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A novel method for assessing poor quality of life among people with HIV

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Abstract

Background: The U.S.'s National HIV/AIDS Strategy (NHAS) prioritizes improving QoL among people with HIV (PWH) but co-occurrence of different aspects of QoL is not well described. We developed and applied a novel, multi-item assessment of poor quality of life (QoL) among PWH, and examined associations with selected outcomes.

Setting: 2018–2021 CDC Medical Monitoring Project data on 15,855 U.S. PWH.

Methods: The poor QoL index, measured by the number of indicators of poor QoL experienced included: poor/fair self-rated health, unmet needs for mental health services, and subsistence needs (hunger/food insecurity, unstable housing/homelessness, unemployment). Score distributions were analyzed alongside data on individual QoL indicators. Associations with selected adverse outcomes were assessed, including not being retained in care, missing ≥ 1 HIV medical appointments, missing ≥ 1 ART dose, not having sustained viral suppression, and having ≥ 1 emergency room visit or ≥ 1 hospitalization.

Results: Overall, 55.1% of PWH had ≥ 1 indicator of poor QoL; 8.4% had ≥ 3 indicators. Over a quarter (26.5%) of people who inject drugs experienced ≥ 3 indicators of poor QoL. A large percentage of people aged 18–24 years had subsistence needs; 36.4% of Black women had poor/fair self-rated health. After adjusting for age, race/ethnicity, and sex, higher poor QoL index scores—and each indicator of poor QoL—were associated with worse outcomes.

Conclusions: We demonstrated the utility in using the poor QoL index to identify those at higher risk of experiencing health challenges. Expanding national recommendations to include this QoL assessment could help in meeting NHAS goals for improving PWH's well-being.

Introduction

With the advent of highly effective antiretroviral therapy, people with HIV (PWH) in the United States are living longer, healthier lives. Despite successes in treatment, a large percentage of PWH experience challenges related to poor quality of life (QoL), including

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pertaining to physical health, mental or emotional health, and structural/subsistence factors related to social determinants of health (SDOH) (1)—defined as conditions in the environments where people are born, live, learn, work, play, worship, and age (2). Aspects of poor quality of life are highly prevalent among PWH and have been associated with adverse clinical outcomes (3, 4). In addition, certain SDOH, such as food insecurity and homelessness, frequently co-occur among PWH, and experiences with multiple negative SDOH are associated with deleterious outcomes (5). Given the unique challenges that PWH face, focusing on assessing and addressing QoL provides a more holistic approach for addressing overall health and well-being of PWH—beyond viral suppression (6, 7).

The U.S. National HIV/AIDS Strategy (NHAS), which provides the roadmap for ending the HIV epidemic (EHE) in the United States by 2030, now prioritizes improving QoL among PWH—particularly among certain disproportionately affected populations. A multiagency federal workgroup was convened to identify appropriate indicators for monitoring QoL among PWH. During listening sessions held to gather input from persons with lived experience, the community voiced concerns about needing “to consider other factors that influence QoL, including SDOH (e.g., unemployment, food insecurity, housing instability), and not solely focus on health-related QoL.” The workgroup also considered several data sources to monitor QoL. The CDC’s Medical Monitoring Project was chosen given its ability to report representative estimates for a variety of characteristics related to QoL, based on a geographically-diverse group of PWH, both nationally and for jurisdictions that report to MMP (8, 9). Five national indicators were added to monitor QoL annually based on MMP measures—good or better self-rated health (physical health), unmet needs for mental health services (mental or emotional health), and hunger or food insecurity, unemployment, and unstable housing or homelessness (structural or subsistence) (8).

Although QoL is monitored among PWH through NHAS, including among some priority populations, co-occurrence of different aspects of QoL is not well described among PWH, and monitoring of co-occurring QoL indicators is not routinely recommended. We utilized the existing NHAS framework to develop a novel poor QoL index that quantifies the number of indicators of poor QoL experienced by PWH. We then applied this index to MMP data, reporting the distribution of scores among PWH alongside data on individual indicators of poor QoL to identify populations who had the worst QoL and how their QoL was affected—overall and by NHAS priority populations. Finally, we examined associations between the poor QoL index scores and key clinical outcomes.

Methods

Data source

During the 2018–2021 annual data cycles, MMP data were collected electronically during June of each year through May of the following year. MMP uses a two-stage complex sample survey design. In the first stage, 16 states and 1 territory were sampled from all U.S. states, the District of Columbia, and Puerto Rico. In the second stage, a simple random sample of persons aged ≥ 18 years with diagnosed HIV was selected annually for each jurisdiction from the National HIV Surveillance System (NHSS), a census of persons with diagnosed HIV in the United States. The jurisdiction-level response rate was 100% (i.e.,

all sampled jurisdictions participated); at the person level, response rates ranged from 40%–45% by cycle year. More details on MMP methodology are described elsewhere (1, 9).

Data were collected via phone or face-to-face interviews, and medical records were abstracted for interviewed respondents who received HIV care during the previous two years. MMP is conducted as part of routine surveillance and is considered non-research; therefore, CDC institutional board review was not obtained. Participating jurisdictions obtained institutional review board approval for data collection as needed (i.e., Los Angeles County, Virginia, and Puerto Rico) and written/verbal informed consent was obtained from all respondents. CDC-established data security and confidentiality guidelines were followed (10).

Measures

Self-rated health, an indicator of physical health, was assessed at the time of interview, and was dichotomized as good, very good, or excellent versus poor or fair. Unmet needs for mental health services—the indicator for mental or emotional health—was assessed during the past 12 months among persons with any need for services from a mental health professional (i.e., receiving, or needing but not receiving services). Structural/subsistence factors included hunger or food insecurity during the past 12 months, unemployment at the time of interview, and unstable housing or homelessness during the past 12 months. More details can be found elsewhere and are also described in Appendix Table 1 (11).

