODUCTION

Progress in HIV treatment has resulted in more people living with HIV (PLWH) living longer.[1] Although such positive progress has been made, the increase in survival may potentially amplify economic burden among PLWH. PLWH in the United States face an estimated $20,000 in excess health expenditures each year,[2] and continued management of CD4 count and HIV viral loads among PLWH incurs ongoing costs.[3] Gay, bisexual, and other men who have sex with men (GBMSM) are the population most affected by HIV in the United States and thus may be at high risk to experience HIV-related economic burden.[4]

Economic burden may be referred to by many terms (financial hardship, financial toxicity, and financial distress)—

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the most important distinction being that it reflects financial challenges or consequences of managing care for a disease.[5] Economic burden after HIV diagnosis—frequently expressed through employment changes that influence income, health insurance, and experiences of financial difficulty—lowers quality of life[6] and may lead to differential medication access, lower adherence to care, and disparities in mortality among PLWH.[7] Although many of these indicators also serve as traditional measures of the socioeconomic position, changes in these measures can also reflect the financial challenges or consequences of managing care for a disease, thus are also measures of economic burden. In addition, those who are economically challenged by poverty[8] or who are unemployed[9,10] incur the highest HIV prevalence rates, whereas those with the fewest financial assets have greatest mortality risk.[11] These trends have persisted despite assistance programs for those with low income and who are uninsured or underinsured.

Yet, the relationship between economic burden and virologic (HIV viral load) or immunologic treatment (CD4 count) endpoints during chronic HIV/AIDS care has received little attention in the published literature, especially in the United States.[12] One study in the earliest cohorts of the Multicenter AIDS Cohort Study (MACS) estimated that GBMSM LWH were 2.7 times more likely to lose their job than GBMSM living without HIV (LWOH), which led to loss of insurance and income[13]; however, that study did not provide estimates of the impact on HIV immunologic or virologic outcomes. That study also reported few changes in employment and income after HIV diagnosis, although changes could have occurred before enrollment in MACS.[13] Another study showed that lower labor force participation among GBMSM LWH was associated with lower quality of life[6] but did not link employment to immunologic outcomes or include PLWOH participants as a comparator. Previous studies included data collected before both the Affordable Care Act and a recent economic downturn, leaving a knowledge gap in how PLWH navigate the current economic landscape.

To fill gaps left by previous studies, we explored the relationship between the economic burden of HIV among GBMSM—as defined by employment, income, insurance, and subjective financial difficulty after diagnosis—on resultant immunologic HIV treatment outcomes (CD4 count). We examined these economic burden indicators among enrollees in the 2001–2003 and 2010+ new recruit MACS conducted by sites in Baltimore, Los Angeles, Chicago, and Pittsburgh. The MACS is an ongoing longitudinal study that tracks the natural history of HIV among GBMSM LWH and GBMSM LWOH. Although previous MACS analyses focused on change in economic burden indicators,[13] our goal was to investigate the overall relationship between economic burden indicators across a population of GBMSM and to see how economic burden indicators were associated with disease progression after an HIV diagnosis.

METHODS

Participants

We analyzed public-use data from 1721 GBMSM LWH and GBMSM LWOH in the third (2001–2003) and fourth (2010) enrollment cohorts of the MACS. The MACS is a 30-year longitudinal cohort study of HIV-1 infection in GBMSM. It is an ongoing longitudinal study that tracks the natural history of HIV infection among GBMSM LWH and GBMSM LWOH at 4 sites in the United States: Baltimore, MD/Washington, DC; Chicago, IL; Los Angeles, CA; and Pittsburgh, PA. MACS participants have study visits every 6 months, which include self-administered questionnaires (computer-assisted, scannable forms, and hard copy), an interview on demographics, employment, medical history, insurance type, and quality of life, as well as blood sampling for HIV antibody tests. Research ethics approvals were completed at each site's respective institutional review board.

