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Debra Malina, Ph.D., *Editor*

Long-Acting HIV Medicines and the Pandemic Inequality Cycle — Rethinking Access

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The world may look back on 2024 as a pivotal time in the fight against AIDS — the start of a revolution in the global biomedical response to HIV using long-acting antiretroviral medicines. Young women in southern Africa have described new prevention options as empowering, allowing them to "own their own sexual destiny" for the first time. Young people with HIV, many of whom have lived their lives dependent on daily pills, long to be free of the daily reminder of their stigmatizing infection. Members of criminalized groups, such as gay men in Uganda and Malaysia, are seeking HIV options they can leave at the clinic. New long-acting prevention and treatment innovations have the potential to change the HIV narrative — from dependency and stigma to empowerment and healthy lives. Whether they will do so depends on whether policymakers and pharmaceutical companies avoid repeating past mistakes in the few years that remain before 2030, the target date set by United Nations member states for ending the AIDS pandemic.

A similar opportunity presented itself in 1996, when it was announced at the International AIDS Conference in Vancouver, Canada, that triple-combination antiretroviral (ARV) treatment had proved effective in preventing deaths from AIDS.[1,2] The HIV-treatment era had begun. But in the ensuing decade, as AIDS-related deaths plummeted in the United States and Europe, they increased dramatically in low- and middle-income countries (LMICs).[3] UNAIDS estimates that 12 million people in Africa died of AIDS between 1997 and 2006 because pharmaceutical monopolies kept prices of life-saving medicines high and supplies low.[4-6]

Now that we know that treatment blocks HIV transmission,[7,8] it's clear that millions of avoidable HIV infections can also be traced to this unequal access. As the HIV/AIDS community looks ahead to a new era of long-acting antiretrovirals, it must interrupt that cycle. Doing so will require a new, nonlinear approach to global access to ARVs that combines far more rapid sharing of technology, decentralized global production, and research and development of products that meet the needs in Africa, Asia, Latin America, and the Caribbean, even if those needs are not the priorities of high-income countries.

THE LONG-ACTING ARV ERA

The science of long-acting ARVs for prevention and treatment is advancing quickly.[9] In the PURPOSE 1 study of lenacapavir (in which one of us was a national principal investigator), this HIV-prevention technology afforded 100% protection.[10] That study included thousands of young women in South Africa and Uganda, who received the medication as a subcutaneous injection just two times a year — which many experts see as potentially transformative. A follow-up study, PURPOSE 2 — conducted in Argentina, Brazil, Mexico, Peru, South Africa, Thailand, and the United States and involving cisgender men, transgender men, transgender women, and people of nonbinary gender who have sex with men — found an HIV-acquisition rate 96% lower than the expected background incidence rate.[11]

These results followed those of two studies, HPTN 083 and HPTN 084, showing that injectable cabotegravir administered every 2 months was also highly effective in preventing HIV infection and significantly more so than daily use of the current oral formulation.[12] Cabotegravir for long-acting preexposure prophylaxis (PrEP) has now been rolled out in the United States, where about 11,000 people had been prescribed

long-acting PrEP by January 2024.[13] A visitor to Washington, DC, might notice advertisements for long-acting PrEP on bus stalls and subway stations throughout the city. Longer-acting oral PrEP taken monthly may move into phase 3 trials in 2025, potentially demonstrating that a year of PrEP could require just 12 pills.

Meanwhile, long-acting HIV treatment is emerging. A combination of cabotegravir and rilpivirine was proven effective as treatment, with viral suppression rates equivalent to those achieved with daily oral medication.[14,15] People with HIV, albeit a limited number of them, are using this injectable treatment effectively in high-income countries,[16-22] where guidelines are shifting to include long-acting treatment.[21,22] Lenacapavir has shown efficacy and been approved in several countries for use, in combination with other antiretrovirals, in treating adults with multidrug-resistant HIV.[23] An even longer-acting cabotegravir, to be administered every 4 months, is under development and could make treatment even less burdensome.[24] Another option involving a regimen of lenacapavir and islatravir as a once-weekly oral pill has shown promise in phase 2 trials.[25]

INEQUITY IN ACCESS

But the world does not start the long-acting–antiretroviral era from a position of equity. Access has been a continuing problem (Fig. 1). Oral PrEP first received U.S. marketing approval in December 2012, but three and a half years passed before the drugmaker submitted for, and received, its first regulatory approval in an African country.[26] Scale-up has been deeply uneven. It took 10 years for as many people to be started on oral PrEP in South Africa as in the United States, where risk of HIV is far lower.[26] Regulatory approval of long-acting PrEP (cabotegravir), which came in the United States in 2021, has been quicker, though the delay is still considerable: as of September 2024, drug approval had been secured in 13 African countries.

More than 7 million people currently need PrEP but lack access, as compared with current global targets of 10.6 million using PrEP consistently.[27] There is expected to be only enough cabotegravir in LMICs for a few hundred thousand people through 2025, and rollout of what's available will be difficult.[28] Both price and supply are barriers. The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) has purchased some doses to support programs in Zambia, Zimbabwe, Malawi, Ukraine, and Eswatini and hopes to scale up to 12 countries to reach at least 100,000 people by 2025 — an important contribution, but small compared with the need.[29] South Africa hopes to purchase cabotegravir, but the "noncommercial" price set by the only current producer, Viiv, is about U.S.$30 per injection (U.S.$180 per year), which is 2.5 times the rate that would make it cost-effective, according to an analysis by the South African government, and the quantity available to South Africa is unclear.[30] Meanwhile, countries in Latin America and Asia facing high rates of HIV infection — even some, such as Brazil and Peru, that hosted clinical trials — are not eligible for the "noncommercial" price. Generic versions are badly needed but may still be years away.

For treatment, long-acting medicines are in use in high-income countries but unavailable in LMICs. Research has shown that cabotegravir–rilpivirine can be used in African settings despite clinical and operational shortcomings.[31] But the makers of those drugs (Viiv and Johnson & Johnson, respectively) are not selling the combination in LMICs, and no generic version exists.[32] The combination product for treatment is not currently included in World Health Organization (WHO) guidelines.

NONLINEAR MODEL NEEDED

For decades, new HIV medicines have come out first in the United States and Europe and only years (often more than a decade) later reached wide circulation in the communities with the highest HIV rates in Africa, Asia, Latin America, the Caribbean, and Eastern Europe. Multiple factors contribute to these long delays, including the necessity of bringing down prices, boosting supply, securing financing, and overcoming regulatory and programmatic barriers. The lag time has been shrinking, but substantial inequality persists.

For each important new medicine with global utility, the AIDS community of clinicians, government officials, international organizations, and activists has secured production by generics manufacturers. LMIC governments have exercised flexibilities in intellectual property law to enable generic production of medicines, and originator companies have been pressured to license their

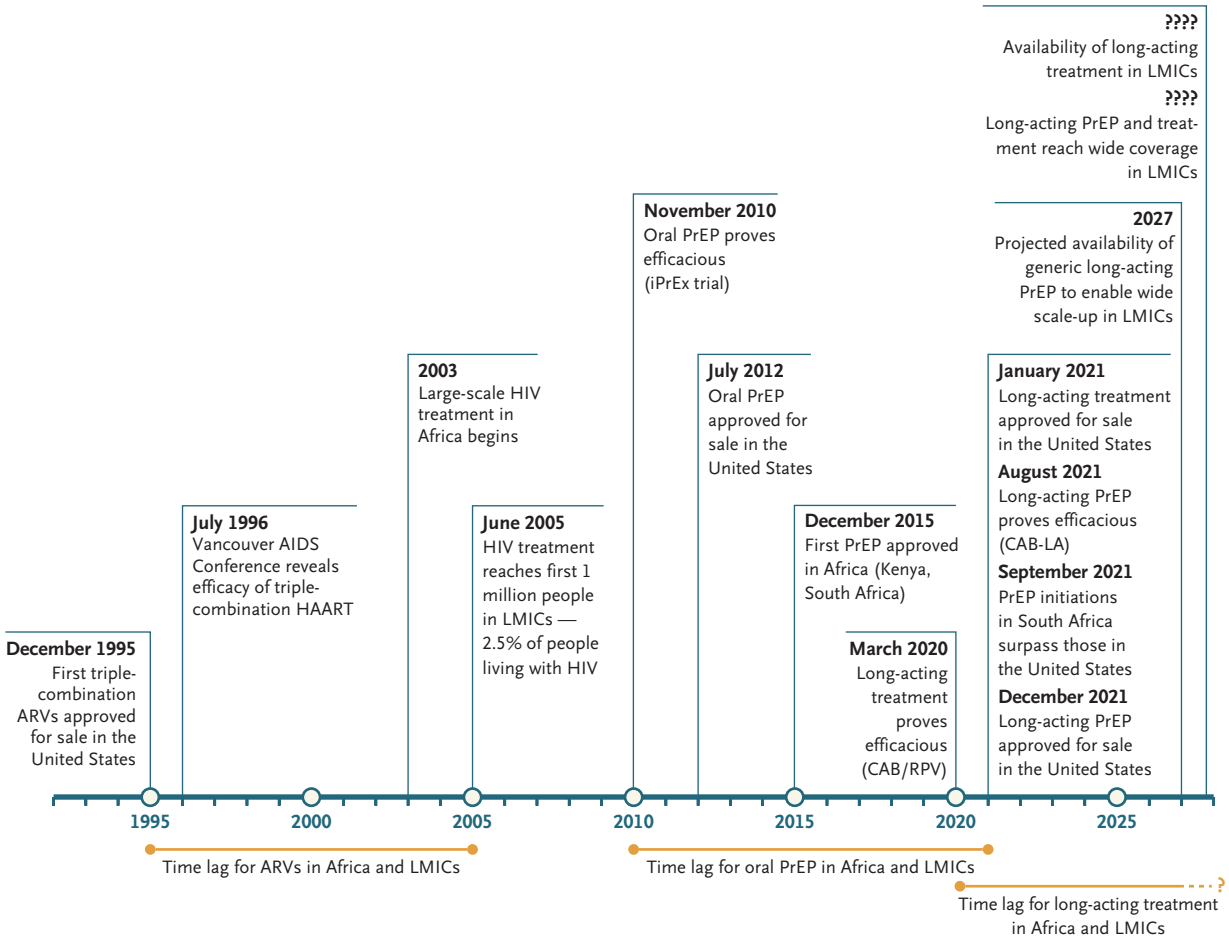

Figure 1. Time Lags in Access to HIV Treatment and Prevention Technology in Africa and LMICs.

ARV denotes antiretroviral, CAB-LA cabotegravir–lenacapavir, CAB/RPV cabotegravir–rilpivirine, HAART highly active antiretroviral therapy, LMICs low- and middle-income countries, and PrEP preexposure prophylaxis.

medicines voluntarily.[33,34] As a result, the price for a WHO-recommended first-line treatment involving tenofovir, lamivudine, and dolutegravir has fallen by more than 99%, to less than $45 per patient per year for eligible countries. This regimen is now used by millions of people worldwide.[35]

This combination of national legal action, voluntary licensing, decentralized production for generic competition, and financing has achieved treatment coverage levels that many observers thought were impossible. But the process continues to be too slow, too restricted to AIDS and a few other diseases, and too linear in that it doesn't start until originator companies decide to license their products to generic-drug producers. When governments of countries excluded from voluntary licenses try to use their rights under international law to access affordable generics, governments of high-income countries often pressure them not to do so.[36,37] If the AIDS pandemic is to end, all players must work to make new technologies available at the same time in countries with the highest HIV rates as they are in countries with the highest gross domestic products.

FASTER, WIDER LICENSING AND DECENTRALIZED PRODUCTION

Studies have shown that both generic cabotegravir and generic lenacapavir could be produced for $40 or less per person per year. This cost

would make them about as affordable as current oral PrEP and treatment products and cost-effective for LMICs.[38] Specifically, it's estimated that lenacapavir could be introduced at a price of less than $100, which could drop to $35 to $40 as volumes grew.[39] The cost of raw materials for cabotegravir has been estimated to be $30 to $40 at introduction and $14 to $18 once the number of users reaches 800,000 per year, plus a margin for the up-front investment in production equipment, unless this cost is supported by global health funding agencies.[40] But the prices charged by originator companies are far higher — $25,000 to $45,000 per patient per year in high-income settings and a lowest price for cabotegravir of $180 per patient per year in selected lower-income countries. As experience with previous HIV medications has shown, prices fall by orders of magnitude when generics are introduced.[41]

Long-acting medications may be revolutionary, but for an actual revolution to happen they need to be licensed in a way that recognizes that the Global South is as important as the Global North. ViiV granted licenses for generic production of cabotegravir to the U.N.-backed Medicines Patent Pool in July 2022, nearly 2 years after clinical trials proved its efficacy for treatment and 7 months after it was approved for prevention in the United States. Since licensing is only the first step toward generic production, there will probably be no generics on the market until 2027.[42,43] Gilead licensed lenacapavir before receiving regulatory approval for its use as PrEP and a few months after the PURPOSE 1 trial was completed, but that was still more than 2 years after it was proven effective for treatment.[23]

We believe that manufacturers can and should license these products as soon as they are deemed efficacious, if not before. Access planning should start well before the end of a trial. Licensing simply grants rights for a company or agency to use a technology or product without infringing on intellectual property (IP). It is the beginning of a time-consuming process of technology transfer, building production lines, training staff, and other actions. There is no reason to wait for marketing approval in wealthy countries before beginning the process by licensing to generics producers in the Global South. The National Institutes of Health, for example, has licensed key early-stage medicines, vaccines, and diagnostics so that IP would not be a barrier if products proved efficacious.[44] Regulatory approval is still required regardless of what manufacturer is involved. But just as originator companies prepare for production long before a medicine is approved, generics manufacturers require adequate lead time to avoid years-long delays.

Furthermore, now that antiretroviral agents have proven effective for treatment and prevention, we believe that licenses granting permission to produce a medicine should not limit how the medications can be used. A harmful precedent was set when ViiV licensed cabotegravir only for prevention: making the drug to prevent infection is no different from making it to prevent illness and death.

Licensing should also be widened. Many middle-income countries in Asia, Latin America, the Caribbean, and Eastern Europe are excluded from current licensing agreements, yet the majority of new HIV infections are occurring in middle-income countries, many of which have stark internal inequalities and health systems that are struggling to afford medicines for their populations.[27] Particularly for prevention, we have seen that health systems cannot afford to pay the prices set by originator companies.

Finally, pharmaceutical production should be diversified. In particular, long-acting medications need to be produced in Africa, which has by far the greatest need. Such a shift will require investment in capacity and commitments by governments and global health financing agencies to purchase from these producers, whose products may not be the least expensive at the start but could become less expensive with support.