Currently, NHAS priority populations include gay, bisexual, and other men who have sex with men (MSM)—overall, and among Black/African American (hereafter known as Black), Hispanic/Latino, and American Indian/Alaska Native (AI/AN) MSM—Black women, persons aged 13–24 years, and people who inject drugs (PWID). Because MMP only reports data for adults with diagnosed HIV, data on the group representing persons aged 13–24 years could only be reported for persons aged 18–24 years. QoL estimates were statistically unstable for AI/AN MSM due to a small sample size and therefore could not be reported, but AI/AN MSM were included in QoL indicator estimates overall and for all MSM. Priority populations were not mutually exclusive groups. More details on how these populations were defined are described elsewhere (11).

Analytic outcomes included: not being retained in care, missing ≥ 1 HIV care appointments, missing ≥ 1 antiretroviral therapy (ART) dose during the past 30 days, not having sustained viral suppression, having ≥ 1 emergency room (ER) visit, and having ≥ 1 hospitalization. Not being retained in HIV care was defined as having < 2 elements of outpatient HIV care ≥ 90 days apart and was primarily assessed through medical record abstraction. ART dose adherence was self-reported via interview among PWH taking ART and was based on the past 30 days. Sustained viral suppression was ascertained from medical record abstraction and was defined as having all HIV viral load measurements in the past 12 months being < 200 copies/mL or undetectable; those with no viral loads available were considered to be unsuppressed. ER visits and hospitalizations were based on self-report. All outcomes were based on the past 12 months unless otherwise indicated. More details are described elsewhere (1).

Analytic methods

Each QoL measure was dichotomized as 1 or 0, with 1 representing poor QoL (i.e., poor or fair self-rated health, unmet needs for mental health services among those who needed them, hunger/food insecurity, unemployment, and unstable housing/homelessness). Based on this scoring algorithm, those without needs for mental health services, in addition to those whose mental health service needs were being met, were coded as 0. Scores from the 5 QoL variables were summed to create a composite index representing the number of indicators of poor QoL experienced. The index scores ranged from 0–5, with higher scores indicating poorer quality of life. Because the percentage of people with an index score of 4 or 5 indicators totaled to approximately 2%, index scores of 3–5 were combined into a single category for detailed, stratified analyses to maximize reliability of estimates presented.

We used the 2018–2021 MMP data cycles to assess the distribution of poor QoL index scores among PWH (N=15,855), overall and for each NHAS priority population. These scores were used to identify populations affected by poor QoL. Scores were then assessed alongside the distribution of individual indicators of poor QoL to identify areas needing improvement. Finally, we reported associations between poor QoL index scores and selected clinical outcomes, adjusting for age, race/ethnicity, and sex, which were assumed to be potential confounders a priori.

We reported weighted percentages and corresponding 95% confidence intervals (CIs) for all characteristics and evaluated differences between groups using prevalence ratios (PRs) with predicted marginal means. PRs with CIs that did not cross the null and had $P < .05$ were considered meaningfully different. Data were weighted to adjust for person nonresponse and post-stratified to known population totals from NHSS by age, race/ethnicity, and sex. All analyses were conducted using SAS, version 9.4 (SAS Institute, Cary, NC), and SAS-callable SUDAAN, version 11.0.3 (RTI International, NC).

Results

Detailed information on demographic characteristics and SDOH among PWH using MMP has been extensively described elsewhere (1). Based on the scores of the poor QoL index, over half of all PWH (55.1%) had ≥ 1 indicator of poor QoL; 31.5% had 1 indicator, 15.2% had 2 indicators, 6.4% had 3 indicators, 1.7% had 4 indicators, and 0.3% had 5 indicators (Figure 1). Structural/subsistence factors were strongly associated with each other (Appendix Table 2). Of all NHAS priority populations, the prevalence of having ≥ 3 indicators of poor QoL was highest among PWID (26.5%) and persons aged 18–24 years (12%).

Of NHAS priority populations, PWID had the highest percentage of poor or fair self-rated health (PWID: 38.2% vs. range of poor or fair self-rated health among other NHAS priority populations: 12.8%–36.4%), unemployment (32.8% vs. 14.0%–25.1%), hunger/food insecurity (40.0% vs. 15.9%–28.9%), and unstable housing/homelessness (44.2% vs. 17.5%–36.7%; Figure 2, Appendix Table 3). Relative to all adults with HIV, notably large percentages of persons aged 18–24 years also experienced unemployment (25.1% versus 15.1%), hunger/food insecurity (28.9% versus 17.8%), and unstable housing/homelessness

(36.7% versus 18.7%). In addition, large percentages of Black women had poor or fair self-rated health, relative to all adults with HIV (36.4% versus 29.4%). Of all NHAS priority populations, people aged 18–24 years had the lowest prevalence of poor or fair self-rated health (12.8% vs. 21.8%–38.2%). The prevalence of unmet needs for mental health services among those with needs was lowest among Hispanic/Latino MSM (22.4%) and highest among Black MSM (27.2%).

After adjusting for age, race/ethnicity, and sex, every indicator of poor QoL was significantly associated with adverse clinical outcomes, including not being retained in care, missing ≥ 1 HIV care appointments, missing ≥ 1 ART dose in the past 30 days, not having sustained viral suppression, and having ≥ 1 ER visit or hospitalization (Table). Having poor or fair self-rated health was strongly associated with having ≥ 1 ER visit (adjusted PR [aPR]: 1.70; 95% CI: 1.62–1.78) or hospitalization (aPR: 2.34; 95% CI: 2.15–2.54). Experiencing hunger/food insecurity (aPR: 1.94; 95% CI: 1.80–2.10) or unstable housing/homelessness (aPR: 1.86; 95% CI: 1.73–1.99) were strongly associated with missing ≥ 1 HIV care appointment. We also observed dose-response associations between higher poor QoL index scores and all adverse clinical outcomes included in the analysis, with many non-overlapping CIs (e.g., missing ≥ 1 HIV care appointments, missing ≥ 1 ART dose in the past 30 days, having ≥ 1 ER visits). The strongest associations (i.e., those with the greatest magnitude) were observed with missing ≥ 1 HIV care appointment (aPR range: 1.60–3.23), having ≥ 1 hospitalization (aPRs range: 1.84–3.22), and having ≥ 1 ER visit (aPR range: 1.45–2.18).