Details on the study cohorts[14,15] and recruitment[16] have been previously published. Participants in the 2001–3 cohort were enrolled between October 2001 and August 2003. The 2001–2003 cohort aimed to assess effects of race/ethnicity, long-term ART effects, and aging. Participants in the 2010 cohort opened for enrollment in May 2010 and are in ongoing recruitment. The 2010 cohort focused on those with no HIV treatment before 2011 and high-risk populations that might yield seroconverters; however, fewer than 5% of MACS participants are seroconverters. Follow-up data were available through 2015, with the 2001–2003 cohort contributing data for up to 26 study visits (13 years) and the 2010 cohort contributing up to 13 study visits (6.5 years). Retention rates observed in pre-2001 cohorts is high at 9.5 years (88.5%), and the same retention strategies (ie, previsit reminders, portable blood test kits for those who move away, quarterly phone contact, and extended searches using social security and license numbers)[15] were used in subsequent cohorts. Participants missing data on HIV serostatus or who seroconverted (<5% of all MACS participants) were excluded from the analysis. Research ethics approvals were completed by each site's respective institutional review board, in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 2000.

Economic Burden Indicators

Objective economic burden measures of including employment, income, insurance status, and a subjective economic burden measure of financial difficulty since the last study visit (reflective of the past 6 months or more) were assessed by self-report. Participants were classified as employed if they self-reported employed, student or retired status (assuming that a student or retiree would have some form of sustainable income, even if based on loans or retirement benefits), and unemployed if they self-reported a disability or not currently working, regardless of whether they were seeking employment at the time of assessment. Participants were classified as having extremely low income if they reported personal annual income of <$10,000, as performed in previous MACS studies.[13,17] Participants were classified as insured if they reported having any form of public, private, or other form of insurance, including use of prescription assistance payment programs (eg, AIDS Drug Assistance Program) and uninsured otherwise. Financial difficulty was

based on participants' response (yes or no) to the question: are you experiencing financial difficulty meeting your basic expenses?

HIV/AIDS Treatment Factors (for the GBMSM LWH Sample Only)

HIV Status

At study baseline, the self-reported HIV status was confirmed by medical records and HIV testing.

HIV Viral Load Suppression

The plasma HIV RNA viral load count was collected by blood draws at baseline. DHHS guidelines classify >200 copies/ML as virologic failure.[18] The baseline viral load was modeled as an indicator variable with cut points at <50, 51–200, 201–500, and >500 copies/mL.

Risk of Disease Progression

The CD4 T lymphocyte cell count was collected at blood draws at study visits every 6 months. Economic burden data were collected at the same study visit, with questions about economic burden capturing the 6 months or more before disease progression. In accordance with DHHS guidelines, participants with CD4 counts ≤500 cells/uL were considered being at risk for progressive immune suppression, and participants with CD4 counts ≤200 cells/uL were considered at risk for progression to AIDS.[18] Most MACS participants were on treatment and would be expected to maintain a higher CD4 count than if they were not on treatment.

Timing of ART initiation was not collected for these 2 MACS cohorts.

Statistical Analysis

We estimated and compared demographic and clinical characteristics of participants by the HIV status. We performed nonparametric trend tests to compare trends over time for each economic burden indicator, by the HIV status and cohort. Our primary analysis was in 2 parts (analysis 1 and analysis 2). For both analyses, we used Poisson-generalized estimating equations (GEEs) with a log link to estimate population-averaged relative risks of each outcome at each 6-month timepoint, adjusting for fixed baseline covariates (race, age, education, and study site) and visit number. This was chosen over the logistic regression approach because the latter often overestimates the effect sizes for outcomes with prevalence >10%. GEE was chosen because we desired to make inferences about populations of PLWH and population-level solutions rather than focus on individual trajectories for patients or to make inferences about how changes in economic burden impacted individual patients differently.[19] Previous research on MACS cohorts found little individual-level variation in economic indicators over time,[13] further reinforcing a population-based approach. Participants' missed attendance and number of visits was not related to the variables of interest and thus the MCAR assumption was reasonable. Under this assumption, GEE models offer valid inference.[20] The models accounted for within-individual correlation, assuming an exchangeable correlation between time points. We did not pursue site-specific analyses because of the small numbers within sites for some cohorts. All statistical analyses were conducted using Stata 15.1.

Analysis 1

For analysis 1, we compared the risk of each economic burden indicator—employment, financial difficulty, insurance, and income (outcomes)—by HIV status (exposure). The income model was additionally adjusted for employment. Sensitivity analysis for observations beyond respondent age 65 was attempted, in part to account for retirement; however, the respondent sample above age 65 was too small (<2% of all observations) to compare across the HIV status.