Coverage is a key component of impact, and it is vital that governments and donors act together to purchase these products at scale. If the volumes purchased are small, then prices will stay high, impact will remain low, and a sustainable, affordable market for multiple manufacturers will not come to fruition. Coordinated work by UNAIDS; the Global Fund to Fight AIDS, Tuberculosis, and Malaria; PEPFAR; Unitaid; the WHO; and AVAC is building momentum, but more is needed.[45]

PRIORITIZING LONG-ACTING TREATMENT FOR LMICS

Meanwhile, long-acting treatment options for the 30 million people in LMICs receiving treatment for

HIV, and especially the nearly 10 million people with HIV who lack access, must become a priority for the international community.[27] The opportunity to move from a pill every day to an injection every few months could be as transformative for people living with HIV as it is for those seeking to avoid infection. Many people living with HIV say they want long-acting options.[46-49]

Long-acting treatment could also prove more sustainable in the long term for national AIDS programs, if structured well. The long-acting combination of cabotegravir and rilpivirine has been in use for 3 to 4 years in the United States, Canada, and the European Union,[50] and lenacapavir is approved as a treatment, in combination with oral therapy, for people with extensive drug resistance. But these medications have not been rolled out in the Global South. High cost and limited supply are important factors. Though there are operational concerns, such as the need for cold-chain storage and frequent clinic visits and the potential for resistance, that may make cabotegravir–rilpivirine less than ideal for LMICs, recent studies suggest that these challenges may be navigable.[31,46]

Better options should also be studied — some leading researchers and clinicians, for example, believe that a cabotegravir–lenacapavir combination could prove more effective as treatment in the Global South.[9] A regimen could combine cabotegravir every 2 months and lenacapavir every 6 months (with promising longer-acting cabotegravir formulations in development that may even allow more synchronous dosing).[24] But ViiV and Gilead compete for markets in the Global North and are not yet cooperating with researchers to robustly explore this possibility. We believe that global health agencies and funders should support researchers in the Global South now to conduct the needed trials and then continue backing them to innovate on this front in the years ahead.

GAME CHANGERS, NOT SILVER BULLETS

There is still no cure and no preventive vaccine for HIV. But long-acting ARVs are the closest thing to a vaccine that the world has today, and they could support long and healthy lives for people living with HIV. Perhaps most important, they could be a tool for putting the lives of people living with or at risk for HIV at the center of the AIDS response. Whether for adolescent girls in Nairobi or men who have sex with men in Manila, for people who inject drugs in Kiev or sex workers in São Paulo, for the millions of migrants on the move worldwide or people facing precarious employment or housing, the option of receiving HIV treatment or preventive interventions just a few times a year could be game changing.

It's essential to remember that inequality in access to technology is just one of the inequalities driving the AIDS pandemic, so continued work toward securing human rights, building equitable health systems, and supporting communities must also be prioritized. There are no silver bullets. But the HIV/AIDS community now has an opportunity to break the long-standing pattern of failing to get HIV technologies to the people who need them most, to stop playing catch-up, stop accepting that innovations must reach people in the Global South years late, and use long-acting medicines to help end the pandemic.

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Income inequality and pandemics: insights from HIV/AIDS and COVID-19—a multicountry observational study

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ABSTRACT

Objectives Assess the relationship between income inequality and HIV incidence, AIDS mortality and COVID-19 mortality.

Design Multicountry observational study.

Setting 217 countries for HIV/AIDS analysis, 151 countries for COVID-19 analysis.

Participants Used three samples of national-level data: a sample of all countries with available data (global sample), a subsample of African countries (African sample) and a subsample excluding African countries (excluding African sample).

Main outcome measures HIV incidence rate per 1000 people, AIDS mortality rate per 100 000 people and COVID-19 excess mortality rate per 100 000 people. The Gini index of income inequality was the primary explanatory variable.

Results A positive and significant relationship exists between the Gini index of income inequality and HIV incidence across all three samples ($p<0.01$), with the effect of income inequality on HIV incidence being higher in the African sample than in the rest of the world. Also, a statistically positive association exists for all samples between income inequality and the AIDS mortality rate, as higher income inequality increases AIDS mortality ($p<0.01$). For COVID-19 excess mortality rate, a positive and statistically significant relationship exists with the Gini index for the entire sample and the excluding African sample ($p<0.05$), but the African sample alone did not deliver significant results ($p<0.1$).

Conclusion COVID-19 excess deaths, HIV incidence and AIDS mortality are significantly associated with income inequality globally—more unequal countries have a higher HIV incidence, AIDS mortality and COVID-19 excess deaths than their more equal counterparts. Income inequality undercuts effective pandemic response. There is an urgent need for concerted efforts to tackle income inequality and to build pandemic preparedness and responses that are adapted and responsive to highly unequal societies, prioritising income inequality among other social determinants of health.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Earlier in the AIDS pandemic, a positive relationship between income inequality and HIV prevalence in sub-Saharan Africa was found.
⇒ The relationship was less clear outside African countries.
⇒ Some single-country studies suggest a link between income inequality and HIV transmission among specific groups.
⇒ Studies primarily from higher income contexts, where data are available, show a positive relationship between income inequality and COVID-19 cases or mortality.

WHAT THIS STUDY ADDS

⇒ Income inequality is globally associated with less effective pandemic response across at least two recent pandemics.
⇒ More unequal countries show higher HIV incidence, AIDS mortality and COVID-19 excess mortality.
⇒ The study highlights that both COVID-19 *excess* mortality and AIDS mortality are associated with income inequality at a global level for the first time, including low and middle-income countries often considered to have poor-quality data.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ There is an urgent need to craft more effective pandemic preparedness and response strategies for highly unequal contexts.
⇒ This study highlights the need for global policy responses to tackle income inequality, which is significantly associated with adverse pandemic outcomes.
⇒ Research at the regional or global level should consider income inequality as an essential variable in explaining and attenuating adverse pandemic outcomes.

INTRODUCTION

Pandemics constitute a significant public health problem, posing threats to the health and well-being of substantial population segments across countries, especially marginalised populations. Estimates suggest over 300 excess COVID-19 deaths per 100 000 people as of July 2023[1] for a pandemic that recorded its first mortality in 2020. The UNAIDS data show that AIDS-related deaths have declined by 52% since 2010. Additionally,

in 2022, there were 1.3 million new HIV infections, the fewest since the 1980s, with the declines especially strong in regions with the highest HIV burdens.[2] Although marginalised populations and countries in the Global South are disproportionately affected, the reality that pandemics do not respect national boundaries calls for collective global action, paying attention to countries with weak infrastructure and vulnerable health systems.[3] They also necessitate significant solidarity, which is still challenging, as found with COVID-19 vaccines with substantial inequalities in vaccination rates, leaving less wealthy countries behind.[4]

Governments and social entities across various sectors need swift and robust responses. Still, these responses often focus heavily on addressing proximate determinants of health, such as individual behaviours. Yet, it is vital to underline the significance of the broader social determinants of health inequalities which influence these behaviours and health outcomes because, as with many pandemics, including the HIV and COVID-19 pandemics, mortality rates in very deprived areas exceeded that in affluent areas.[5–8] These social determinants comprise broader policy environment and socioeconomic and environmental factors that indirectly or directly impact health by moulding individuals' living, schooling, working life, and ageing choices and conditions that are actionable with effective responses.[9] Despite being less immediately apparent compared with proximate determinants, these social determinants exert considerable influence on health outcomes, often shaping the trajectory of pandemics by affecting disease spread and impact within and across communities.[8 10] Therefore, their inclusion in pandemic responses is crucial to tackling the root causes of health inequalities, as any policy to change health behaviours cannot substantially reduce health inequalities without tackling the underlying causes outside the health sector.[11]

Several pathways, often linked to class or power structure (including economic, political, social and cultural) within and between societies, exist on how income inequality generally affects health, health outcomes and health inequalities.[12–15] In the context of pandemics, a likely causal pathway from income inequality to higher rates of pandemic disease within and between countries is evident. Since the 1990s, a large and robust literature comprising several hundred studies links income inequality to health outcomes.[16–21] A systematic review showed that this evidence includes data meeting epidemiological causality criteria.[22] Knowing that pandemics exacerbate income and economic inequalities,[8] this paper highlights three relevant causal pathways from the literature linking income inequality and pandemic infectious diseases. First, inequality can be linked to deprivation among a significant portion of the population in areas from nutrition to education, increasing their vulnerability to infection and disease. In Malawi, for example, higher income inequality was linked to HIV mainly through limited individual choice, higher risk sex and violence,[23] increasing vulnerability among key populations. Second, inequality is linked to social factors limiting effective pandemic response, including lower social cohesion and trust.[22] Third, inequality is linked to political factors undermining health, which makes it harder to coordinate an effective response to HIV and COVID-19,[24] and this weakens the solidarity needed to tackle pandemics.

Increased inequality is hypothesised to be linked to worse pandemic health outcomes, with research highlighting the impact of pandemics on widening inequality[8] and the ways inequality shaped pandemic responses and subjected specific populations to greater risk and lesser protection in certain countries and regions.[25–28] However, studies showing how income inequality, a critical social determinant of health inequalities, is associated with major recent pandemics on a global scale are lacking. For the HIV pandemic, most of these studies concentrate on sub-Saharan Africa,[29] while COVID-19 studies leave out lower income countries[30] because of claims of data quality for COVID-19 deaths. However, reliable modelled data on COVID-19 excess mortality are now available, providing an avenue to extend the analysis to countries that have been previously excluded. Thus, this paper adds to this literature by assessing the relationship between income inequality and health outcomes (HIV/AIDS and COVID-19, the two most devastating recent pandemics) globally and regionally. It seeks to answer the research question of whether income inequality, measured using the Gini index, is significantly associated with HIV incidence or AIDS mortality and COVID-19 excess mortality. It also highlights the need for concerted efforts to address income inequality and its detrimental effects on pandemic outcomes.

METHODS

Study design and data sources

Data used for analysis include AIDS mortality rate per 100 000 people, HIV incidence per 1000 people, COVID-19 excess deaths per 100 000 people, Gini index of income inequality, current health expenditure per capita in US$, World Bank income categories and the UNAIDS regions. The data sources included the World Bank,[31] UNAIDS,[2] the Economist Intelligence Unit[1] and the World Inequality Database,[32] as shown in table 1. For HIV/AIDS analysis, time series data covered 2000–2021, while the COVID-19 analysis covered 2020/2021. Overall, there were 217 countries for the HIV/AIDS analysis and 151 countries for the COVID-19 analysis. However, the actual number of observations for each analysis varies and depends on complete data availability. Because of concerns regarding under-reporting COVID-19 deaths in many countries, especially in Africa and Asia, this paper uses excess mortality caused by COVID-19 as modelled and reported through the Economist Intelligence Unit[1] mainly because of the transparency

Table 1 Descriptive statistics

Variable	Mean	SD	Min	Max	n	Source
AIDS mortality rate per 100 000 people*	44.456	119.167	0.009	1118.747	3784	UNAIDS[2]
HIV incidence per 1000 people*	0.795	2.206	0.001	21.684	3784	UNAIDS[2]
COVID-19 excess deaths per 100 000 people†	73.359	97.365	151.108	655.319	171	The Economist and Solstad[1]
Gini index*	0.573	0.087	0.370	0.781	3434	World Inequality Database[32]
Health expenditure per capita (US$)*	927.486	1649.671	4.000	11 702.000	3542	World Bank[31]

*Period covered is 2000–2021.
†Period covered in 2020/2021. COVID-19 excess deaths refer to an estimate of the deaths that occurred during the COVID-19 pandemic over and above what would be expected in the absence of the pandemic.
max, maximum value; min, minimum value; n, number of observations.

and public availability of the underlying codes used to generate excess mortality due to COVID-19 in each country. Notably, the Economist Intelligence Unit used data from sources including Karlinsky and Kobak's[33] World Mortality Dataset and the Human Mortality Database.[34]

Statistical analysis

Analytically, this paper assesses the relationship between income inequality (where the Gini index ranged from 0, a case of perfect equality, to 1 for perfect inequality) and HIV incidence, AIDS mortality and COVID-19 excess mortality using the linear regression model.[35] The general model can be written as follows:

$$H_{it} = \alpha + \beta_1 IN_{it} + \beta_2 X_{it} + \varepsilon_{it}$$

where H corresponds to the primary health outcomes (ie, HIV incidence per 1000 people, AIDS mortality rate per 100 000 people or COVID-19 excess mortality per 100 000 people) in country i in year t. IN_{it} is the Gini index of income inequality and X is the vector of control variables.

For the HIV analysis, H_{it} is replaced with lnH_{it+1}, the natural logarithm, because this was non-negative, where $t+1$ signifies that values of the following year were used because it is hypothesised that current income inequality is associated with future health outcomes. β_1 is the coefficient associated with our primary indicator of income inequality (Gini index) in country i in year t. β_2 is a vector of coefficients of several alternative factors in country i in year t that impact health outcomes: the country's income level or category, per capita health expenditure and UNAIDS region. Although economists would argue against allowing income to determine people's access to health services, it is the case that income level, at the country level and between countries, is a critical determinant of health outcomes and differences in health outcomes between countries.[36] Higher income typically provides better access to resources needed for a healthier lifestyle, including quality food, housing, education and healthcare services. It can also mitigate the impact of stressors that can negatively impact health. By controlling for income levels using the World Bank income categories of countries, we can separate the effect of income (wealth) from that of inequality since they are inter-related but distinct factors influencing health outcomes. Health expenditure per capita directly measures the resources allocated for health in a country at an individual level. It captures aspects related to the availability and quality of health services, which are crucial factors in health outcomes. Health expenditure per capita may be associated with inequality and health outcomes,[37] so including it as a covariate prevents omitted variable bias and provides a more accurate estimate of the effect of inequality on health.

The HIV/AIDS models included regional and year fixed effects to control the average differences across regions and years in unobservable predictors.[38] The COVID-19 model contains only regional fixed effects as the complete data included information on COVID-19 deaths between 2020 and 2021 because the latest available data on per capita health expenditure were in 2021,[31] and many countries did not record significant COVID-19 mortality until mid-2020. Africa is most severely affected by HIV and AIDS,[2 39] and the reportedly low COVID-19 mortality in Africa was described as a paradox.[40] So, even though modelled COVID-19 excess mortality data were used[1] in the case of COVID-19 estimations, to avoid skewed regression estimates, three separate regression models were estimated for each dependent variable—a global sample, an Africa-only sample and a sample excluding Africa.