Discussion

Using nationally representative data and the existing NHAS framework for QoL, we developed and applied a novel index to identify groups of PWH most highly affected by poor QoL. The index includes structural factors, such as unemployment, hunger/food insecurity, and housing instability, based on community input. These factors are not in other established QoL indices like the MOS or the WHOQOL-BREF (12, 13). We demonstrated the utility of using such an index alongside data on individual indicators to provide a more complete picture of people's QoL and identify areas for improvement for QoL among PWH. Specifically, the index can first be used to identify groups of PWH who are most affected by poor QoL (i.e., those with higher scores), and the individual indicator data can then be used to identify how to prioritize valuable resources in the clinical and public health settings to improve people's QoL. Using this method of assessment, we found that over 1 in 4 PWID experienced ≥ 3 indicators of poor QoL. In addition, a large percentage of people aged 18–24 years experienced structural or subsistence factors associated with poor QoL, and 1 in 3 Black women had poor or fair self-rated health. Dose-response relationships were also observed between the number of indicators of poor QoL and adverse clinical outcomes, with poorer QoL being associated with worse outcomes—thus demonstrating the utility of using a poor QoL index to identify people who may be at higher risk of experiencing health challenges.

This method of assessment could be applied more broadly to improve PWH's lives. First, this method could be used to monitor—both nationally and locally—patterns in QoL among

PWH to identify areas of improvement and directing resources for improving PWH's QoL. Second, it could be used in the clinical setting to identify HIV patients with poor QoL and intervene in ways to improve their health—including through linkage to needed services. As NHAS continues to prioritize improving QoL among PWH, expanding recommendations to include assessment of co-occurring QoL domains aligns with a whole-person approach. Using this study's proposed method for poor QoL assessment could help identify and prioritize interventions for PWH who may be at higher risk for experiencing adverse health outcomes. Identifying areas for improvement in meeting NHAS-related goals for improving QoL among PWH could help inform resource allocation for targeted public health action. In addition, updating national guidance for developing local epidemiologic profiles—which are used to inform local HIV prevention and treatment funding—to include co-occurrence of QoL factors through our proposed approach would help ensure local monitoring (14). Updating national guidance and improving national and local monitoring through a multi-dimensional approach could be helpful in improving the health and well-being of PWH.

At a systems level, local availability of services to address physical health, mental or emotional health, and subsistence needs—which may at least partially be affected by local monitoring of patterns—should reflect the needs of PWH. Mismatches in service availability versus need could result in adverse outcomes. A recent analysis demonstrated that national funding for the Department of Housing and Urban Development's Housing Opportunities for People with HIV/AIDS (HOPWA) program—the only federally-funded program dedicated to addressing housing instability among PWH—was insufficient overall and may not have matched housing assistance needs among PWH in certain jurisdictions (15). One potential reason for this could be that funding is partially based on local poverty rates among the general population; however, PWH may have greater documented needs for housing assistance than the total US population (16), and this disparity could vary by jurisdiction. PWH may have greater needs related to mental health and SDOH, including subsistence needs, than the total US population (16, 17). Ensuring that federal and local funding structures are based on reporting of QoL in epidemiologic profile reports could help ensure appropriate resource allocation based on need.

Our proposed method of assessment could be used in the clinical setting to identify and intervene to improve the health of HIV patients with poor QoL. The Infectious Diseases Society of America currently recommends initial assessment and ongoing evaluation of social and structural factors such as unstable housing, food insecurity, and access to transportation, as well as annual mental health evaluations (18), but the frequency of assessment is unspecified or is inconsistent between guidelines (18–20). Lack of initial and routine assessment of such factors could result in missed opportunities for timely linkage to needed services and could negatively impact patient care and outcomes. Within the clinical setting, integrating routine evaluations of physical health with mental and emotional health and subsistence factors reflects a patient-centered, whole person approach. Incorporating the use of the poor QoL index—via a self-administered questionnaire in the patient portal or a staff-administered intake assessment—could provide an efficient method for assessment. Linking responses to ICD codes (e.g., ICD-10 “Z” codes for SDOH-related factors) could facilitate documenting patient responses to the index, helping providers easily identify and track patients' issues that may impact their health, and identify patients with the greatest

need for intervention (21). Such an approach could provide opportunities for building patient-provider relationships and linkage to services in a timely fashion by meeting patients where they are, ensuring patient-centered care. This could be especially helpful for patients disproportionately affected by HIV who may be less likely to be engaged in care and more likely to have unmet needs for ancillary services or adverse outcomes, such as PWID (22). Specifically, using the poor QoL index to prioritize data-to-care efforts could be helpful in prioritizing limited public health resources in addressing the needs of patients at highest risk of having adverse outcomes.

Connecting people to appropriate ancillary services is essential for addressing certain SDOH and supporting PWH's health and QoL, as unmet needs for such services were found to have dose-response relationships with negative outcomes (23). However, services related to addressing complex physical health, mental health, or subsistence needs may not be available onsite or through referral at every facility. For instance, a recent analysis of HIV care facilities attended by MMP respondents demonstrated that over 1 in 6 facilities did not offer mental health services, 1 in 4 did not offer housing assistance, and 1 in 3 did not offer food bank or meal delivery services onsite or through referral (24). Connecting people to needed services may require additional time and logistics for referrals or submitting appropriate documentation for receiving subsistence benefits. Having a patient navigator or case manager available could help manage these logistics. However, nearly 1 in 6 PWH reported needing but not receiving HIV case management services, which could limit access to needed ancillary services (1). Broadening access to patient navigation or case management services aligns with a patient-centered care approach, as recommended through NHAS, and ensures seamless follow through once needs are identified. Such an approach also mirrors the structure used by Ryan White HIV/AIDS Program (RWHAP)-funded clinics, which are more likely than other HIV clinics to co-locate ancillary services with HIV care (25, 26). For non-RWHAP-funded clinics without co-located services, strengthening local partnerships may help connect patients to services not available onsite.