Analysis 2

In analysis 2, we compared the risk of disease progression (as outcomes) among PLWH only, by economic burden indicator (as exposures), adjusting for baseline viral load and respondent demographics. We chose the CD4 count as the measure of risk of disease progression instead of the viral load because the viral load may reflect medication management, and we lacked baseline data about medication or time on HIV treatment. To explore how disease progression would occur in the absence of AIDS-specific insurance assistance, we included models of insurance and disease progression among GBMSM LHIV not receiving assistance for AIDS-specific drugs. As performed in previous analysis,[6] no lag terms were included because the study design incorporated a lag; although CD4 count and economic burden were measured concurrently, economic burden questions asked about a period in time 6 months or more before collection of the CD4 count.

RESULTS

A total of 1721 GBMSM from the MACS 2001–3 and 2010 cohorts were included in the analytic sample, of which 40.5% (n = 697) were LWOH and 59.5% (n = 1024) were LWH. Demographic characteristics are detailed in Table 1. Nearly 60% were employed (n = 1107; 59.1%) at baseline, and 42.3% (n = 723) had an annual income of <$10,000. Most participants (n = 1273; 80.7%) had insurance; just under half (n = 818; 47.5%) were experiencing financial difficulty at baseline. Correlations between baseline economic burden indicator measures ranged from −0.30 to 0.58. GBMSM LWH were more likely than GBMSM LWOH to be unemployed at baseline but were also more likely to have health insurance. At baseline, 47.5% GBMSM LWH had viral loads indicating virologic failure (>200 copies/mL), 40.7% (n = 474) had a CD4 count indicating a high risk of progressive immune suppression at ≤500 cells/uL, and 9.4% (n = 95) had a CD4 count indicating high risk of disease progression to AIDS at ≤200 cells/uL.

Figure 1 displays the prevalence over time of each economic indicator by the HIV status and cohort. The mean duration of follow-up across the pooled cohorts was 7 years (SD = 5.1). GBMSM LWH enrolled in both waves of

TABLE 1. Baseline Characteristics of Participants in the 2001–2003 and 2010 MACS Cohorts

	All, N = 1721 (%/SD)	GBMSM LWOH, n = 697 (40.5)	GBMSM LWH, n = 1024 (59.5)
Demographics			
Age (yrs)	38 (10)	36 (10)	38 (9)
Age category			
<30	390 (22.7)	212 (30.4)	178 (17.4)
30–<40	616 (35.8)	214 (30.7)	402 (39.3)
40–<50	522 (30.3)	206 (29.6)	316 (30.9)
≥50	186 (10.8)	64 (9.2)	122 (11.9)
Missing	7 (0.4)	1 (0.1)	6 (0.6)
Race			
Non-Hispanic Black	803 (46.7)	348 (49.9)	455 (44.4)
Non-Hispanic White	521 (30.3)	215 (30.9)	306 (29.9)
Hispanic/Latino	343 (19.9)	115 (16.5)	228 (22.3)
Multiracial/Others	47 (2.8)	18 (2.6)	29 (2.8)
Missing	7 (0.4)	1 (0.1)	6 (0.6)
Education			
≤12	657 (38.2)	253 (36.3)	404 (39.5)
≥1 yr of college	493 (28.7)	195 (28.0)	298 (29.1)
≥College graduate	545 (31.7)	247 (35.4)	298 (29.1)
Missing	26 (1.5)	2 (0.29)	24 (2.3)
Economic and insurance factors			
Employment status*			
Unemployed	697 (40.5)	262 (37.6)	435 (42.5)
Employed	1017 (59.1)	434 (62.3)	583 (56.9)
Missing	7 (0.4)	1 (0.1)	6 (0.6)
Annual income			
< $10,000	723 (42.3)	283 (40.7)	440 (43)
≥ $10,000	985 (57.2)	412 (59.1)	573 (56)
Missing	13 (0.76)	2 (0.29)	2 (1)
Insurance status			
Uninsured	435 (25.3)	246 (35.3)	189 (18.5)
Insured	1273 (80.7)	447 (64.1)	826 (80.7)
Missing	13 (0.8)	4 (0.6)	9 (0.9)
Financial difficulty	818 (47.5)	321 (46.1)	497 (48.5)
Missing	42 (2.4)	12 (1.7)	30 (2.9)
HIV RNA viral load† (copies/mL)			36,213 (163,189)
<50	—	—	415 (40.5)
51–200	—	—	73 (7.1)
201–500	—	—	42 (4.1)
≥501	—	—	475 (46.4)
Missing	—	—	19 (1.9)
CD4 count (cells/uL)			555 (296)
Risk of immune suppression†			
CD4 count ≤500	—	—	474 (46.3)
CD4 count >500	—	—	518 (50.6)
Missing	—	—	32 (3.1)
Risk of progression to AIDS†			
CD4 count ≤200	—	—	95 (9.4)
CD4 count >200	—	—	897 (87.6)
Missing	—	—	32 (3.1)

*Employed includes those currently employed, students, or those who receive retirement income. Unemployed are those who are not working, who may or may not be seeking employment, or who are disabled.