All analyses were done in Stata V.17,[41] and the paper follows the Strengthening the Reporting of Observational Studies in Epidemiology cross-sectional reporting guidelines.[42]

Patient and public involvement

This study analyses secondary data sets and does not directly involve patients or the public. Although patients were not involved, the findings from the

Table 2 Income inequality and HIV/AIDS outcomes

	HIV incidence model			AIDS mortality model		
	Global sample	Excluding Africa	Only Africa	Global sample	Excluding Africa	Only Africa
Gini index	6.31*** (0.384)	4.70*** (0.464)	8.48*** (0.715)	7.62*** (0.462)	8.33*** (0.604)	6.13*** (0.759)
Covariates	Yes	Yes	Yes	Yes	Yes	Yes
UNAIDS regions and year fixed effects	Yes	Yes	Yes	Yes	Yes	Yes
Observations (n)	3183	2211	972	3283	2211	972
HIV incidence (t+1) and AIDS mortality (t+1) response to 25% reduction in Gini index	0.14*** [0.007]	0.29*** [0.005]	2.11*** [0.048]	6.58*** [0.341]	17.39*** [0.174]	11.45*** [3.191]

Dependent variables were the natural logarithm of HIV incidence rate per 1000 people at time t+1 and the natural logarithm of AIDS mortality rate per 100 000 at time t+1.
Analytical SEs in parenthesis (); bootstrapped SEs using 500 replications in square brackets []; ***p<0.01.
Covariates include current health expenditure per capita and World Bank income categories (low, lower middle, upper middle and upper income countries); UNAIDS regions included East and Southern Africa, West and Central Africa, Asia and Pacific, Eastern Europe and Central Asia, Latin America and the Caribbean, North Africa and the Middle East, West and Central Europe and North America.

paper have been presented to a broader audience from many countries.

RESULTS

Basic and descriptive statistics

Over the period covered in the analysis, the descriptive statistics in table 1 show that the average annual per capita current health expenditure was slightly less than $1000. Income inequality measured by the Gini index ranged from 0.37 (in Hungary, the least unequal case) to 0.78 (in Botswana and Namibia, the most unequal case), with an average Gini index estimated at 0.57. The average AIDS mortality rate was 44.46 deaths per 1 000 000 people, while the average HIV incidence rate was about 0.80 per 1000 people. The average COVID-19 excess mortality was estimated at 73.36 per 100 000 people. The negative value for minimum COVID-19 excess mortality (−151.11 in Seychelles) occurs because the death rate during COVID-19 was lower than expected without the pandemic.

Income inequality and HIV/AIDS outcomes

The regression results in table 2 are for two broad models. The first segment is for the HIV incidence model, while the second is for the AIDS mortality model. The three separate analyses for each model included the global sample, excluding the African countries and only African countries. The results show a positive and significant relationship between income inequality and the natural logarithm of HIV incidence per 1000 people in the following year across all three samples (p<0.01). As predicted, higher levels of income inequality, measured using the Gini index, are significantly associated with an increased incidence rate of HIV per 1000 people in the following year (p<0.01). Loosely speaking, overall and in Africa, higher levels of income inequality in a year are associated with higher HIV incidence in the next year, all things being equal. Specifically, the effect of income inequality on HIV incidence was higher in the African subsample than in the rest of the world, probably due to higher HIV rates in the sub-Saharan Africa region.

Applying Duan's smearing estimator[43] to the results in table 2, a 25 percentage point reduction in the Gini index corresponds to the HIV incidence rate for the next year, significantly dropping by 0.14 per 1000 people for the global sample (p<0.01). For the African subsample, this will significantly reduce the HIV incidence rate by 2.11 per 1000 people in the next year (p<0.01). Similarly, for AIDS mortality, a 25% reduction in the Gini index is associated with a significant decline in AIDS mortality rate by 6.58 (p<0.01), 11.45 (p<0.01) and 17.39 (p<0.01) per 100 000 people in the next year for the global sample, the African sample and the sample excluding Africa, respectively.

Figure 1 shows the positive relationship between income inequality and the natural logarithm of HIV incidence per 1000 people, with a steeper slope for the African subsample.

Similar patterns emerge when examining the relationship between income inequality and the AIDS mortality rate per 100 000 people. A positive association between income inequality, as measured by the Gini index, and the natural logarithm of AIDS deaths per 100 000 people (figure 2) exists as higher levels of income inequality in a year are linked to an increase in next year's AIDS mortality rate (p<0.01). Unlike the results for HIV incidence, the effect size was not highest in the African subsample even though it is statistically significant at the 1% significance level. Reducing income inequality (ie, the Gini index by 25%) is significantly associated with a reduction in the AIDS mortality rate by 6.58 (p<0.01) and 11.45 (p<0.01) deaths per 100 000 people in the following year for the entire sample and the African subsample, respectively.

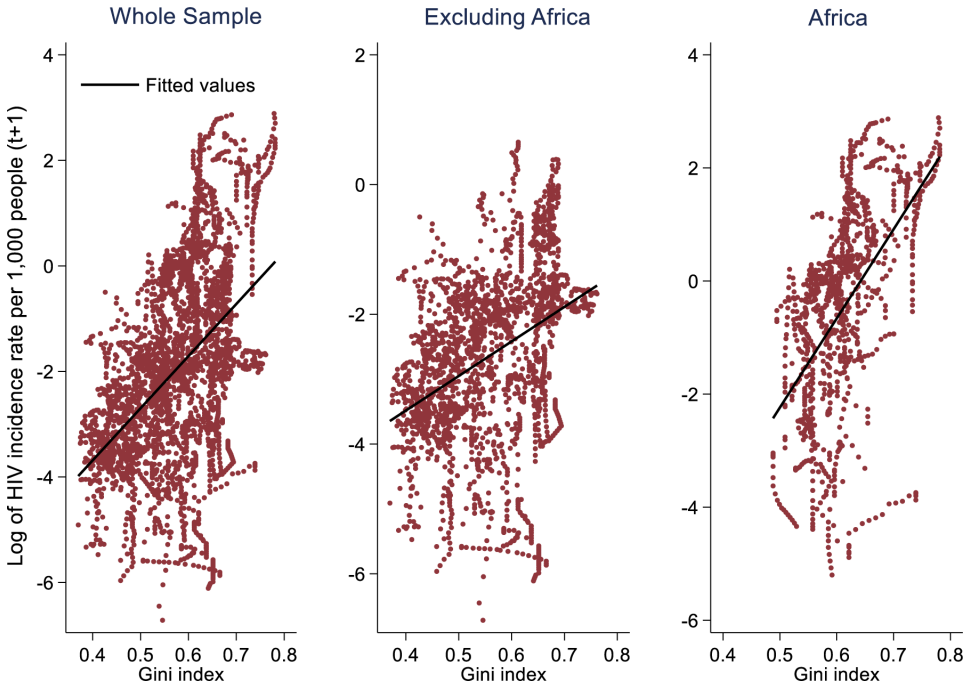

Figure 1 Income inequality and HIV incidence, 2020–2021.

Income inequality and COVID-19

The relationship between income inequality (using the Gini index) and COVID-19 excess mortality rate per 100 000 people, as shown in figure 3, was not initially positive for the entire sample. However, a positive relationship emerged using the regression model presented in table 3.

After controlling health expenditure per capita, regions and income groups, a positive and statistically significant relationship between the Gini index and COVID-19 excess mortality rate per 100 000 people was found for the entire sample and the subsample excluding Africa ($p<0.05$), as shown in table 3. This result means that more unequal countries tend to report more COVID-19 excess mortality than their more equal counterparts, all other things being equal. The results for the African subsample were not statistically significant ($p>0.1$), even though a positive relationship was found. This may be partly due to a smaller sample of countries[44] and the near homogeneity in the distribution of COVID-19 excess mortality

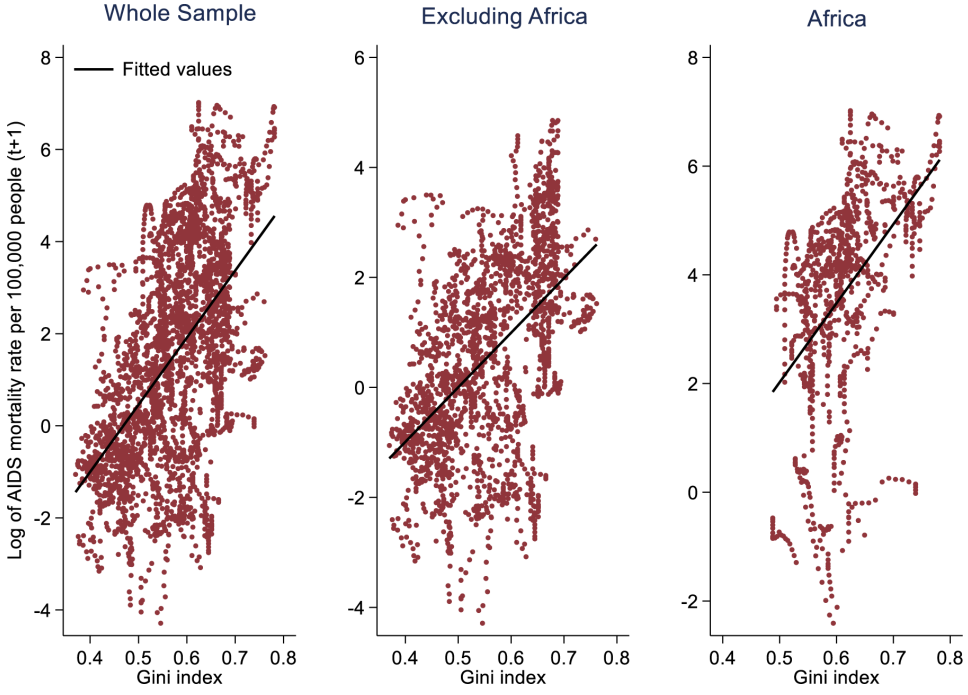

Figure 2 Income inequality and AIDS mortality, 2000–2021.

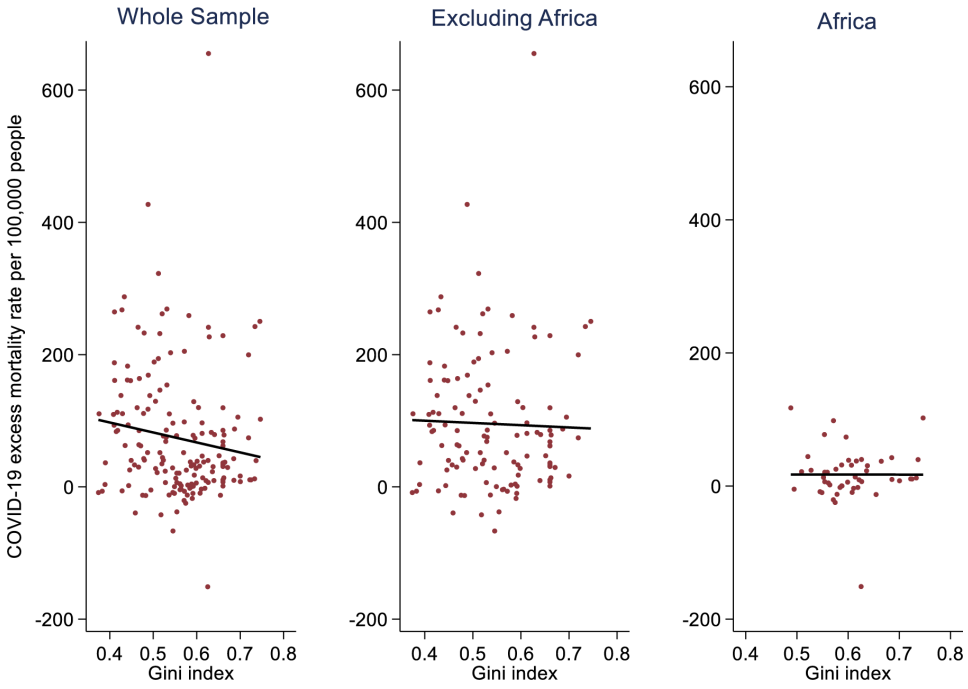

Figure 3 Income inequality and COVID-19 excess mortality, 2020/2021.

for the African subsample in figure 3. A sensitivity analysis was conducted for Africa's subsample by excluding Seychelles' data point with −151.1 COVID-19 excess mortality, and the results remain remarkably similar, still not statistically significant.

DISCUSSION

This paper highlights the significant relationship between income inequality measured using the Gini index and key pandemic variables, including HIV incidence, AIDS mortality and COVID-19 excess mortality. It emerged that unequal societies are burdened more by HIV/AIDS and COVID-19 excess deaths than their more equal counterparts, with the results remaining similar for Africa and the rest of the world. These findings show that income inequality is significantly and adversely associated with pandemic outcomes. The robust association between higher levels of inequality and critical indicators such as HIV incidence per 1000 people, AIDS mortality per 100 000 people and COVID-19 excess mortality suggests income inequality is a factor that may limit effective pandemic response because income inequality creates conditions that perpetuate and exacerbate pandemics, leaving marginalised populations more vulnerable to the devastating consequences of pandemics.

Table 3 Income inequality and COVID-19 excess mortality

	Global sample	Excluding Africa	Only Africa
Gini index	246.30** (110.30)	331.10** (154.00)	80.71 (63.14)
Covariates	Yes	Yes	Yes
UNAIDS regions fixed effects	Yes	Yes	Yes
Observations (n)	171	123	48
COVID-19 excess mortality response to 25% reduction in Gini index	−35.27 [23.11]	−11.55 [12.02]	−47.43 [33.55]

Dependent variable is COVID-19 excess mortality rate per 100 000 people.
Analytical SEs in parenthesis (); bootstrapped SEs using 500 replications in square brackets []; **p<0.05.
Covariates include current health expenditure per capita and World Bank income categories (low, lower middle, upper middle and upper income countries); UNAIDS regions included East and Southern Africa, West and Central Africa, Asia and Pacific, Eastern Europe and Central Asia, Latin America and the Caribbean, North Africa and the Middle East, West and Central Europe and North America.

Strengths and weaknesses of this study

A major strength of the analyses in this paper is its multicountry nature, with data from all the UNAIDS regions with available data. Also, the paper uses a standardised measure of income inequality, the Gini index, to assess the relationship between income inequality and pandemic health outcomes. The paper was not limited to one pandemic outcome but considered three outcomes. As a limitation, this paper focused solely on income inequality and its relationship with pandemic outcomes. It did not delve into other essential dimensions of inequality, such as disparities based on gender, race, sexuality and other key population characteristics, which often intersect with income inequality, exacerbating the challenges of marginalised communities and increasing the burden of health disparities.[45 46] Another limitation of the paper is that it did not assess causality, as the results imply association.

But the significance of the relationships in many cases signifies the strength of the association between income inequality and pandemic health outcomes. In turn, the results represent an initial step for future investigations that delve into the robustness of the relationship between inequality and pandemic outcomes.