This analysis was subject to limitations. Self-reported QoL indicator data may have been subject to social desirability bias. All measures were assumed to be co-occurring if respondents had experiences with >1 factor, which may not have been the case if they did not occur at the same point in time. The QoL index components were purposely chosen based on the existing NHAS QoL framework; future studies could evaluate the benefit of adding additional index components. The index weights each component equally; future work could consider weighting components differently (e.g., based on associations with clinical outcomes) to prioritize data to care lists or resources for patients with the greatest need. Associations between individual indicators and outcomes were not adjusted for other indicators; relationships between indicators are complex, and may co-occur, affect each other, and be time-varying. Future studies could consider examining causal relationships with outcomes. This study was cross-sectional; therefore, associations may not imply causality. Future longitudinal studies could be conducted to evaluate downstream effects of poor QoL on health outcomes. The COVID-19 pandemic affected aspects of QoL over time; annual estimates of individual QoL indicators have been previously described (1). In addition, response rates during the 2019 and 2020 MMP data cycles, which could have affected overall patterns in QoL in NHAS priority populations if response rates

were differential with respect to variables of interest. Although MMP’s response rate was suboptimal, estimates were adjusted for nonresponse and post-stratified to NHSS population totals by age, race/ethnicity, and sex.

Using the existing NHAS framework for QoL, this was the first national analysis to demonstrate the utility of using a novel index alongside the distribution of individual indicators of QoL to identify populations most disproportionately affected by poor QoL and how to prioritize valuable resources for improvement. Unlike many other established measures, this index incorporates factors related to unemployment, housing instability and food insecurity based on input from the community of PWH. When we applied this method of assessment to a representative sample of PWH in the United States, we found that a substantial percentage experienced multiple, co-occurring indicators of poor QoL, and certain populations highly affected by HIV have specific needs for improving QoL. Poor QoL was associated with a variety of adverse outcomes, with a dose-response relationship between the number of poor indicators and outcomes. This assessment method could be used to monitor national and local patterns in QoL among PWH and to identify and provide services in the clinical setting for PWH with poor QoL to improve their well-being and health. Expanding national reporting and clinical recommendations to include this multi-dimensional method of assessment of QoL could improve interventions targeted to improve people’s QoL, and therefore, meet NHAS and EHE goals related to improving QoL and health and well-being of all PWH in the United States.

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APPENDICES

Appendix Table 1.

Definitions of components included in poor quality of life index—Medical Monitoring Project, United States, 2018–2021 data cycles.

Quality of life domain	Quality of life indicator	Questions and responses used to create variable	Analytic categories	How variable was calculated
Physical health	Good or better self-rated health	In general, is your health: • Poor • Fair • Good • Very good • Excellent	• Good, very good, excellent physical health • Poor or fair	Original responses categorized dichotomously as good, very good, or excellent vs. poor or fair.

Quality of life domain	Quality of life indicator	Questions and responses used to create variable	Analytic categories	How variable was calculated
			physical health	
Mental/emotional health	Unmet needs for mental health services among persons with any need for services from a mental health professional	During the past 12 months, have you seen or talked to a mental health professional such as a psychologist, psychiatrist, psychiatric nurse, or clinical social worker about your health? • Yes • No During the past 12 months, have you needed to see or talk to a mental health professional about your health? • Yes • No	• Yes • No	• Need for services from a mental health professional: Defined as people who received a service from a mental health professional or needed but did not receive services from a mental health professional • Unmet need for services from a mental health professional: Defined as needing, but not receiving, services from a mental health professional – Calculated among persons with any need (regardless of whether they received it)
Structural/subsistence factors	Hunger or food insecurity	During the past 12 months, were you ever hungry but didn't eat because there wasn't enough money for food? • Yes • No	• Yes • No	--
	Unemployment	Are you currently...? • Employed for wages • Self-employed • Out of work for more than 1 year • Out of work for less than 1 year • A homemaker • A student • Retired	• Yes • No	Unemployed persons who were out of work for any period of time (out of work for more than 1 year, out of work for less than 1 year), excluding those who were unable to work. This measure was calculated among all respondents.

Quality of life domain	Quality of life indicator	Questions and responses used to create variable	Analytic categories	How variable was calculated
		Unable to work		
	Unstable housing or homelessness	During the past 12 months, have you done any of the following? Lived on the street? - Yes - No Lived in a shelter? - Yes - No Lived in a single room occupancy (SRO) hotel? - Yes - No Lived in a car? - Yes - No During the past 12 months, did you ever move in with other people even for a little while because of financial problems? - Yes - No How many times did you move during the past 12 months? Have you ever been evicted at any time during the past 12 months? - Yes - No	- Yes - No	“Unstable housing or homelessness” defined as experiencing unstable housing (i.e., moving in with others due to financial issues, moving 2 or more times, or being evicted at any time) or homelessness (living on the street, in a shelter, in a single-room–occupancy hotel, or in a car at any time) during the past 12 months.

Appendix Table 2.

Associations between individual indicators of poor quality of life—Medical Monitoring Project, United States, 2018–2021 data cycles.