†Cutoffs recommended by the US Department of Health and Human Services.

recruitment were less likely to be employed over the same time period and more likely to be insured over time than GBMSM LWOH. GBMSM LWH were also more likely to have very low income in the early cohort. In the later cohort, however, GBMSM LWH were less likely to be low income at the start but over time moved toward similar rates of low income as LWOH participants. Trend tests suggested significantly positive trends for income and insurance for PLWH for both cohorts, and positive trends for all PLWOH driven by upward trends in the early cohort. Financial difficulty was the same at enrollment into the initial cohort for both GBMSM LWH and GBMSM LWOH; but GBMSM LWH were more likely to report financial difficulty over time. Trends for self-reported financial difficulty within PLWH and PLWOH groups were negative overall and for the early cohort and significantly positive over time for the later cohort alone.

Analysis 1 Results

Figure 2 displays the relative risks of each economic burden indicator for GBMSM LWOH and LWH. GBMSM LWH were significantly less likely to be employed [relative risk (RR) = 0.88, 95% confidence interval (CI): 0.82 to 0.94], more likely to have income >$10,000 (RR = 1.06, 95% CI: 1.00 to 1.12), more likely to have health insurance (RR = 1.16, 95% CI: 1.11 to 1.22), and more likely to experience financial difficulty (RR = 1.09, 95% CI: 1.00 to 1.18).

Analysis 2 Results

Figure 3 displays the relative risks of progressive immune suppression (CD4 ≤500) and progression to AIDS (CD4 ≤200) for the 1024 GBMSM LWH, by categories of the economic burden indicators. Being employed was associated with a lower likelihood of progressive immune suppression (RR = 0.94, 95% CI: 0.87 to 1) and risk of progression to AIDS (RR = 0.68, 95% CI: 0.58 to 0.81). The income was associated with a lower likelihood of progression to AIDS (RR = 0.86, 95% CI: 0.74 to 1). Insurance and financial difficulty were not associated with disease progression.

DISCUSSION

Our analyses expand past research on economic burden and HIV by (1) including both subjective (ie, reports of financial difficulty) and objective (ie, income, employment, and insurance statuses) measures of economic burden and (2) providing estimates using recent data of how economic burden is linked to subsequent HIV disease progression in a long-term cohort across 4 sites. Our results suggest that economic burden forms a context for disease progression among GBMSM LWH. After adjustment for demographic covariates, GBMSM LWH were 12% less likely to be employed, 6% more likely to have higher income, 16% more likely to have health insurance, and 9% more likely to have financial difficulty than GBMSM LWOH. Among PLWH, being employed was associated