Although this study was about global phenomena like pandemics, requiring comparable information and data from diverse countries and societies, data availability and quality posed a significant challenge. It is important to note that this analysis cannot discount how disparities in data collection methods, reporting accuracy, and scope across different regions and periods could impact the reliability and comparability of results. For example, the COVID-19 analysis relied on excess mortality data based on epidemiological modelling because of the paucity of COVID-19 mortality data in Africa and Asia, where reported COVID-19 mortality was scanty and not comprehensive. While the HIV/AIDS analyses were based on time series data, the COVID-19 analysis uses almost cross-sectional data, limiting the analysis power. It is undisputed that numerous factors (at the microlevel, mesolevel and macrolevel) other than those controlled in this paper's analyses influence pandemic outcomes. For example, health system capacities, country-level policy responses and heterogeneities, governance quality, cultural behaviours and pre-existing health conditions play substantial roles in determining pandemic responses and outcomes. These variables may interact with income inequality in complex ways, adding complexity to the analysis. These notwithstanding, this paper serves as a starting point to take this research forward to understand how complex factors interact and the pathways through which income inequalities affect pandemic outcomes.

Comparison with other studies

This study breaks new ground on several fronts—presenting truly global associations between income inequality and multiple pandemic outcomes, using updated AIDS mortality and COVID-19 excess mortality data to enable wide coverage of low and middle-income countries, and doing so with data accounting for major shifts in recent decades in the AIDS response.

Most studies on HIV from earlier in the pandemic's history did not focus on inequality per se, but rather on poverty and wealth. This focus was particularly driven by surprising evidence from some population surveys suggesting that HIV infection was not consistently higher among the poor; in fact, it was often more prevalent among wealthier individuals[44 47 48] and is higher in Africa's wealthiest countries.[49] Some smaller studies using data from sub-Saharan Africa[29 50–52] show a significant relationship between income inequality and HIV prevalence, and occasionally transmission. Income inequality, for example, has been linked to the spread of HIV among women in Malawi at the neighbourhood and district levels[23] and persons who inject drugs in Vietnam at the community level.[53] In a smaller area setting, New York City in the USA, the relationship between income inequality and adverse HIV health outcomes has been reported.[45] In contrast, a study in Asia (one of the only analyses outside Africa) found no association between income and HIV prevalence.[48] Most use HIV prevalence, a less meaningful measure we would argue than HIV incidence. Meanwhile, there is a paucity of literature on the income inequality and AIDS mortality nexus. There is evidence of higher risk of mortality among persons of low socioeconomic status in South Africa and the USA,[54 55] but to the best of our knowledge, there is no literature that discusses the relationship between income inequality and AIDS mortality, particularly at the global level. In addition, studies have not considered the most recent decade of data, during a time a significant change in the AIDS pandemic. Our paper uses the most recent data to bridge these gaps. This paper demonstrates a statistically significant relationship between inequality and both new HIV infections and AIDS deaths through to the present time and does so beyond a country or region to present evidence at a global level.

While the COVID-19 pandemic could exacerbate income and economic inequality,[56] a significant positive relationship between income inequality and COVID-19 cases or mortality has also been reported.[30 46 57 58] Most studies have focused on a smaller subset of countries including Organisation for Economic Co-operation and Development member countries where data are robust. These findings largely align those reported in this paper for COVID-19 excess mortality. Notably, there is a dearth of studies using COVID-19 excess mortality, considered to reflect better the impact of COVID-19 deaths over and above the expected death rates within countries.[59] In particular, many low and middle-income countries have been excluded from previous studies assessing the association between COVID-19 health outcomes and income inequality mainly because of data paucity. Although the relationship between income inequality and COVID-19 excess mortality was not significant for Africa, the overall similarity of this paper's findings regarding the role of income inequality in aggravating the effects of the COVID-19 pandemic is critical to note.

Implications of findings

The correlation between income inequality and other social variables demonstrates the ways that inequality undermines pandemic response. More unequal countries are likely to have higher HIV and COVID-19 rates both because of unequal access to essential health services and other relevant services outside the health sector, including education and shelter.[23] Beyond reporting the association between income inequality and pandemic outcomes, which is crucial, it is imperative to understand the mechanisms more deeply through which income inequality influences health outcomes amidst a pandemic. For the AIDS pandemic, the means of influence likely operate on multiple levels. At a social and political level, widening income inequality may foster greater

othering in pandemic response both within and between countries, which undermines universal responses and the deprioritisation of services, disproportionately serving a disfavoured portion of the population, as has been shown in some contexts.[60] As those with good healthcare access, living in well-off communities, get pre-exposure prophylaxis through private means, for instance, HIV rates for such communities may fall rapidly. At the same time, the political priority for reaching the rest diminishes. At an individual level, income levels and inequality may reduce choices for preventing HIV transmission—for example, by pushing more people into higher HIV risk or transactional sex. In other words, the relationship between income inequality and pandemics means that despite the widespread availability of HIV testing, prevention and treatment options, societies with greater inequality have struggled to use these resources to reduce rates of HIV infection and AIDS-related deaths effectively.

Meanwhile, the overall health of people, which has been concretely tied to various social determinants,[23] likely makes people in unequal societies more vulnerable to HIV mortality and less able to access good HIV care and cutting edge medicines.[61] Similar mechanisms likely apply to the COVID-19 pandemic. The COVID-19 pandemic presented a unique challenge as it led to many drastic measures undertaken by governments. Wealthier countries with more resources could provide relief and better policy responses than their less affluent counterparts.[3] The relationship between COVID-19 excess mortality and income inequality likely means that more unequal countries were challenged to ensure access to preventive measures, testing and treatment, including vaccination,[62] leading to elevated COVID-19 excess mortality rates in these countries relative to less unequal countries. In the subsample of African countries, the insignificant relationship between income inequality and COVID-19 excess deaths may not be surprising due to the smaller number of observations and relatively low variability in the Gini index of income inequality compared with the subsample that excludes African countries. This further supports inequality's role in exacerbating COVID-19 excess mortality, especially in a sample of unequal countries. Indeed, the data seem to suggest that economic inequality is a more significant driving force than net wealth.

Based on the findings of this study, to effectively respond to future health crises, it is crucial to prioritise policies and interventions that aim to reduce income inequality. But pandemics will not wait for changes in economic distribution. As such, it is crucial to consider how pandemic responses in highly unequal societies could act to counter, rather than reinforce, those inequalities. Although the results from this study show that income inequality is bad for effective pandemic responses using HIV/AIDS and COVID-19 pandemics, as noted in the limitations of this paper, focusing on income inequalities is just one aspect of broader social inequality. Future research should incorporate additional dimensions of inequality to fully understand the complex dynamics of pandemics and their societal impacts. This comprehensive approach will help develop more effective and equitable pandemic responses, promote social justice and improve health outcomes across diverse segments of society. By taking a holistic approach, we can build a more resilient and equitable society better equipped to mitigate the devastating effects of future pandemics.

CONCLUSION

Income inequality significantly correlates with HIV incidence, AIDS mortality rate and COVID-19 excess mortality rate using a cross-country analysis involving the UNAIDS regions. The findings reported in this paper underscore the urgent need for concerted efforts to tackle income inequality and its detrimental effects on pandemic outcomes and to craft pandemic responses that work more effectively in highly unequal contexts—countering rather than reinforcing inequality. We argue that this sits at the heart of the global call to leave no population behind in attaining development goals.

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Contributors JE-OA, CB, SC and MK conceived the study. JE-OA, SC and CB were primarily responsible for statistical analysis supported by MK. JE-OA, CB, SC and MK prepared the manuscript. All authors approved the final version of the manuscript. JE-OA and CB are the study guarantors.

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Intersectional forces of urban inequality and the global HIV pandemic: a retrospective analysis

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ABSTRACT

To determine how the intersection of increased urban growth and poverty has impacted HIV incidence and prevalence, given growing HIV inequalities globally. Retrospective analysis using combined data from five publicly available, population-level datasets to determine city- and within-urban countrywide estimates of 95-95-95 treatment targets, prevalence and incidence rates from 2015 to 2019. For city-level estimates, we analysed combined data from: Fast-Track City (FTC), SINAN from Brazil and UNAIDS Naomi-Spectrum. Countrywide estimates of HIV prevalence in the urban slum versus non-slum since 2012 were compiled from Population-Based HIV Impact Assessment (PHIA) surveys in 12 countries and Demographic Health Surveys (DHS) in 28 countries. HIV prevalence is generally higher among the urban slum, compared to their non-slum counterparts, thus resulting in national HIV estimates masking nuances in HIV inequalities between the urban slum and non-slum. Specifically, national and city-level HIV estimates mask inequalities within and between cities, with secondary cities often having higher HIV prevalence and incidence rates than capital cities and large urban areas. The urban divide between slum and non-slum populations is a contributor to HIV inequality, often with poorer outcomes in smaller cities than their larger counterparts. Interventions tailored to cities, and particularly those considering local nuances in subpopulations (eg, different genders, ages, roles), are necessary to reduce HIV inequality. Focused HIV programming accounting for structural drivers of inequalities between urban slum and non-slum populations such as inequalities in wealth, education, employment and housing are crucial to closing gaps driving HIV inequalities globally.

SUMMARY BOX

- ⇒ There is a global rise in growth among urban slum populations in the world, and cities remain the epicentre of the global HIV pandemic.
- ⇒ Subnational variation in HIV burden has been well documented with some cities faring better than others.
- ⇒ There is a demonstrated link between structural inequalities such as inequalities in education, housing and income, and inequalities in health outcomes.
- ⇒ We found that HIV prevalence is higher among the urban slum populations compared with urban non-slum counterparts, which ultimately results in national estimates of HIV masking nuances in HIV inequalities between the two populations
- ⇒ We found that large secondary cities (1–5 million population) often have equal or greater HIV incidence and prevalence compared with major cities.
- ⇒ These data provide a framework for focused HIV programming crucial to closing gaps driving HIV inequalities globally.

INTRODUCTION

Approximately 56% of the world's population currently lives in urban areas, and that proportion is expected to increase to 68% by 2050.[1] Ninety per cent of projected urban growth will be in African and Asian cities alone, with a disproportionate increase among the poorest.[1] The SARS-CoV-2 pandemic has compounded this trajectory by increasing the number of people who are newly poor within a short timeframe.[2 3] Cities also remain the centre of the HIV pandemic globally, with a single city accounting for up to 30% of a country's HIV burden in some cases.[4] This pattern has emerged despite that the many advantages cities have in offering cost-effective HIV service infrastructure and resources.[5] Understanding the intersectional forces of rising urban inequality with the global HIV pandemic is crucial to reaching the 95-95-95 targets and ending the global HIV epidemic by 2030, as set forth by the latest UNAIDS Global AIDS Strategy 2021–2026.[6]

The conceptual link between HIV and intersecting facets of inequality in urban contexts is longstanding; however, it was

largely studied in high-income countries and before the era of treatment-as-prevention. Early studies in the 1980s and 1990s identified a link between poverty and HIV in urban concentrated epidemics in high-income countries,[7 8] and subsequent studies in the early 2000s across generalised epidemics in African countries showed the opposite—that HIV infection is higher among wealthier individuals.[9–11] Recent findings have indicated that the association between wealth and HIV has weakened over time and that urbanicity is a confounding factor.[12] Urban issues and challenges are particularly important to consider, given the rapid expansion of cities and continued evolution of urban population dynamics.[13] For example, in the last three decades, the number of megacities has more than tripled. The determinants of socioeconomic inequalities in the global HIV pandemic, particularly in low- and middle-income countries (LMICs), are poorly understood; however, previous studies in Sub-Saharan Africa have found that inequality is often a more important risk factor for HIV prevalence than actual wealth at the aggregate level.[14] The intersectional forces of economic inequality on other marginalised identities and social positions globally can have a compounding effect.[15] In 2021, key populations such as men who have sex with men, people who inject drugs, transgender people, and sex workers and their clients accounted for 70% of HIV infections globally.[16]

Geographic factors, such as urban residence, also factor prominently. Prior research using the data from the Demographic Health Survey (DHS) and AIDS Indicator Surveys to measure inequalities in HIV prevalence in 24 countries in Sub-Saharan Africa suggested that HIV is more prevalent among relatively wealthier countries and individuals within the region.[17] However, within urban areas in countries such as Uganda, Kenya, Zimbabwe and Swaziland, HIV was more prevalent among the poor.

This study sets out to explore the intersectional HIV inequalities in contemporary cities based on a common absolute definition of poverty and deprivation, recognising that cities are highly heterogeneous and disease and social dynamics in giant global megacities are likely quite different from those in small regional hubs. We used data from publicly available, population-level datasets to examine HIV incidence and prevalence variability at the intersection of urbanity and poverty (thus referred to as urban slum and non-slum) and to answer the following research questions: What is the variation in HIV incidence and prevalence across large and smaller urban areas globally? What is the variation in HIV incidence and prevalence within urban areas between urban slum and non-slum populations?

METHODS

We performed a retrospective analysis using data from city-level and individual-level public datasets to determine city- and within-urban estimates of prevalence and incidence rates (from 2015 to 2019). For city-level estimates, we analysed combined data for 222 cities across UNAIDS-defined regions where we had data for >10 cities. Resulting regions included: Eastern and Southern Africa (98 cities); West and Central Africa (83 cities); Latin America and the Caribbean (18 cities); and Western and Central Europe and North America (23 cities). We did a search of public domain city databases and identified three sources: Fast-Track City (FTC) database with incidence and prevalence directly reported by city authorities (primarily surveillance data), SINAN with directly reported prevalence from Brazilian city authorities and UNAIDS Naomi-Spectrum subnational modelled estimates in Africa. Prevalence and incidence data were extracted for all cities that reported it, and all cities in the regions that had >10 cities were included in the analysis. The Naomi-Spectrum estimates are produced by administrative units, so we used administrative unit estimates where they were geographically aligned with city boundaries. UNAIDS Global AIDS Monitoring and the AHEAD database from the USA were also considered but not included because cities either had a more recent direct estimate from FTC or SINAN or a more recent modelled estimate in Naomi-Spectrum. Countrywide estimates of HIV prevalence in urban slum versus non-slum populations (since 2012) were compiled from Population-Based HIV Impact Assessment (PHIA) surveys in 12 countries and DHS in 28 countries. PHIA and DHS follow similar robust multistage sampling designs, use of standardised questionnaires and protocols, biometric testing for HIV, and standard data management and cleaning protocols.[18 19]

Statistical methods

City prevalence and incidence indicators were spatially joined to city boundaries from the Functional Urban Areas dataset by the European Commission and mapped.[20] The Naomi-Spectrum estimates modelled by administrative units were matched to Functional Urban Area boundaries in a Geographic Information System using visual inspection. The Functional Urban Areas dataset included population estimates for 2015, which were used to classify cities by population size based on Dijkstra *et al*[21] and whether it was a capital city, as follows: capital/extra-large (>5 million); large (1 million–5 million); medium (250 000–1 million); and small (<250 000). We refer to capital cities and cities with more than 5 million people as 'major cities,' and all other cities as 'secondary cities.' Prevalence and incidence rates were compared across city types within regions (where we had data for at least 50 cities) using the t-test statistic, and p values less than 0.1 were interpreted as indicating a potential difference.