	Fair/poor self-rated health				Unmet needs for mental health services among those with needs				Unemployed				Experienced	
	n	wted row %	uPR (95% CI)	aPR (95% CI)	n	wted row %	uPR (95% CI)	aPR (95% CI)	n	wted row %	uPR (95% CI)	aPR (95% CI)	n	wted row %
Self-rated health														
Fair, poor					529	22.7 (20.3–25.1)	1.03 (0.92–1.15)	0.99 (0.89–1.11)	730	16.6 (15.4–17.8)	1.15 (1.05–1.27)*	1.00 (0.87–1.15)	1313	27.8 (26.5–29.2)
Good or better					786	22.0 (20.1–24.0)	Ref	Ref	1570	14.4 (13.5–15.3)	Ref	Ref	1458	13.6 (12.8–14.4)
Unmet needs for mental health services among those with needs														
Yes	529	38.5 (35.6–41.4)	1.02 (0.94–1.12)	0.99 (0.91–1.08)					259	20.7 (17.9–23.5)	1.19 (1.01–1.41)*	1.16 (0.99–1.36)	402	31.2 (28.5–33.9)
No	1895	37.6 (36.0–39.3)	Ref	Ref					834	17.4 (16.0–18.7)	Ref	Ref	1213	24.3 (22.8–25.8)
Unemployment														
Yes	730	32.4 (30.1–34.8)	1.13 (1.04–1.22)*	1.00 (0.90–1.11)	259	25.5 (22.0–29.0)	1.18 (1.01–1.38)*	1.15 (0.99–1.34)					653	29.4 (27.1–31.8)
No	4033	28.8 (27.9–29.8)	Ref	Ref	1057	21.6 (19.7–23.5)	Ref	Ref					2124	15.8 (15.1–16.5)
Food insecurity/hunger														
Yes	1313	46.0 (44.2–47.8)	1.78 (1.69–1.88)*	1.51 (1.41–1.63)*	402	26.9 (24.2–29.6)	1.30 (1.16–1.46)*	1.30 (1.16–1.46)*	653	24.8 (22.9–26.7)	1.92 (1.75–2.10)*	1.42 (1.24–1.63)*		
No	3456	25.8 (24.9–26.7)	Ref	Ref	914	20.7 (18.7–22.6)	Ref	Ref	1651	13.0 (12.2–13.7)	Ref	Ref		
Unstable housing or homelessness														
Yes	1161	38.3 (36.5–40.0)	1.40 (1.32–1.48)*	1.07 (0.98–1.17)	346	23.3 (20.5–26.1)	1.06 (0.93–1.22)	0.96 (0.84–1.11)	717	26.0 (24.1–27.9)	2.07 (1.89–2.26)*	1.48 (1.30–1.69)*	1251	42.6 (40.4–44.7)
No	3613	27.4 (26.4–28.4)	Ref	Ref	969	21.9 (19.9–23.9)	Ref	Ref	1589	12.6 (11.8–13.3)	Ref	Ref	1526	12.1 (11.5–12.8)

* Statistically significant p-value at the alpha=.05 level.

Abbreviations: uPR, unadjusted prevalence ratio; aPR, adjusted prevalence ratio, CI, confidence interval.

Notes: Adjusted models control for all other QoL indicators. “Good or better self-rated health” defined as rating one’s health as good, very good, or excellent (as opposed to poor or fair) at the time of interview. “Unmet need for mental

health services from a mental health professional” defined as needing, but not receiving, services from a mental health professional among those who indicated needing mental health services (i.e., receiving, or needing but not receiving) during the past 12 months. “Hunger/food insecurity” defined as going without food due to lack of money during the past 12 months. Unemployed persons included those who reported being unemployed at the time of the interview. Persons who were unable to work were not considered unemployed. “Unstable housing or homelessness” defined as experiencing unstable housing (i.e., moving in with others due to financial issues, moving 2 or more times, or being evicted at any time) or homelessness (living on the street, in a shelter, in a single-room-occupancy hotel, or in a car at any time) during the past 12 months.

Appendix Table 3.

Percentages of people with diagnosed HIV with indicators of poor quality of life, overall and among National HIV/AIDS Strategy (NHAS) priority populations—Medical Monitoring Project, United States, 2018–2021 data cycles.

	All adults with HIV		MSM		Black MSM		Hispanic/Latino MSM		Black women		Persons aged 18–24 years		People who inject drugs	
	n	wtd col %	n	wtd col %	n	wtd col %	n	wtd col %	n	wtd col %	n	wtd col %	n	wtd col %
Total (row%)	15855	100	7948	51.1 (49.2–52.9)	2173	14.1 (12.7–15.6)	1930	12.7 (11.0–14.5)	2302	13.6 (11.9–15.4)	303	2.1 (1.7–2.4)	440	2.7 (2.4–3.1)
Poor or fair self-rated health														
Fair, poor	4775	29.4 (28.5–30.3)	1825	22.8 (21.6–24.0)	482	21.8 (19.4–24.1)	441	22.3 (20.1–24.4)	863	36.4 (33.9–39.0)	42	12.8 (8.4–17.2)	176	38.2 (32.7–43.6)
Good or better	10991	70.6 (69.7–71.5)	6104	77.2 (76.0–78.4)	1680	78.2 (75.9–80.6)	1486	77.7 (75.6–79.9)	1424	63.6 (61.0–66.1)	260	87.2 (82.8–91.6)	264	61.8 (56.4–67.3)
Unmet needs for mental health services among those with needs														
Yes	1317	22.3 (20.5–24.0)	746	24.3 (22.2–26.3)	202	27.2 (23.9–30.5)	191	22.4 (18.5–26.4)	180	25.2 (21.0–29.3)	33	26.3 (17.1–35.5)	72	25.0 (18.6–31.5)
No	4942	77.7 (76.0–79.5)	2479	75.7 (73.7–77.8)	589	72.8 (69.5–76.1)	663	77.6 (73.6–81.5)	616	74.8 (70.7–79.0)	92	73.7 (64.5–82.9)	235	75.0 (68.5–81.4)
Unemployment														
Yes	2308	15.1 (14.4–15.8)	1151	14.9 (13.9–15.8)	384	18.5 (16.6–20.3)	313	16.3 (14.2–18.3)	299	14.0 (12.4–15.7)	82	25.1 (19.1–31.0)	139	32.8 (27.1–38.6)
No	13461	84.9 (84.2–85.6)	6782	85.1 (84.2–86.1)	1788	81.5 (79.7–83.4)	1615	83.7 (81.7–85.8)	1988	86.0 (84.3–87.6)	220	74.9 (69.0–80.9)	301	67.2 (61.4–72.9)
Food insecurity/hunger														
Yes	2782	17.8 (17.1–18.6)	1233	15.9 (14.9–16.9)	432	19.9 (17.9–22.0)	356	17.6 (15.5–19.6)	382	16.3 (14.5–18.1)	96	28.9 (23.2–34.6)	176	40.0 (34.0–46.1)
No	13006	82.2 (81.4–82.9)	6709	84.1 (83.1–85.1)	1740	80.1 (78.0–82.1)	1571	82.4 (80.4–84.5)	1909	83.7 (81.9–85.5)	206	71.1 (65.4–76.8)	264	60.0 (53.9–66.0)