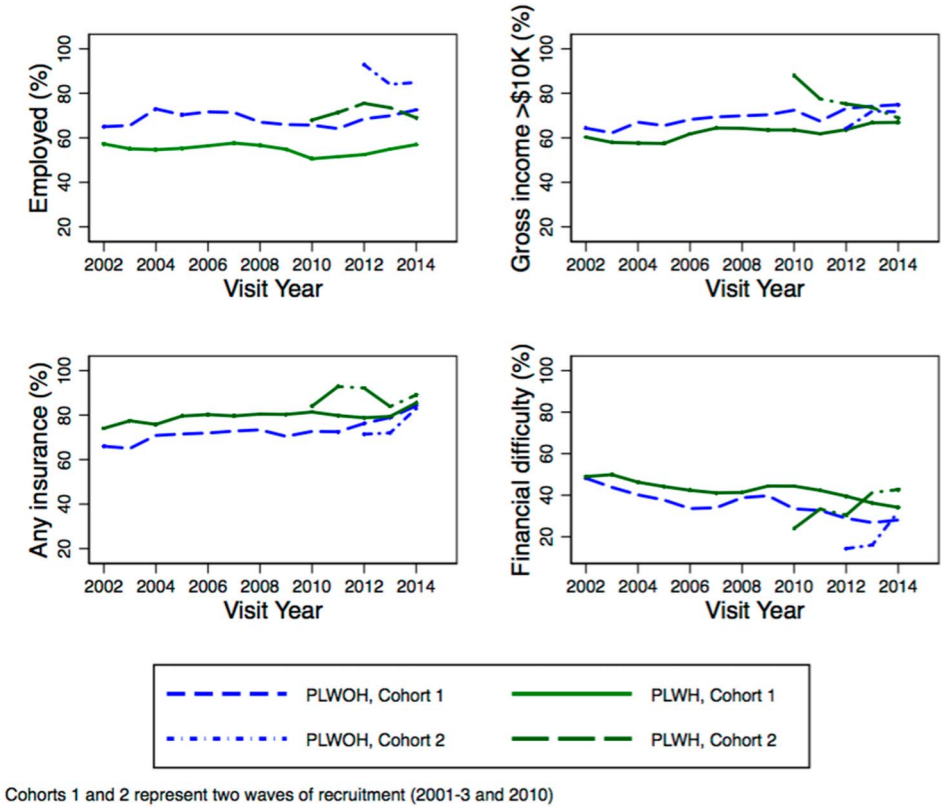

FIGURE 1. Prevalence of economic burden indicators for 2001–2015 for MACS participants by HIV status.

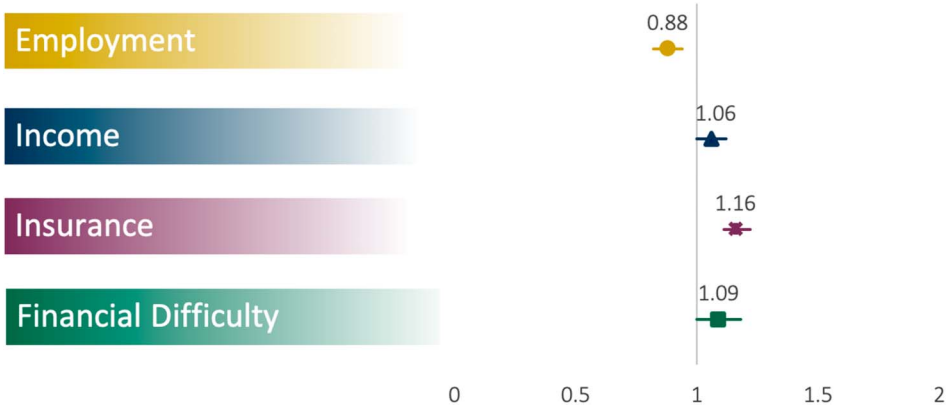

FIGURE 2. Relative risk of economic burden among GBMSM LWH and GBMSM LWOH in the MACS (N = 1721). *Reference for relative risk is GBMSM LWOH Results adjusted for study site, study visit, cohort, race, age, year, and education; income model additionally adjusted for employment Income assessed as annual income of <$10,000 versus ≥$10,000. Insurance classified as yes/no to currently having any form of insurance.

with a 6% reduced likelihood of progressive immune suppression and a 32% reduced likelihood of progression to AIDS. Higher income was not related to progressive immune suppression but was associated with a 15% lower likelihood of progression to AIDS. Documenting these economic challenges is the first step toward addressing economic barriers that arise during long-term HIV/AIDS management.

In the United States, unemployment has been associated with less improvement in the CD4 count within the first year of treatment[21] and poorer viral load outcomes.[12,17,22] Our study's results extend those findings to suggest that the relationship between employment and lower likelihood of being at risk for disease progression persists over time. Given that those who are least healthy are at greatest risk of losing or leaving employment after an HIV diagnosis,[6] policies that help stabilize employment