To understand within-city disparities, HIV prevalence estimates were calculated from PHIA and DHS survey data sets by urban 'slum' and urban non-'slum' households. Incidence data were not available in a

majority of these surveys and thus are not reported in this analysis.

'Slum' households are defined by UN-Habitat as lacking improved water, improved sanitation, durable floor or sufficient space.[22] Although 'slum' households are not necessarily located in areas with informal settlement, this asset-based definition is a strong proxy of the urban poorest and populations living in the most deprived areas of cities. The 'slum' household definition is an absolute measure of poverty that is measured with the same assets consistently across countries and over time.

Mean prevalence estimates were calculated by 'slum'/non-'slum' household type applying sampling weights specific to individuals interviewed about HIV in each survey and plotted with 95% CIs by country and region accounting for clustering. Statistical analysis was conducted using SAS Enterprise Guide,[23] STATA 17[24] and Python.[25] Spatial data management, analysis and mapping were performed in ArcGIS 10.8.[26]

RESULTS

The maps in figure 1 underscore the importance of disaggregating HIV indicators beyond national to the city scale where there is large variability in prevalence and incidence rates. In Tanzania, for example, the Naomi-Spectrum model estimated a prevalence of 0.8% and incidence of 25 cases per 100 000 people in Zanzibar City (population 700 000), 9.0% prevalence and 242/100 000 incidence in Makambako (population 70,000), and 3.9% prevalence and 116/100 000 incidence in Dar es Salaam (population 5.6 million). Similar disparities were observed across cities in Ethiopia, Ghana and other countries. We found that capital cities and other major cities (ie, 5 million or more population) did not always experience the greatest HIV burden per capita; in many cases, large secondary cities (ie, 1–5 million population) had similar or higher HIV prevalence and incidence rates, though these patterns differ by region.

In Eastern and Southern Africa (ESA), the mean prevalence of HIV in major cities was 6.5% on average compared with 11.8% in large cities ($p<0.05$), but no differences in mean prevalence were detected between major cities and secondary cities with fewer than 1 million residents (medium, 4.9%, $p >=0.1$; small, 4.6%, $p>=0.1$) (table 1). Mean HIV incidence followed a similar pattern in this region with 247 cases per 100 000 in major cities and a higher, but not statistically different rate, in large cities (314/100 000, $p>=0.1$). Unlike the prevalence pattern, however, incidence rates were lower in secondary cities of less than 1 million people compared with major cities (medium, 127/100,000, $p<0.1$; small, 131/100 000, $p<0.1$) (table 1).

In West and Central Africa (WCA), no statistical differences were detected in HIV prevalence or incidence in major versus secondary cities of any size (table 1), though several secondary cities had similar incidence and prevalence as major cities. Mean prevalence was 1.57% in major cities, compared with 1.44% ($p>=0.1$) in large cities, 1.03% ($p>=0.1$) in medium cities and 1.65% ($p>=0.1$) in small cities. However, comparatively lower levels of HIV infection in this region make differences more difficult to detect. We did not perform statistical comparisons among cities in Latin America and the Caribbean or in Western and Central Europe and North America because we had data on relatively few cities, and levels of HIV infection are relatively lower in these regions; however, mean prevalence and incidence across city types do not vary widely (table 1). While it is known that key population epidemics, for example, among sex workers, people who inject drugs, and men who have sex with men, account for large segments of the HIV epidemic in many of these cities,[16] analysis of subpopulation epidemics is outside the scope of this analysis.

Figures 2–4 show HIV prevalence across four regions of the world where DHS or PHIA data are available since 2012. Countries are ordered by prevalence among urban 'slum' populations from highest to lowest. Within urban areas, we found that HIV prevalence is generally higher among 'slum' residents especially in Eastern and Southern Africa (Ethiopia, Lesotho, Malawi, Namibia, Rwanda, South Africa, Zambia, Zimbabwe) as well as Latin America (Dominican Republic and Haiti). Although there were several surveys in which non-'slum' dwellers had a higher prevalence of HIV than 'slum' dwellers (Zambia, Zimbabwe, Tanzania, Lesotho, Cameroon), these were all PHIA surveys, and all countries had another survey which measured higher prevalence among 'slum' dwellers at a different point in time (figure 3, online supplemental tables S1 and S2). We hypothesise in the Discussion about discrepancies between DHS and PHIA surveys and the directionality of urban inequalities, though what is clear is that HIV had a disproportionate burden on the most deprived and vulnerable 'slum' households.

In ESA, most countries except for Namibia and Malawi had higher HIV prevalence among 'slum' compared with non-'slum' populations. Meanwhile, in Burundi, Ethiopia, Malawi and Uganda, 'slum' and non-'slum' populations had similar HIV prevalence rates. Burundi, Ethiopia, Uganda and Angola had smaller differences in HIV prevalence between 'slum' and non-'slum' groups. Overall, narrower differences in HIV prevalence were observed across economic groups in East African countries, whereas disparities were greater in Southern African countries.

In WCA, there were few statistical differences in HIV prevalence between 'slum' and non-'slum' populations; however, the overall trend was higher HIV prevalence in 'slums' compared with non-'slums' in eight out of 13 countries (62%): Chad, Gambia,

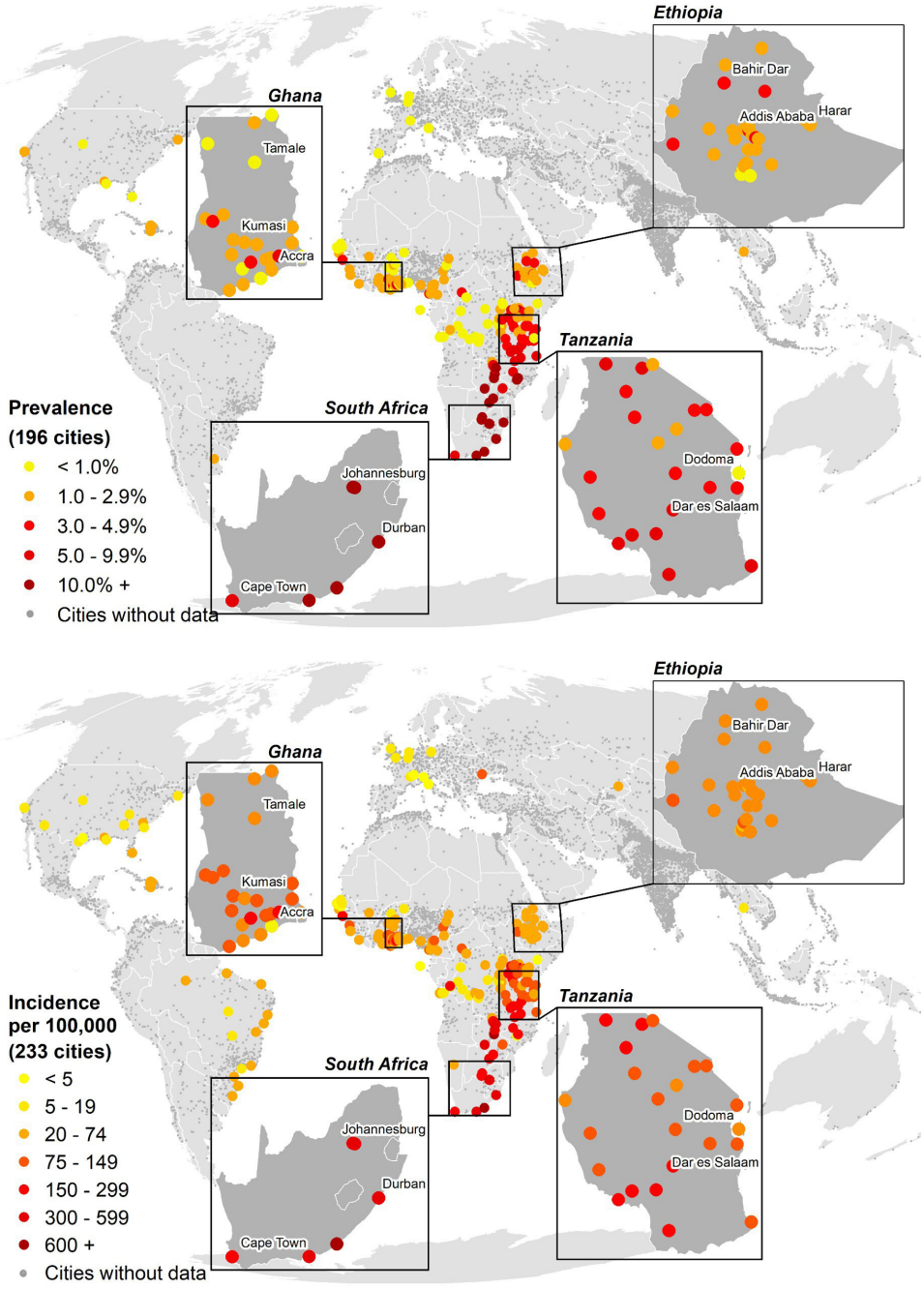

Figure 1 HIV prevalence (top) and incidence (bottom) since 2015, by city. Sources: Naomi-Spectrum model estimates (81% of prevalence and 91% of incidence data), Fast-Track Cities direct reports (13% of prevalence and 9% of incidence data) and SINAN direct reports (6% of prevalence data).

Gabon, Guinea, Togo, Liberia, DR Congo and Senegal. However, we found a different trend for Côte d'Ivoire, Cameroon, Ghana, Sierra Leone and Mali where non-'slum' populations seem to have higher prevalence than 'slum' populations. Senegal showed a narrower variation in HIV prevalence estimates between the groups.

In Latin America, HIV prevalence among 'slum' populations was roughly three times higher than non-'slum' populations in Haiti, Dominican Republic and Nicaragua. In India, where we have data from 2015, HIV prevalence disparities between 'slum' and non-'slum' households were less obvious.

DISCUSSION

In this retrospective study analysing combined data from five population-level datasets, we found the urban divide between slum and non-slum households is correlated with HIV inequalities, with a significant trend towards the urban slum (ie, poor) suffering higher HIV prevalence rates compared with their urban non-slum (ie, non-poor)

Table 1 City prevalence and incidence by city population and region

City type	Prevalence				Incidence				Interpretation
	N	Mean	SD	t-test	N	Mean	SD	t-test	
Africa: Eastern and Southern	97	5.34	4.54		97	156	213		
Capital/XL (5M+)	14	6.54	4.36	Ref.	14	247	451	Ref.	A similar proportion of people are living with HIV (prevalence) in small- and medium-sized as capital/XL cities, and large cities have the largest proportion of people living with HIV (greater than capital/XL cities). Additionally, more people are testing positive (incidence) in large, XL, and capital cities than in small- or medium-sized cities.
Large (1 M–5M)	5	11.76	4.74	5.22*	5	314	135	67	
Medium (250 k–1M)	26	4.92	4.71	−1.62	26	127	147	−120†	
Small (<250 k)	52	4.62	4.04	−1.92	52	131	126	−116†	
Africa: West and Central	81	1.45	1.09		83	50	49		
Capital/XL (5M+)	20	1.57	1.08	Ref.	20	51	66	Ref.	Prevalence and incidence rates are not substantially different in capital/XL cities than smaller non-capital cities, though a larger sample size of cities may be needed to detect differences.
Large (1 M–5M)	10	1.44	0.88	−0.13	10	52	32	<1	
Medium (250 k–1M)	20	1.03	0.83	−0.54	22	31	24	−21	
Small (<250 k)	31	1.65	1.27	0.08	31	64	51	12	
Latin America and Caribbean	5	1.50	0.38		17	34	14		
Capital/XL (5M+)	2	1.60	0.56	N/A	3	25	2	N/A	Insufficient sample size to evaluate differences across city types.
Large (1 M–5M)	0	--	--		7	37	19		
Medium (250 k–1M)	2	1.60	0.28		5	35	10		
Small (<250 k)	1	1.10	--		2	33	19		
West and Central Europe, North America	12	0.68	0.44		22	14	10		
Capital/XL (5M+)	4	0.68	0.32	N/A	5	18	13	N/A	Insufficient sample size to evaluate differences across city types.
Large (1 M–5M)	4	0.44	0.22		7	12	6		
Medium (250 k–1M)	4	0.93	0.64		8	15	10		
Small (<250 k)	0	--	--		2	10	10		

Key: *p<0.05, †p<0.1.
Note: The regions of 'Asia and Pacific' and 'Eastern Europe and Central Asia' are not reported because we had prevalence and/or incidence data for only two cities in each region. The following countries had a large number of cities in the analysis which might influence results: USA (13), Tanzania (23), Kenya (13), Ghana (24), Ethiopia (28), DR Congo (21), Cameroon (12) and Brazil (13).