	All adults with HIV		MSM		Black MSM		Hispanic/Latino MSM		Black women		Persons aged 18–24 years		People who inject drugs	
	n	wted col %	n	wted col %	n	wted col %	n	wted col %	n	wted col %	n	wted col %	n	wted col %
Unstable housing or homelessness														
Yes	2942	18.7 (17.8–19.6)	1371	17.5 (16.4–18.6)	521	23.8 (21.5–26.2)	375	18.4 (16.3–20.5)	437	19.0 (17.2–20.9)	114	36.7 (30.4–42.9)	198	44.2 (38.2–50.3)
No	12846	81.3 (80.4–82.2)	6567	82.5 (81.4–83.6)	1646	76.2 (73.8–78.5)	1554	81.6 (79.5–83.7)	1852	81.0 (79.1–82.8)	189	63.3 (57.1–69.6)	242	55.8 (49.7–61.8)

Abbreviations: Wted, weighted; col, column; MSM, gay, bisexual, or other men who had sex with men; AI/AN, American Indian, Alaska Native.

Notes: Priority populations are not mutually exclusive groups; people could be in >1 population. People who inject drugs included persons with diagnosed HIV who reported injecting drugs during the past 12 months. Black/African American MSM included MSM with diagnosed HIV who identified as non-Hispanic/Latino, Black/African American race/ethnicity. Hispanic/Latino MSM included MSM who identified as Hispanic/Latino race/ethnicity. Hispanics or Latino persons could be of any race. MSM included men with diagnosed HIV who reported having sex with ≥1 men in the past 12 months (among persons who had sex during the past 12 months) and men with diagnosed HIV who reported identifying as gay or bisexual (among those who did not have sex during the past 12 months). Black/African American women included women with diagnosed HIV who identified as non-Hispanic/Latino, Black/African American race/ethnicity. Data could not be reported for AI/AN MSM due to small numbers.

“Good or better self-rated health” defined as rating one’s health as good, very good, or excellent (as opposed to poor or fair) at the time of interview. “Unmet need for mental health services from a mental health professional” defined as needing, but not receiving, services from a mental health professional among those who indicated needing mental health services (i.e., receiving, or needing but not receiving) during the past 12 months. “Hunger/food insecurity” defined as going without food due to lack of money during the past 12 months. Unemployed persons included those who reported being unemployed at the time of the interview. Persons who were unable to work were not considered unemployed. “Unstable housing or homelessness” defined as experiencing unstable housing (i.e., moving in with others due to financial issues, moving 2 or more times, or being evicted at any time) or homelessness (living on the street, in a shelter, in a single-room-occupancy hotel, or in a car at any time) during the past 12 months.

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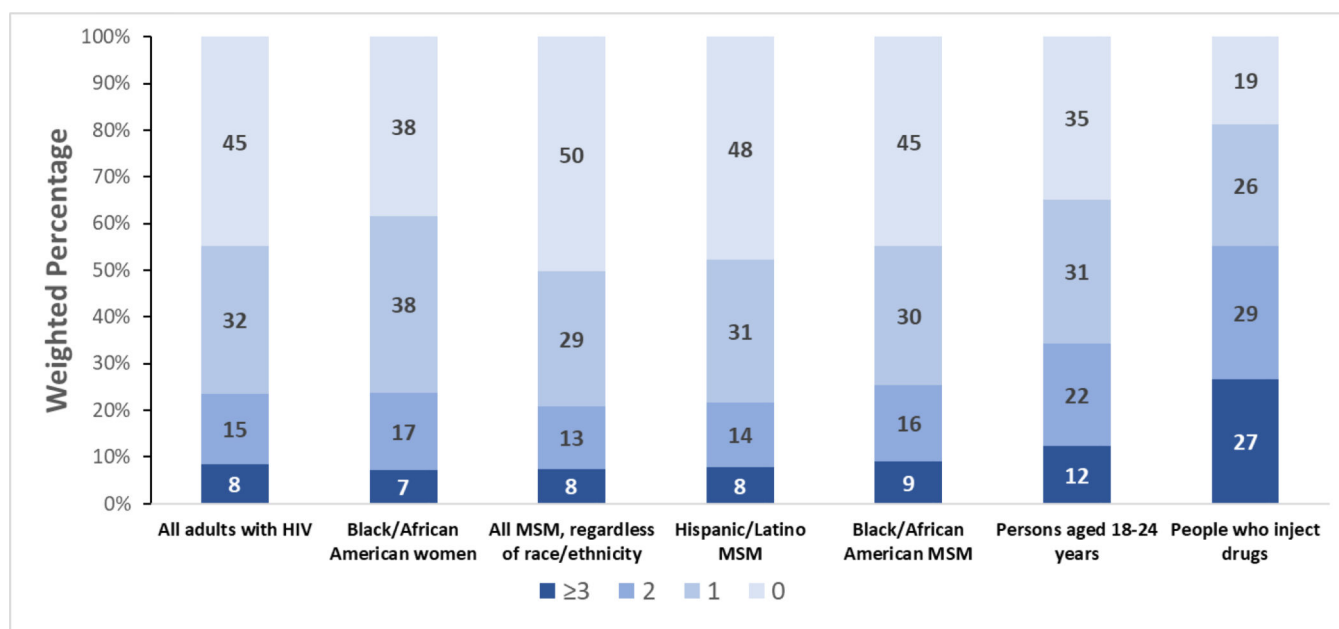


Figure 1.

Number of indicators of poor quality of life among National HIV/AIDS Strategy (NHAS) priority populations—Medical Monitoring Project, United States, 2018–2021 data cycles. Abbreviations: MSM, gay, bisexual, or other men who had sex with men; AI/AN, American Indian, Alaska Native.