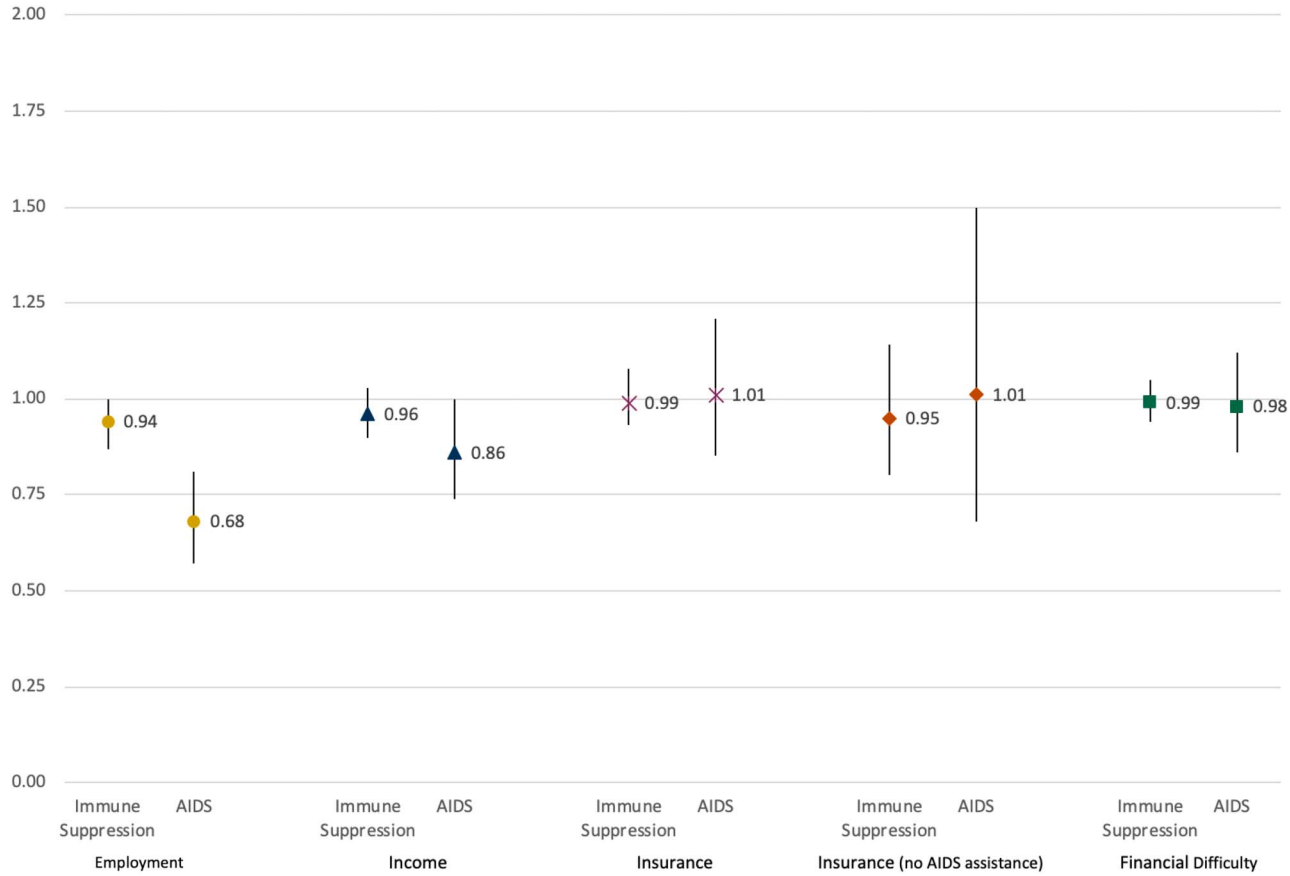

FIGURE 3. Relative risk for progressive immune suppression (CD4 ≤500 cells/uL) or progression to AIDS (CD4 ≤200 cells/uL) outcomes by economic burden indicator among GBMSM LWH in MACS (n = 1024). *Results adjusted for study site, study visit, cohort, race, age, education, and viral load; income model additionally adjusted for employment. Income assessed as annual income of <$10,000 versus ≥$10,000. Insurance classified as yes/no to currently having any form of insurance.

after HIV may improve both the health and quality of life of PLWH.[6] Although a policy intervention to stabilize employment after chronic disease is sensible for humanitarian reasons, and may have been evident even before this analysis, our analysis is valuable in showing that employment has even greater implications for PLWH who are at risk of progression to AIDS.