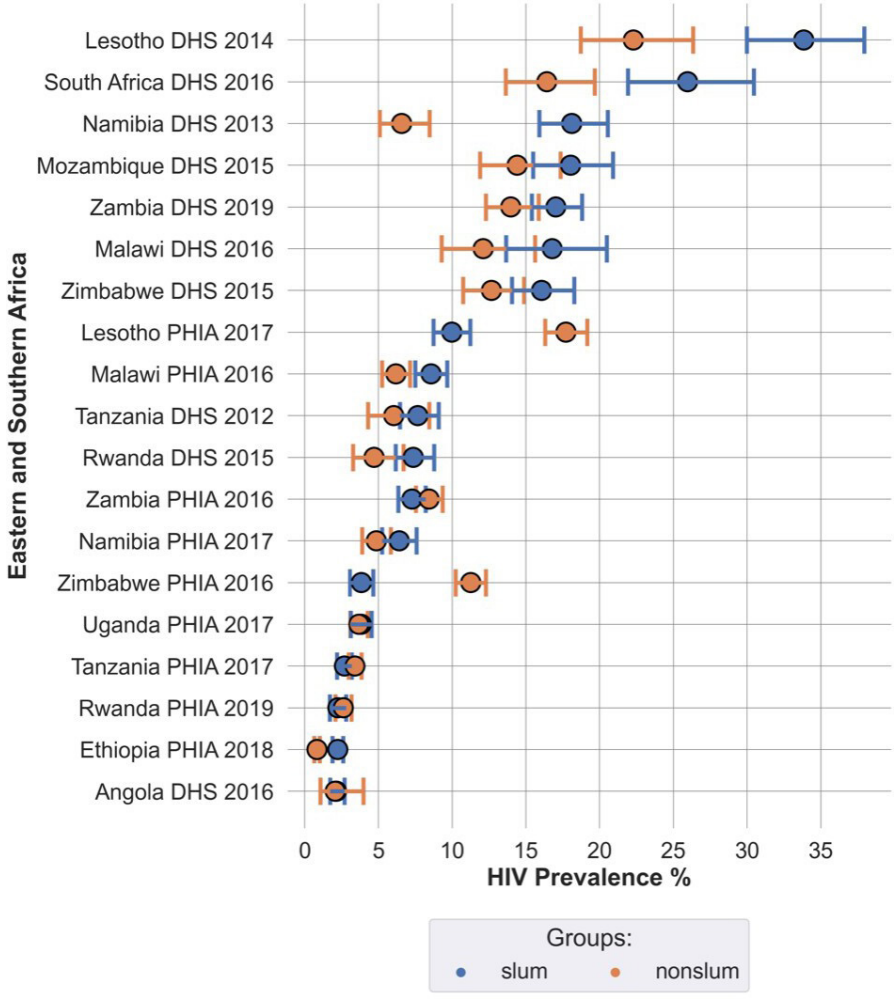

Figure 2 Prevalence of HIV in Eastern and Southern African Countries by setting (urban 'slum' and non-'slum'). DHS, Demographic Health Surveys; PHIA, Population-Based HIV Impact Assessment.

counterparts. This phenomenon is likely due to structural drivers of inequalities between urban poor and non-poor populations such as inequalities in wealth, education, employment and housing, which have been well documented to negatively affect HIV outcomes for the poor compared with their richer counterparts, including through higher rates of prevalence and mortality, lower testing uptake and lower levels of HIV knowledge.[27–31] For example, a systematic study on socioeconomic differences and HIV/AIDS mortality in Sub-Saharan Africa demonstrated that persons of low socioeconomic status defined through income level and education had over 50% risk of dying from HIV/AIDS.[28] Few studies have additionally demonstrated that HIV further exacerbates the effects of poverty.[27 32] Our study adds to extant literature as one of the first analyses to use multiple publicly available cross-national datasets to assess the combined impact of poverty and urbanity on HIV outcomes. It additionally demonstrates that national estimates of HIV mask nuances in HIV inequalities between the urban 'slum' and non-'slum' populations.

Beyond disparities within a given urban setting, our cross-regional analyses highlighted similar or worse outcomes in smaller cities (eg, a population between 1 and 5 million) in ESA and WCA than their larger counterparts (eg, a population of >5 million). Possible explanations of this phenomenon could be related to disparities in resources or funding between major and secondary cities; geographical location of Ministries of Health, National AIDS Councils, large academic institutes and research hospitals driving prioritisation of HIV programming; and additional resourcing for capacity building or quicker uptake of innovative programming and interventions in major cities. While the existence of subnational variations in HIV outcomes (ie, mortality, incidence, prevalence) has been well established,[33–35] this is the first global analysis to incorporate urbanity and population size to better understand sub-national variations. Our analysis demonstrates that inequalities between cities, particularly major and secondary cities, may help inform geographically equitable resourcing and financing towards closing 95-95-95 gaps.

This study has some critical limitations. City datasets used were not perfectly comparable as methodologies differed with a mix of surveillance and modelled data. We accounted for this discrepancy by using surveillance data

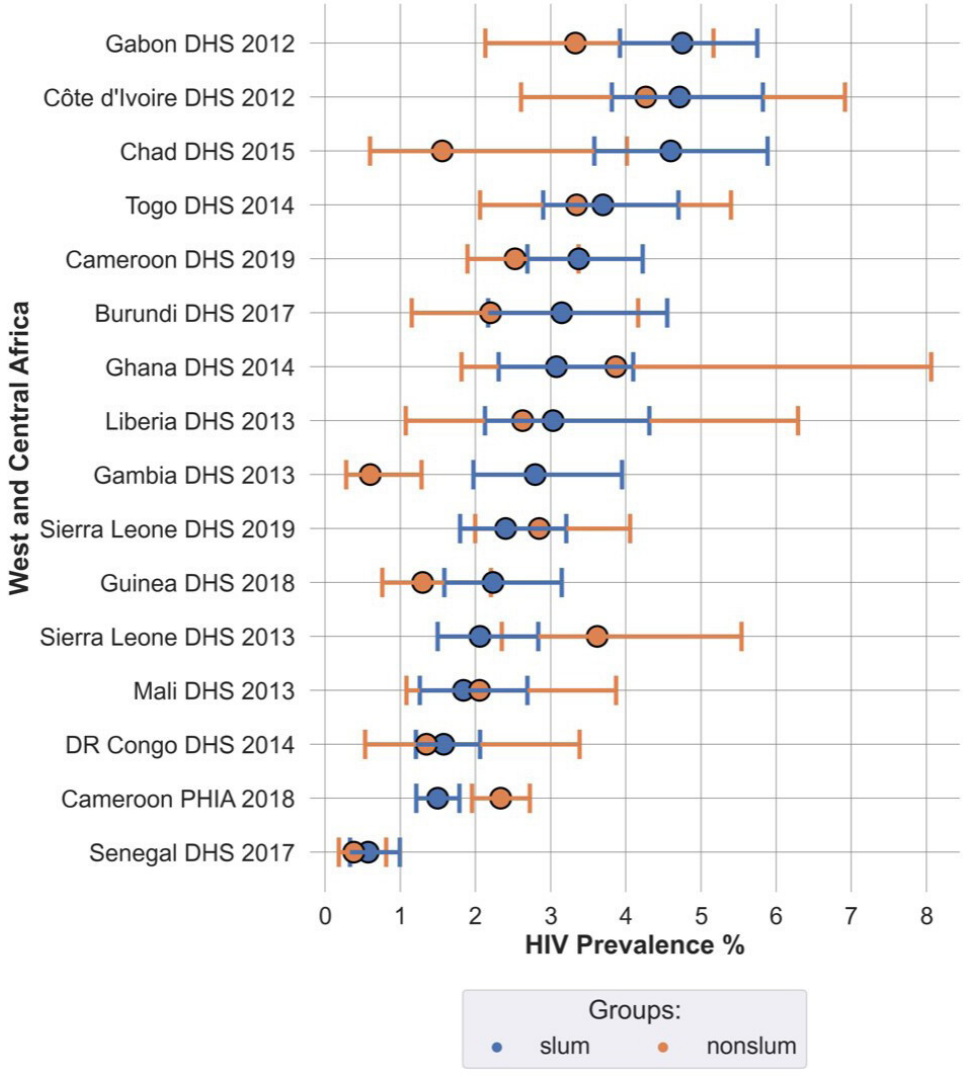

Figure 3 Prevalence of HIV in West and Central African Countries by setting (urban 'slum' and non-'slum'). DHS, Demographic Health Surveys; PHIA, Population-Based HIV Impact Assessment.

where possible (online supplemental table S3). The datasets reported data for different years spanning from 2019 to 2021, with the majority of the data reported in 2021. The cities included in the study were based on the availability of data, so we were not able to have a representative number of cities from each region for the regional analysis. Additionally, the following countries had a large number of cities in the analysis which might influence results: USA (13), Tanzania (23), Kenya (13), Ghana (24), Ethiopia (28), Democratic Republic of Congo (21), Cameroon (12) and Brazil (13). Assessment of urban 'slum' versus non-'slum' included merging two separate data sets, DHS and PHIA, both of which use standardised cross-sectional survey methodologies and collect blood samples from subsamples of respondents to test for HIV.[18 19] In countries where both a DHS and PHIA were conducted within a year of each other, the estimates of HIV prevalence in non-'slum' populations were generally consistent, whereas the estimates of HIV in 'slum' populations were divergent, with PHIA surveys recording lower HIV prevalence among 'slum' households than non-'slum' households in several instances (figures 2–4, online supplemental tables S1 and S2). While it is possible that the epidemiology of the HIV pandemic in ESA cities changed during the period of measurement, another possible explanation is how the DHS and PHIA approached 'slum' communities that were selected to be in the survey, by chance. Depending on the context, extra security and community leader permissions are needed to conduct surveys in slums and informal settlements; in practice, when such a community is selected or if local leaders fail to approve the survey implementation, another cluster within the same city might be randomly or purposefully substituted, potentially leading to systematic bias in the representation of the urban poorest in household surveys. These substitutions are not always documented and reported and are an important topic of study in household survey methodology.[36]

Poverty can be difficult to define in any context, especially urban contexts where asset ownership does not necessarily reflect vulnerabilities to food, housing and other insecurities during economic shocks such as

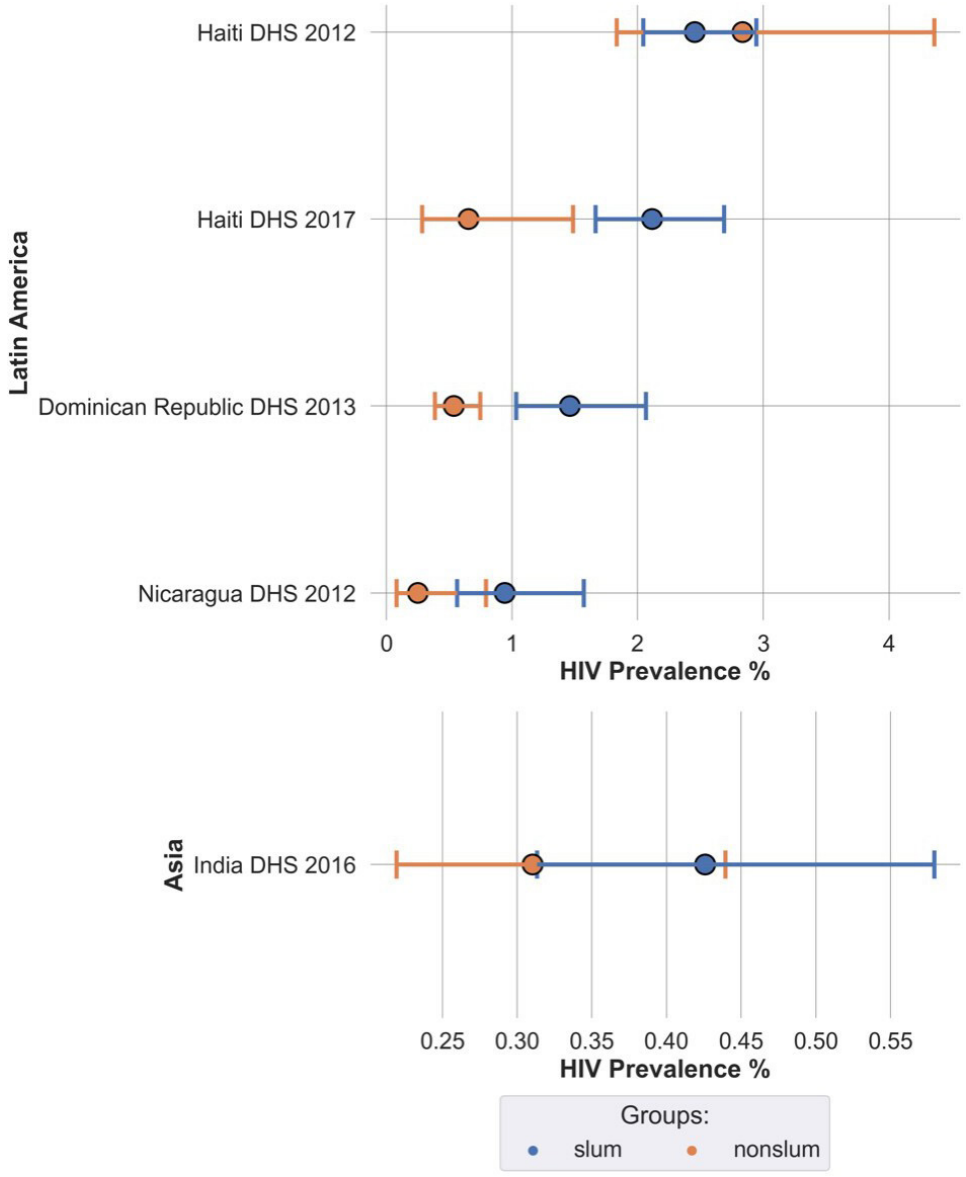

Figure 4 Prevalence of HIV in Latin America and Asia by setting (urban 'slum' and non-'slum'). DHS, Demographic Health Surveys; PHIA, Population-Based HIV Impact Assessment.

accident, illness, job loss, COVID-19 lockdowns/curfews, or food or fuel price fluctuations. Furthermore, in many countries, poverty from censuses and surveys is known to undercount 'slum' dwellers and other vulnerable urban residents.[37] In our analysis of household survey data, we used 'slum households,' a widely accepted metric of poverty which is based on four specific household assets to assess relative and absolute poverty, though this dataset might have under-represented data on the urban poorest as it does not reflect other dimensions of inequality such as those related to income, gender, employment, migration, disability and transportation. Previous studies have found that different forms of wealth, for example, wage economy compared with agricultural economy, are differentially associated with HIV infection.[38] The present study does not disaggregate wealth along different dimensions, which may conceal varied effects.

Additionally, we would be remiss not to acknowledge that HIV inequalities are most prominent among key populations (ie, men who have sex with men, people who inject drugs, sex workers) and adolescent girls and young women.[16] Despite key populations making up only 5% of the global population, 70% of new infections in 2021 were among key populations and their sexual partners.[16] A key limitation in our study was the inability to assess intersecting vulnerabilities between poverty and key and vulnerable populations due to scarcity in data, a particularly important question given that key and vulnerable populations are often economically marginalised and likely disproportionately represented among the urban poorest.[27 39–41] Although global and national HIV reporting systems, including several of those included in our study, try to encourage tracking and

reporting of HIV indicators among key and vulnerable populations, only a very limited number of cities or national HIV surveys actually collect and report these data in urban areas.

This study presents a novel analysis of HIV inequalities across urban settings of varying sizes and across multiple regions. To our knowledge, this is the largest global analysis of HIV prevalence and incidence data at the city level. By combining and harmonising data from multiple sources, including both surveillance and modelled estimates, the study demonstrates a novel approach for understanding global HIV trends, despite the challenges posed by varying data collection methods and definitions across sources. To our knowledge, this is the first study that examines differences in HIV outcomes by city size, and it reveals significant variations in HIV burden that national averages often conceal. It importantly highlights the heightened HIV prevalence in large secondary cities, where these cities sometimes surpass even capital cities in HIV incidence rates. Additionally, our findings underscore that the urban slum populations bear a disproportionate HIV burden compared with their non-slum counterparts, further emphasising inequities that are largely masked in national surveys.