Notes: People who inject drugs included persons with diagnosed HIV who reported injecting drugs during the past 12 months. Black/African American MSM included MSM with diagnosed HIV who identified as non-Hispanic/Latino, Black/African American race/ethnicity. Hispanic/Latino MSM included MSM who identified as Hispanic/Latino race/ethnicity. Hispanics or Latino persons could be of any race. MSM included men with diagnosed HIV who reported having sex with ≥ 1 men in the past 12 months (among persons who had sex during the past 12 months) and men with diagnosed HIV who reported identifying as gay or bisexual (among those who did not have sex during the past 12 months). Black/African American women included women with diagnosed HIV who identified as non-Hispanic/Latino, Black/African American race/ethnicity. Data could not be reported for AI/AN MSM due to small numbers.

Each individual QoL measure was dichotomized as 1 or 0, with 1 representing negative aspects of QoL (i.e., poor or fair self-rated health, unmet needs for mental health services among those who needed them, hunger or food insecurity, unemployment, and unstable housing or homelessness). Those without needs for mental health services were coded as 0. Scores from the 5 QoL variables were summed to create a composite index representing the number of poor QoL indicators each PWH has. The index ranged from 0–5; however, because of small numbers, having 3–5 poor QoL indicators was combined into a single category.

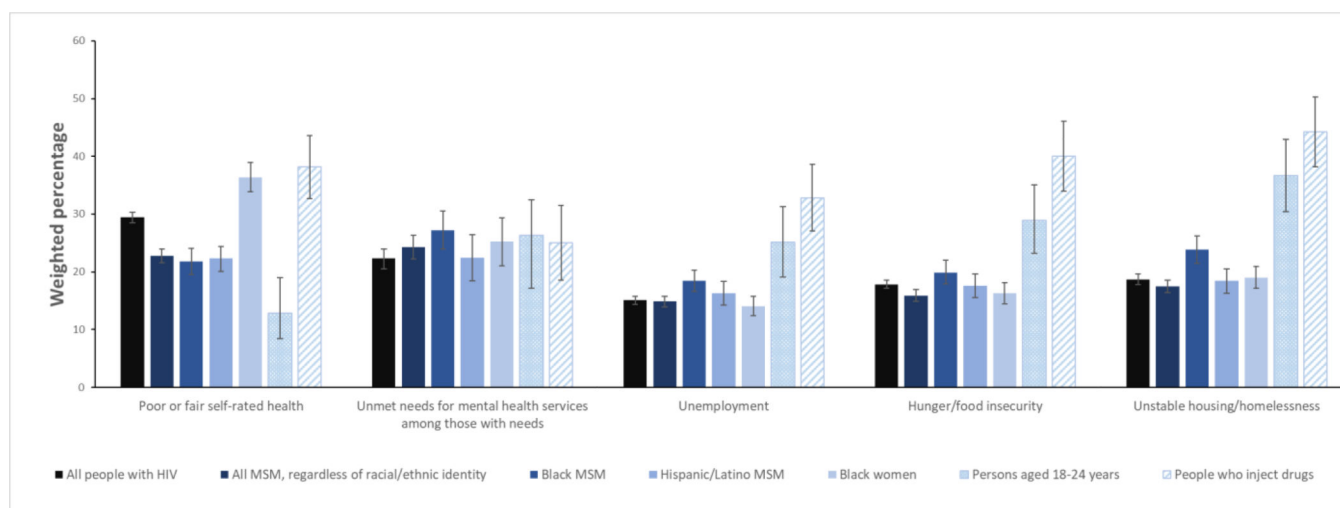


Figure 2.

Percentage of adults with diagnosed HIV with indicators of poor quality of life, overall and among National HIV/AIDS Strategy (NHAS) priority populations—Medical Monitoring Project, United States, 2018–2021 data cycles.

Abbreviations: MSM, gay, bisexual, or other men who had sex with men; AI/AN, American Indian, Alaska Native.

Notes: Priority populations are not mutually exclusive groups; people could be in >1 population. People who inject drugs included persons with diagnosed HIV who reported injecting drugs during the past 12 months. Black/African American MSM included MSM with diagnosed HIV who identified as non-Hispanic/Latino, Black/African American race/ethnicity. Hispanic/Latino MSM included MSM who identified as Hispanic/Latino race/ethnicity. Hispanics or Latino persons could be of any race. MSM included men with diagnosed HIV who reported having sex with ≥ 1 men in the past 12 months (among persons who had sex during the past 12 months) and men with diagnosed HIV who reported identifying as gay or bisexual (among those who did not have sex during the past 12 months). Black/African American women included women with diagnosed HIV who identified as non-Hispanic/Latino, Black/African American race/ethnicity. Data could not be reported for AI/AN MSM due to small numbers.

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Table.
Associations between poor quality of life and selected clinical outcomes—Medical Monitoring Project, United States, 2018–2021 data cycles.