Unemployment and losses or changes in health insurance may also be associated with lower quality of life,[23] which have been independently associated with greater treatment nonadherence.[24,25] Assistance programs may be important safety nets that may buffer the impact of a loss of health insurance, and explain our study results of higher insurance rates for GBMSM LWH than for GBMSM LWOH. All groups saw an uptick in insurance between 2013 and 2014, which did not follow employment trends, suggesting an effect from the Affordable Care Act's Medicaid expansion. Although health insurance was not significantly associated with disease progression risk in the primary analysis, we expected that the subanalysis excluding patients with insurance assistance would show greater risk of disease progression when insurance supports were removed. Regression results did not support that hypothesis, but the large width of the CIs in the sensitivity analysis of insurance without assistance programs suggests that this analysis may have been underpowered; the majority (91%) of those who were at risk for AIDS were insured through an AIDS-related insurance assistance program, and only 32 respondents at risk of progression to AIDS had no form of insurance. This may affirm that insurance supports for those at risk for HIV or AIDS is critical and may be helping to prevent disease progression.

Despite lower employment rates, GBMSM LHW were more likely than GBMSM LWOH to have income ≥$10,000 in adjusted analysis. It is possible that GBMSM LHW who are employed have higher-paying jobs than employed GBMSM LWOH, and even at a higher income, GBMSM LWH were more likely to report subjective financial difficulty than GBMSM LWOH. Among GBMSM LHW, previous associations between income and HIV outcomes in the United States have had mixed results, with most showing null results.[12,17,21,26] The 1 study suggesting a positive relationship was among women alone[26] and may not be relevant to this study's population of GBMSM. Our results showed that higher income was not associated with progression to HIV but was associated with lower risk of progression to AIDS. This may represent that having low-income compounds or exacerbates challenges with maintaining health after one has been diagnosed with HIV.

Experiencing financial difficulty may pose a challenge in maintaining treatment regimens, and those experiencing financial difficulty are less likely to seek necessary medical care for HIV because of financial challenges.[13] Yet, most studies of economic burden and HIV have not included a subjective measure of financial difficulty. This study results suggest that GBMSM LWH experience 9% greater financial difficulty than GBMSM LWOH. Although we expected that financial difficulty would be further exacerbated for those at risk for disease progression, it was not. This may be because insurance assistance for PLWH or other available charitable supports may help buffer against financial difficulty. It could also be that patients avoid financial difficulty by avoiding care that is unaffordable. It could also be that the severity of disease after an initial diagnosis of HIV has no additional bearing on financial difficulty. Regardless of which reason may apply, all of these explanations point to a need to alleviate financial difficulty among PLWH, and that insurance, income, and employment supports could optimize GBMSM LWH's ability to engage in HIV or AIDS care.

Limitations

Although the focus on GBMSM is warranted given that GBMSM are at highest risk for HIV, the results of this study may not be generalizable to women. Nearly half the sample had an annual income of $10,000, with relatively few respondents in each income category above $10,000; however, HIV prevalence is higher among those with low income,[27] so having a large sample of those with very low income may well match the target population of inference.

The CD4 count as an outcome may be influenced by the length of time since HIV diagnosis, but the time since HIV diagnosis was not available for respondents in these 2 MACS cohorts. We did not directly assess treatment nonadherence as a mediator because the study goal was to associate the overall effect of LWH on economic burden; however, inclusion of the viral load at baseline was intended to account for the fact that patients entering the cohort may have entered at different points in treatment or at different levels of treatment adherence. PLWH participating in the cohort study may have been more likely to have well-controlled HIV because those contributing the most to the cohort data would be coming in regularly for study visits and were likely to be well connected to care. Thus, our results may understate the role of economic burden for those outside of a cohort study population who may not be in consistent care; in that sense, our results represent minimum estimates for economic challenges that PLWH may experience. Respondents who developed HIV while in MACS would have been an ideal group to explore changes in economic burden; however, fewer than 5% of MACS participants were seroconverters. MACS samples also have few cases of major shifts in employment and income categories.[13] Thus, despite the longitudinal nature of this analysis, the results cannot distinguish whether or not economic shifts occurred due to HIV or before HIV, and our results may underestimate the actual economic burden among PLWH.

CONCLUSIONS

This analysis expounds previous work on the economic burden experience of PLWH and suggests that certain economic indicators may be associated with risk of disease progression. Our results reaffirm that economic burden persists to be higher among GBMSM. Higher insurance rates among GBMSM LWH support that insurance assistance has helped to close insurance gaps and may suggest that parallel programs to eliminate gaps in employment, income, and financial difficulty could be worthwhile to pursue. Further analysis should explore differences in these gaps by age, race, and education. Our results highlight the need to reduce adverse economic burden as a context for poor HIV outcomes

for PLWH. Interventions and policies that stabilize employment, income, and offer health insurance support may enrich the ability of PLWH to prevent disease progression.

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