There is a large scope for additional research to better map out and understand the contexts for geographical and structural HIV inequalities. Further explorations are required to better understand how spatial inequalities affect HIV prevalence rates within countries to guide HIV interventions and policies, particularly as they relate to the secondary cities that experience equal or greater HIV burden compared with major cities, including nuanced regional differences. In addition, it would be informative to understand intersectional vulnerabilities of key and vulnerable populations in the context of poverty, which requires robust collection of subnational subpopulation data. Lastly, understanding the structural drivers underpinning HIV inequalities between urban slum and non-slum populations can inform other health inequalities (eg, pandemics, infectious diseases, non-communicable diseases).

CONCLUSION AND POLICY IMPLICATIONS

We examined five publicly available datasets and found that the urban divide between the urban slum and non-slum populations is correlated to HIV inequalities. Additionally, our cross-national analyses highlighted similar or worse outcomes in large secondary cities (eg, a population between 1 and 5 million) than their major/capital city counterparts (a population of >5 million or capital cities).

Framed within our global efforts to attain the UNAIDS 95-95-95 targets and the goal to end AIDS by 2030, the intersection of poverty and urbanicity on HIV outcomes reinforces the need for policies to address intersecting social, geographical and structural inequalities such as wealth, education, employment and housing. Additionally, subnational geographic variations in HIV burden can inform strategic human and resource investments to close gaps in the HIV response. Further studies may be undertaken to uncover underlying reasons for variations between capital/major and large secondary cities in countries where this was observed. For example, geographic prioritisation by international donors, variation in availability of services or accessibility of services may play a role in subnational geographic variations between capital/major and large secondary cities. While this study is limited to HIV, similar dynamics between urbanicity, poverty and health inequalities may be relevant to other socially determined diseases such as tuberculosis and hepatitis and warrant further investigation. Ultimately, this study underscores the importance of focused HIV programming accounting for subnational variations and structural drivers of inequalities between urban slum and non-slum populations as a critical measure for closing gaps driving HIV inequalities globally.

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The health inequity and socioeconomic inequality faced by adolescent girls and women on the move living with or at high risk of HIV infection, during the COVID-19 pandemic in Nigeria

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ABSTRACT

Background We assessed if women and girls on the move living with or at high risk of HIV faced increased health inequity and socioeconomic inequalities during the COVID-19 pandemic compared with other vulnerable women and girls.

Methods We used data collected through a survey conducted in Nigeria between June and October 2021. Women and girls living with or at risk of HIV were recruited voluntarily, using a combination of venue-based and snowball sampling. We performed multivariable logistic regression models per mobility and HIV status to determine associations between health inequity, socioeconomic inequalities and macrosocial characteristics.

Findings There were 3442 participants, of which 700 were on the move. We found no statistical difference between HIV-negative women and girls on the move and those not on the move. On the opposite, we found substantial differences in health inequity and socioeconomic inequalities between women and girls on the move living with HIV and those not on the move living with HIV. There are very strong associations between being a woman or girl on the move living with HIV and facing economic precarity (aOR 6.08, 95% CI 1.94 to 19.03), food insecurity (aOR 5.96, 95% CI 2.16 to 16.50) and experiencing more gender-based violence since COVID-19 started (aOR 5.61, 95% CI 3.01 to 10.47).

Interpretation Being a woman or girl on the move and living with HIV compound increased health and socioeconomic vulnerabilities. The COVID-19 crisis seems to have exacerbated inequalities and gender-based violence. These findings call for more feminist interventions to protect women on the move living with HIV during health crises.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Most existing studies considered the HIV status of migrants in Europe, but there is limited knowledge on the health inequity and socioeconomic inequality faced by women and girls on the move living with or at high risk of HIV in sub-Saharan Africa.

WHAT THIS STUDY ADDS

⇒ This study provides new information about the health inequity and socioeconomic inequality faced by women and girls on the move living with or at high risk of HIV in Nigeria, one of Africa's countries with the biggest burden of migrants, internally displaced people, returning migrants and asylum-seekers.

⇒ The study confirmed that the COVID-19 pandemic had caused economic precarity, food insecurity and increased risk for gender-based violence for women and girls on the move living with HIV in Nigeria. A piece of new information was the observed high level of resilience of women and girls on the move living with HIV compared with other African women living with HIV but not on the move.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings of this study call for two urgent interventions in conflict zones and migration routes in ways that can enhance programmes designed to address the preparedness of people on the move for future pandemics. First, there is a need for more feminist and bold interventions to protect women on the move living with HIV. Second, for further studies of women and girls on the move living with HIV in Nigeria to learn how to translate lessons on resilience for humanitarian programmes.

INTRODUCTION

Women and girls living with or at high risk of HIV infection face numerous obstacles that hinder their access to equitable health services and increase their risk of experiencing social disparities. These challenges include difficulties accessing comprehensive sexual and reproductive health (SRH) education. It results in insufficient knowledge about HIV prevention, transmission and treatment options.[1] It also leads to gender inequality and discrimination, which limit young women's access to resources, opportunities and decision-making power.[2 3] Societal norms and cultural expectations disadvantage young women, impacting their education, employment prospects and economic empowerment.[4] Barriers related to stigma, discrimination and the intersection of HIV and gender bias impede young women's access to education and employment opportunities.[5] Economic dependence on partners, family members or caregivers compromises autonomy and restricts decision-making regarding healthcare, including accessing appropriate treatment, preventive measures and support services.[6] Limited access to social support networks negatively affects mental health and well-being.[7] Insufficient support hampers their ability to navigate healthcare systems and obtain necessary services.[8] In addition, challenges in accessing comprehensive SRH services, including contraception and antenatal care, further exacerbate existing health disparities.[9] They also have heightened vulnerability to sexual exploitation, abuse and violence.[10]

Women and girls on the move include migrants, refugees, asylum-seekers, returning migrants and internally displaced people (IDP).[11–14] Many have limited or no access to social protection systems,[15] they deal with racialism and experience xenophobia leading to stigmatisation and discrimination,[16] and are at higher risks of gender-based violence, abuse and exploitation.[17] These experiences were heightened during the COVID-19 pandemic. They faced an increased risk of COVID-19 infection,[18] and the loss of employment and wages resulting from COVID-19 was more precarious in the absence of social protection systems and poor access to the COVID-19 special measures in the countries of residence.[19] They also face higher risks of gender-based violence, abuse and exploitation during the COVID-19 pandemic.[20] Finally, the closure of borders and other movement restrictions to curb the spread of COVID-19 may have impacted the human rights of many people on the move[14] and forced them to rely on alternative and unsafe migratory routes.[21]

Although there is limited information regarding people on the move in low-income and middle-income countries like Nigeria, the available evidence suggests that states' response to their needs has been inadequate.[22] As of June 2023, Nigeria was home to large population groups in vulnerable situations, including 98 645 refugees and asylum-seekers and 3.58 million internally displaced persons who had been forced to leave their homes.[23] The country has also provided refuge to individuals fleeing violence in Cameroon.[24] It also accounts for more than 1.7 million unsettled returning migrants, that is, former Nigerian migrants and refugees in other countries, who return to their home country. Many are women returning from unsuccessful attempts to cross the Mediterranean from Libya. Returnees often come back destitute and may be economically worse off than before they left.[25]

This study aimed to assess if women and girls on the move were facing increased health and socioeconomic inequalities than other vulnerable women and girls in Nigeria since the COVID-19 pandemic started. The study focuses on those living with or at high risk of HIV infection.

METHODS

Participants and study design

As mentioned in the Global AIDS strategy 2021–2026: End inequalities end AIDS,[26] adolescent girls and young women in sub-Saharan Africa are among the priority population groups. Women and girls account for 59% of new infections in sub-Saharan Africa. Globally, AIDS remains one of the leading causes of death for women aged 15–49. Women and girls who belong to key populations, that is, women and girls living with HIV, as well as those who inject drugs, those engaging in sex work, those living with disability, and those on the move who experience high risks of acquiring HIV and are less likely to access services.

The current research focuses on women and girls on the move. The participants' data come from a cross-sectional survey on adolescent girls and women living with or at high risk of HIV. The survey was conducted in collaboration with community-based organisations in Nigeria between June and October 2021, corresponding to the period between the second and third waves of COVID-19 in the country. The survey determined the social, economic and health impact of COVID-19 on vulnerable girls and women living with HIV in Nigeria.

The survey covered the country's six geopolitical zones, with participants recruited from Adamawa, Akwa-Ibom, Anambra, Benue, Enugu, Gombe, Kaduna, Lagos, Nassarawa and Niger States. Women and girls living with or at risk of HIV were recruited voluntarily using a combination of venue-based and snowball sampling. Survey participants included women living with disability, those who engaged in sex work or transactional sex, who used psychoactive substances, or who were on the move (migrants, refugees, asylum-seekers, IDPs, and returning migrants). More details of the survey's methodology are provided in online supplemental file 1 and other studies.[27–29]

Exposure measures

In this study, we considered the health and socioeconomic impact of the COVID-19 pandemic on women and girls on the move in Nigeria based on their self-declared HIV status. We created a dichotomic variable for people on

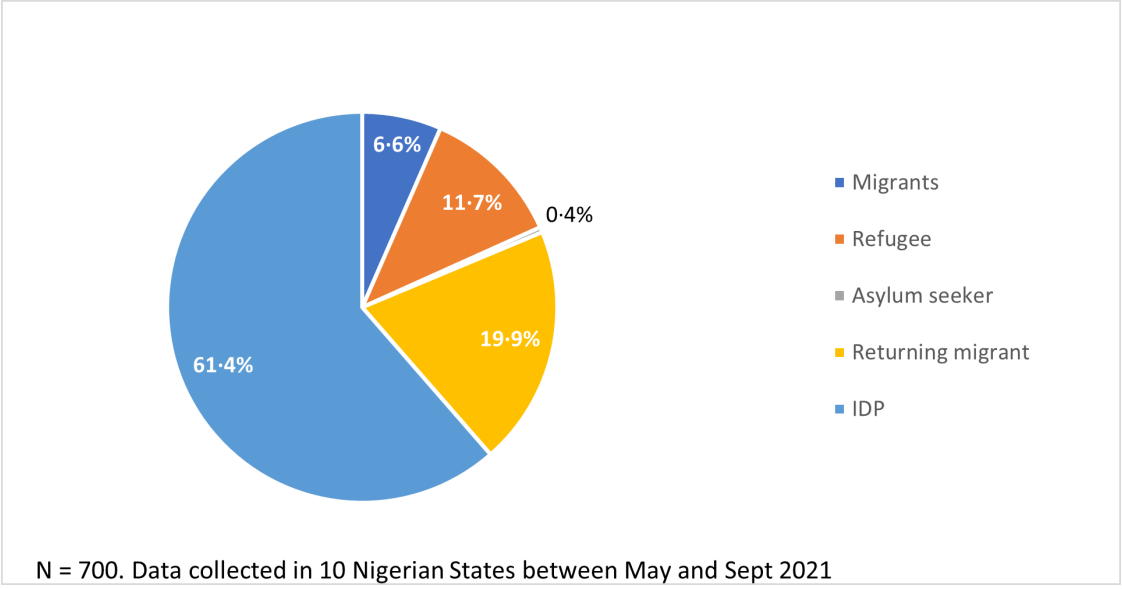

Figure 1 Adolescent girls and women on the move, per category.

the move, including migrants, refugees, asylum-seekers, IDPs and returning migrants.

As described in figure 1, we first explored the sociodemographic characteristics of women and girls on the move depending on their HIV status. In a second step, We considered three outcomes, corresponding to three dimensions of inequality, described in the next section and performed inferential statistical analysis on those women and girls on the move living with HIV and compared their situation to other vulnerable women and girls living with HIV but who are not on the move. Readers may also refer to the conceptual framework in online supplemental material S2.

Outcome measures

We identified key markers to measure health inequities, socioeconomic inequalities and macrosocial categories associated with HIV vulnerability. The selection of each independent variable followed three broad steps: we started with a literature review to identify the potential measures and corresponding variables that could proxy the situation or the behaviours associated with the research question. Following this step, we assembled a long list of measures that we tested for their association with being a woman on the move living with HIV (the exposure or dependent variables). We then checked for collinearity and endogeneity before ending with a short list of relevant measures. Finally, we limited the number of measures to what was strictly necessary, applying the principle of parsimony[30–32] not to overfit the model. We provided a complete description of the measures and variables below in online supplement S1 and S2.

Health inequity

Health inequity was measured with four measures, two related to access to health services: namely 'access to HIV service' and 'access to sexual and reproductive health services'.[33] The two other measures were related to mental health and wellness: 'the severity of symptoms of anxiety and depression' measured using the Patient Health Questionnaire-4 (PHQ-4).[34 35] The fourth measure was the 'HIV Stigma Score', using the validated 12-item short version of the Berger HIV stigma scale.[36–39] We assessed the reliability of both the PHQ-4 and the HIV stigma score. They presented a Cronbach's alpha coefficient[40] of 0.88 and 0.92, respectively. These two measures have thus a very good internal consistency and are considered reliable.[41]

Socioeconomic inequality

Socioeconomic inequality was assessed with three measures, namely the McArthur scale of 'subjective social standing',[42] the 'current main source of income' as a proxy measure for economic precarity. The third measure, 'food insecurity', corresponded to situations where participants had to eat less or skip meals because there was not enough money for food since the COVID-19 crisis began.[43] Participants also informed their main current sources of income and the changes in their income since the COVID-19 crisis started.

Macrosocial markers of vulnerability

Macrosocial markers of vulnerability considered three measures. The first relates to 'being a survivor of gender-based violence'. It was measured using the participants' experience of gender-based violence during the COVID-19 pandemic. The other two measures are 'engaging in sex work' and 'engaging in transactional sex'. We adjusted the model to account for the interactions between the latter two measures, acknowledging that they are not mutually exclusive.

Statistical methods

We first performed a bivariate analysis to study the associations between the independent variables and people on the move per self-declared HIV status. We used Pearson's χ^2 test of association (see results as table 1 and online supplemental S3) and Cramér's V test. We subsequently developed the inferential statistical analysis with a logistic regression model per HIV status. We focused on HIV-positive women and girls on the move compared with other vulnerable women and girls living with HIV but not on the move. See figure 1.

We controlled for confounders, conducted postestimation tests, including likelihood ratio χ^2, and controlled for the hypothesis of a null value for the independent variables for each model. In addition, we performed additional analyses of variance, margins, collinearity and goodness-of-fit. Finally, we controlled for specification errors and tested whether or not the interactions between potentially related variables such as living in precarity and food insecurity. We similarly controlled for interaction between sex work and transactional sex. We considered statistical significance at a p value<0.05 and reported the strength of association and effect size CIs accordingly.[44] All statistical analyses were performed using STATA V.16. More details are provided in online supplement S1.