	Not retained in care			Missed ≥1 appointments			Missed ≥1 ART dose			Did not have sustained viral suppression			Had ≥1 ER visit			Had ≥1 hospitalization		
	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)
Quality of life index score																		
0	1201	23.1 (21.3–24.9)	Reference	890	13.6 (12.4–14.7)	Reference	2155	31.7 (30.3–33.2)	Reference	1899	31.9 (29.7–34.1)	Reference	2000	28.5 (27.3–29.8)	Reference	779	10.9 (10.0–11.9)	Reference
1	843	24.0 (22.0–26.0)	1.03 (0.94–1.13)	1105	22.4 (21.1–23.8)	1.60 (1.45–1.76)*	1821	38.5 (36.9–40.1)	1.20 (1.13–1.28)*	1677	39.6 (37.2–41.9)	1.22 (1.14–1.30)*	2094	41.9 (40.0–43.9)	1.45 (1.37–1.53)*	1057	20.4 (19.2–21.6)	1.84 (1.67–2.02)*
2	456	26.6 (24.2–29.0)	1.11 (1.00–1.23)*	750	31.7 (29.4–33.9)	2.17 (1.95–2.41)*	1095	49.4 (46.6–52.1)	1.49 (1.39–1.59)*	943	45.1 (42.6–47.7)	1.36 (1.27–1.46)*	1264	52.9 (50.2–55.6)	1.82 (1.69–1.95)*	616	23.9 (21.9–25.9)	2.23 (1.98–2.52)*
≥3	322	34.3 (30.5–38.2)	1.41 (1.25–1.58)*	624	47.5 (44.1–50.9)	3.23 (2.88–3.62)*	677	59.8 (56.5–63.1)	1.78 (1.66–1.91)*	701	60.7 (57.5–63.9)	1.82 (1.68–1.97)*	850	63.2 (59.7–66.7)	2.18 (2.03–2.33)*	453	33.3 (30.2–36.5)	3.22 (2.85–3.63)*
Self-rated health																		
Fair, poor	877	26.0 (24.0–27.9)	1.11 (1.03–1.19)	1367	28.0 (26.6–29.5)	1.53 (1.43–1.64)*	1920	42.9 (41.3–44.6)	1.23 (1.17–1.30)*	1891	45.2 (43.1–47.3)	1.29 (1.22–1.35)	2688	55.1 (53.1–57.1)	1.70 (1.62–1.78)*	1528	30.4 (28.8–32.0)	2.34 (2.15–2.54)*
Good or better	1984	24.5 (23.0–26.1)	Reference	2040	19.4 (18.4–20.3)	Reference	3878	36.8 (35.5–38.1)	Reference	3405	36.3 (34.3–38.3)	Reference	3598	32.8 (31.6–34.0)	Reference	1416	12.5 (11.6–13.3)	Reference
Unmet needs for mental health services among those with needs																		
Yes	296	30.6 (26.6–34.6)	1.55 (1.33–1.80)*	444	33.6 (30.7–36.5)	1.20 (1.09–1.33)*	659	53.0 (49.2–56.7)	1.21 (1.11–1.31)*	525	45.8 (42.1–49.5)	1.23 (1.13–1.33)*	619	45.2 (41.9–48.5)	0.94 (0.87–1.02)	242	17.0 (14.9–19.1)	0.73 (0.64–0.83)*
No	711	18.9 (16.9–20.8)	Reference	1317	27.0 (25.5–28.5)	Reference	2017	42.4 (40.5–44.4)	Reference	1600	36.3 (34.0–38.5)	Reference	2381	47.4 (45.2–49.7)	Reference	1210	23.7 (22.1–25.3)	Reference
Unemployment																		

	Not retained in care			Missed ≥1 appointments			Missed ≥1 ART dose			Did not have sustained viral suppression			Had ≥1 ER visit			Had ≥1 hospitalization		
	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)	n	% (95% CI)	aPR (95% CI)
Yes	473	29.3 (26.6–31.9)	1.15 (1.05–1.26)*	739	32.8 (30.6–35.0)	1.51 (1.38–1.64)*	997	47.8 (45.3–50.4)	1.22 (1.14–1.29)*	922	47.0 (44.4–49.7)	1.20 (1.12–1.28)*	1038	45.8 (43.2–48.5)	1.18 (1.11–1.25)*	493	20.7 (18.7–22.6)	1.26 (1.14–1.40)*
No	2393	24.2 (22.8–25.7)	Reference	2667	20.0 (19.1–21.0)	Reference	4794	37.0 (35.9–38.2)	Reference	4392	37.6 (35.7–39.5)	Reference	5252	38.3 (37.1–39.4)	Reference	2453	17.2 (16.4–18.1)	Reference
Hunger/food insecurity																		
Yes	566	27.9 (25.3–30.5)	1.11 (1.01–1.21)*	1082	38.4 (36.3–40.4)	1.94 (1.80–2.10)*	1335	52.0 (49.4–54.7)	1.38 (1.31–1.46)*	1242	50.8 (48.4–53.3)	1.35 (1.28–1.43)*	1545	54.3 (52.2–56.5)	1.48 (1.42–1.55)*	772	26.5 (24.5–28.6)	1.75 (1.61–1.89)*
No	2302	24.4 (22.9–25.8)	Reference	2329	18.4 (17.5–19.3)	Reference	4458	35.8 (34.7–36.8)	Reference	4069	36.4 (34.5–38.2)	Reference	4749	36.1 (34.9–37.3)	Reference	2176	15.8 (15.1–16.6)	Reference
Unstable housing or homelessness																		
Yes	659	31.2 (28.5–33.8)	1.24 (1.13–1.36)*	1092	37.4 (35.5–39.2)	1.86 (1.73–1.99)*	1368	52.3 (49.9–54.6)	1.36 (1.30–1.42)*	1402	53.4 (51.2–55.6)	1.42 (1.35–1.50)*	1619	54.4 (52.2–56.6)	1.48 (1.41–1.56)*	791	25.3 (23.4–27.2)	1.70 (1.56–1.85)*
No	2209	23.5 (22.1–24.9)	Reference	2320	18.4 (17.5–19.4)	Reference	4430	35.7 (34.6–36.7)	Reference	3913	35.7 (33.8–37.5)	Reference	4673	35.9 (34.7–37.1)	Reference	2155	16.0 (15.2–16.8)	Reference

* P<.05

Abbreviations: ART, antiretroviral therapy; ER, emergency room; aPR: adjusted prevalence ratio; CI: confidence interval.

Notes: Not being retained in care was defined as having <2 elements of outpatient HIV care at least 90 days apart in the past 12 months. Outpatient HIV care was defined as any documentation of the following: encounter with an HIV care provider, viral load test result, CD4 test result, HIV resistance test or tropism assay, ART prescription, PCP prophylaxis, or MAC prophylaxis. Not having sustained viral suppression was defined as having ≥1 viral load measurement documented detectable or ≥200 copies/mL during the past 12 months. Those with no viral loads during the past 12 months were considered to be virally unsuppressed. Sustained viral suppression was still assessed if a person had a single viral load during the past 12 months.

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All models are adjusted for age, race/ethnicity, and sex.