Ethical approval

Ethics approval for the study, including a waiver for parental consent for adolescents 15–17 years old, was obtained from the Institute of Public Health, Obafemi Awolowo University Health Research Committee (IPH/OAU/12/1692), which was the ethics committee of record. Additional approval for the study was obtained from the ethics committee in Lagos (LS/C.350/S.1/215), Anambra (MH/AWK/M/321/363), Adamawa (ADHEC07/06/2021), Akwa-Ibom (MH/PRS/99/Vol.V/994), Benue (MOH/STA/208/VOL.1/183) and Kaduna (MOD/ADM/774/VOL.1/1008) States. Written informed consent was obtained for all study participants. No data with identifiers were collected from the respondents. All study methods were carried out in accordance with the National health research ethics code governing research conduct in Nigeria.[45]

Role of the funding source

The funder of this study had no role in study design, data collection, analysis and interpretation. All authors had full access to the data in the study.

Patient and public involvement statement

Civil society organisations (CSOs), community-based organisations (CBOs) and representatives of women and girls living with HIV, transgender people, female sex workers, women on the move, and women who use drugs were involved in all steps of the survey and the current study. The partnering CBO reviewed and suggested revisions to the study protocol, made the decisions on the states for the data collection, conducted community entry programmes and supported the participants' recruitment process using the venue-based sampling technique. The CSOs and CBOs performed a pilot test among participants to assess the burden and time required for the survey. They also consider the vocabulary and the adequacy of translations in different dialects. The Jami Al Hakeem Foundation, a CBO working with migrants and refugees in Nigeria, identified the community entry leads for migrants and refugees.

The CSOs and CBOs also actively participated in the preparation, the submission of the current study and are coauthors. Preliminary results of the survey were disseminated among the national and local CSOs and CBOs. Data and ad hoc analysis were made available to communities for their programming and advocacy purposes.

RESULTS

Descriptive statistics

Sociodemographic characteristics

Table 1 presents the sociodemographic characteristics of adolescent girls and women on the move per HIV status. The sociodemographic characteristics of the 3442 participants included in this study, per HIV and mobility status, are presented in online supplement S3. Of the 700 women and girls on the move, most (53.6 were aged 25–44). Almost a sixth (16.3%) did not know or refused to disclose their HIV status. Nearly half (46.5%) of adolescent girls and young women were unaware of their HIV status. The majority (62.4%) of the women and girls on the move had no education or only completed the primary degree. Additionally, the sociodemographic characteristics of the complete sample, that is, women and girls on the move and those not on the move, per HIV status, are presented in online supplement S4.

HIV-positive women and girls on the move reported fewer moderate to severe symptoms of anxiety and depression (30.2%) compared with their HIV-negative peers (43.3%) but higher and compared with other vulnerable women living with HIV but not on the move (39.9%, see online supplement S3).

Regarding socioeconomic inequality, the majority (61.0%) of women and girls on the move were unaware of special COVID-19 support measures compared with those not on the move (43.6%). When considering only women and girls on the move, the lack of information on these measures was lower among those living with HIV (48.8%) than their HIV-negative peers (70.2%). Consequently, a minority (14.9%) of women and girls on the move were either receiving or waiting to receive the COVID-19 social support measures compared with other vulnerable women living with HIV but not on the move (25.2%, see online supplement S3). Among women and girls on the move, those living with HIV were more likely to receive or wait to receive the COVID-19 social support measures (21.0%) than their HIV-negative peers (10.0%).

Table 1 Sociodemographic characteristics of women and girls on the move by self-reported HIV status

		Total		HIV−	HIV+	Don't know
		N = (700)		N = (252)	N = (334)	N = (114)
		(n)	(%)	(%)	(%)	(%)
	Age groups	Pearson χ^2 (4) = 31.1479 Pr ≤ 0.001, Cramér's V=0.1492				
	Adolescent girls and young women (15–24 years)	194	27.7	23.0	24.9	46.5
	Adults (25–44 years)	375	53.6	59.9	56.3	31.6
	Older adults (45+ years)	131	18.7	17.1	18.9	21.9
	Education (highest degree completed)	Pearson χ^2 (4) = 12.5913 Pr = 0.013, Cramér's V=0.0949				
	From none to primary education	437	62.4	59.5	61.1	72.8
	Secondary education	213	30.4	29.8	32.6	25.4
	Post-secondary or university degree	49	7.0	10.3	6.3	1.8
	Missing	1	0.1	0.4	0.0	0.0
	Geopolitical zones	Pearson χ^2 (10) = 322.3023 Pr ≤ 0.001, Cramér's V=0.4802				
1	North Central	206	29.4	6.7	54.2	7.0
2	North East	118	16.9	30.2	2.1	30.7
3	North West	27	3.9	4.0	2.7	7.0
4	South East	178	25.4	24.2	24.9	29.8
5	South South	97	13.9	28.6	0.6	20.2
6	South West	73	10.4	6.3	15.6	4.4
	Missing	1	0.1	0.0	0.0	0.9
Health inequity						
	Psychological distress (sympt. anxiety and depression)	Pearson χ^2 (2) = 6.2421 Pr = 0.044, Cramér's V=0.0981				
	None to mild symptoms	400	57.1	54.0	57.2	64.0
	Moderate to severe symptoms	249	35.6	43.3	30.2	34.2
	Missing	51	7.3	2.8	12.6	1.8
	Disrupted access to health services					
	HIV services	Pearson χ^2 (2) = 109.0852 Pr ≤ 0.001, Cramér's V=0.4106				
	No	472	67.4	81.3	50.0	87.7
	Yes	175	25.0	11.1	42.5	4.4
	Missing	53	7.6	7.5	7.5	7.9
	Sexual and reproductive health services	Pearson χ^2 (2) = 15.2330 Pr ≤ 0.001, Cramér's V=0.153				
	No	555	79.3	85.3	74.3	80.7
	Yes	89	12.7	7.1	17.7	10.5
	Missing	56	8.0	7.5	8.1	8.8
Economic inequalities						
	Access to COVID-19 support measures	Pearson χ^2 (12) = 102.4880 Pr = 0.000, Cramér's V=0.2721				
	I did not know there was a special relief measure for me	427	61.0	70.2	48.8	76.3
	These measures are not applicable to me	32	4.6	7.5	0.6	9.6
	I have been denied access	110	15.7	7.9	25.4	4.4
	I can access these support measures if I want, but I don't	10	1.4	1.6	1.8	0.0
	Yes, I applied, and I am waiting for the support measure	43	6.1	6.0	7.2	3.5
	Yes, I applied, and I received these support measures	61	8.7	4.0	13.8	4.4
	I cannot or do not wish to answer this question	9	1.3	1.6	1.5	0.0
	Missing	8	1.1	1.2	0.9	1.8
	Subjective social standing	Pearson χ^2 (4) = 23.5919 Pr ≤ 0.001, Cramér's V=0.1298				

Continued

Table 1 Continued

	Total		HIV−	HIV+	Don't know
	N = (700)		N = (252)	N = (334)	N = (114)
	(n)	(%)	(%)	(%)	(%)
Lower tercile	402	57.4	47.2	62.6	64.9
Middle tercile	182	26.0	33.3	20.1	27.2
Higher tercile	116	16.6	19.4	17.4	7.9
Missing	–	–	–	–	–
Skip meals because not enough money	Pearson χ^2 (2) = 8.7438 Pr = 0.013, Cramér's V=0.1131				
No	126	18.0	21.0	13.8	23.7
Yes	557	79.6	73.8	85.0	76.3
Missing	17	2.4	5.2	1.2	0.0
Current main source of income	Pearson χ^2 (12) = 47.3186 Pr ≤ 0.001, Cramér's V=0.1842				
No income/survival mode	177	25.4	20.2	24.8	38.6
Transactional sex	91	13.1	8.3	17.8	9.6
Social transfer, incl. pension	6	0.9	0.4	1.5	0.0
Remittances or charity	56	8.0	5.2	9.1	11.4
Agriculture	157	22.5	25.0	21.1	21.1
Self-employed, petty trade	193	27.7	38.1	23.3	17.5
Paid work	17	2.4	2.8	2.4	1.8
Missing	3	0.4	–	0.9	–
Macrosocial markers of vulnerability					
Survivor of gender-based violence	Pearson χ^2 (6) = 24.6323 Pr ≤ 0.001, Cramér's V=0.1355				
I am not experiencing any violence	452	64.6	74.6	56.3	66.7
Less violence than before COVID-19	30	4.3	4.4	4.8	2.6
Same level of violence as before COVID-19	108	15.4	9.9	20.4	13.2
More violence than before COVID-19	81	11.6	7.5	14.1	13.2
Missing	29	4.1	3.6	4.5	4.4
Engaged in transactional sex	Pearson χ^2 (2) = 11.9471 Pr = 0.003, Cramér's V=0.1350				
No	479	68.4	74.6	61.4	75.4
Yes	177	25.3	21.8	30.5	17.5
Missing	44	6.3	3.6	8.1	7.0
Engaged in sex work	Pearson χ^2 (2) = 6.6533 Pr = 0.036, Cramér's V=0.1006				
No	515	73.6	76.6	70.4	76.3
Yes	142	20.3	19.0	24.0	12.3
Missing	43	6.1	4.4	5.7	11.4

Note: Pearson χ^2 values represent the associations between the independent variables and people on the move per self-declared HIV status. The number between brackets defines the degree of freedom. Cramér's V test values measure the association between two nominal variables.
HIV-positive women and girls on the move reported fewer moderate to severe symptoms of anxiety and depression (30.2%) compared with their HIV-negative peers (43.3%) but higher and compared with other vulnerable women living with HIV but not on the move (39.9%, see online supplement S3).

More than three-quarters (79.6%) of the participants on the move had to skip meals or reduce portions of their meals because there was not enough money since the COVID-19 pandemic started. This percentage rose to 85.0% among those living with HIV. A quarter (24.6%) of women on the move living with HIV have no income compared with women living with HIV but not on the move (17.2%, see online supplement S4).

In terms of macrosocial markers of HIV vulnerability, a third (31.3%) of women and girls on the move reported gender-based violence. This percentage rose to 39.2% among those living with HIV and is substantially higher

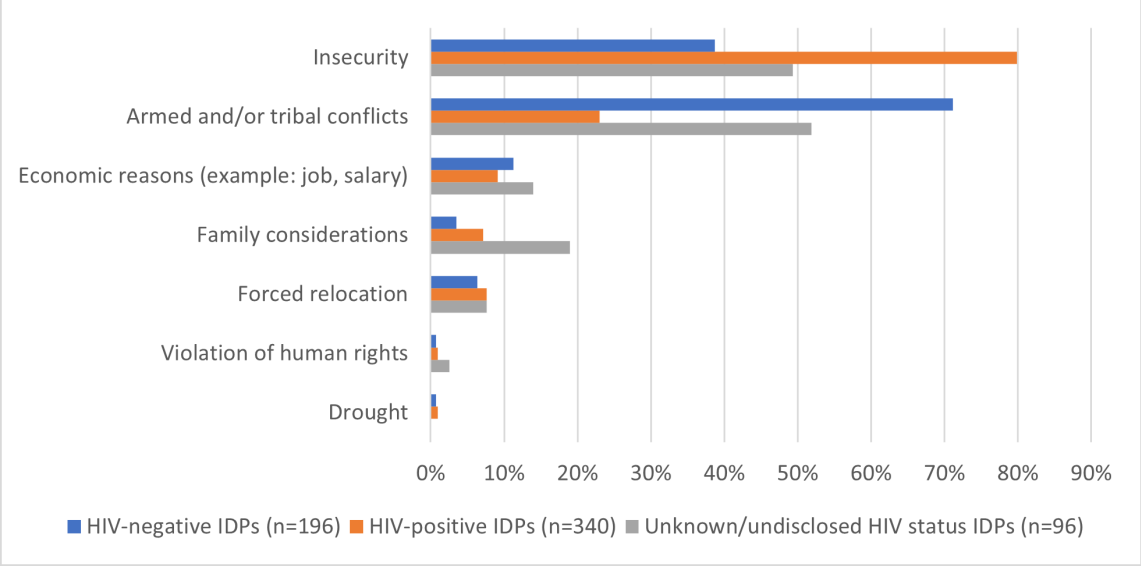

Figure 2 Focus on internally displaced women and girls: most mentioned reasons, per HIV status.

than the proportion of women and girls living with HIV but not on the move who experienced gender-based violence (25.5%, see online supplement S4). The proportions of women and girls on the move who engaged in transactional sex (25.3%) or in sex work (20.3%) were lower than the 48.1% and 43.1% of women and girls not on the move who engaged in transactional sex in sex work respectively (see also online supplement S4).

There was heterogeneity in the profile of the 700 consenting women and girls on the move aged >15. As presented in figure 2, 61.4% of the women and girls on the move were internally displaced, and 19.9% were returning migrants. Also, 11.7% of the sample were refugees, and 6.6% were migrants.

We looked more closely at IDPs and returning migrants. The reasons for their move vary by their HIV serostatus. As presented in figure 2, most IDPs moved because of insecurity (61%), including armed or tribal conflicts (44%). The reasons for movement varied by HIV status.

Table 2 shows that the current source of income differed for different subpopulations of women and girls on the move. The table shows that more than a quarter (25.3%) of women and girls on the move have no current source of income or are in survival mode (eg, recycling and selling in slums, begging). Self-employment provided the main source of income for more than a quarter (27.6%) of women and girls on the move. It represented the main source for almost half of the refugees (48.8%). Agriculture was the main source for more than a fifth of women and girls on the move (22.4%), particularly among the IDP women and girls (30.0%). Finally, we found that transactional sex was the main source of income for 13% of women and girls on the move, essentially among migrants, with 63% of them, followed by returning migrant women for whom transactional sex is the main source of income for a sixth of them (15.8%).

Table 3 shows that more than half (52.0%) of women and girls on the move reported a reduction in their income, and 8.7% lost all their income during COVID-19. The situation is particularly acute among IDPs, the largest group on the move. Among them, 6 in 10 (61.2%) reported a reduction in their income, and 7.7% lost all their income. Refugees are the second most impacted subgroup of women and girls on the move, with more

Table 2 Current main sources of income among vulnerable women and girls in Nigeria

Groups	Total (n=3442)	No income/survival mode (%)	Transactional sex (%)	Social transfers (%)	Remittances (%)	Agriculture (%)	Self-employment (%)	Paid work (%)
On the move	700	25.3	13.0	0.9	8.0	22.4	27.6	2.4
Migrants	46	8.7	63.0	–	–	4.3	17.4	6.5
Refugees	82	28.0	3.7	1.2	7.3	9.8	48.8	1.2
Asylum seekers	3	–	100.0	–	–	–	–	–
Returning migrants	139	32.4	15.8	0.7	3.6	12.9	30.2	4.3
IDPs	430	24.4	7.9	0.9	10.5	30.0	24.0	1.6
NOT on the move	2637	17.1	15.5	1.4	11.0	8.3	39.5	5.2
Did not know	105	36.2	2.9	1.9	8.6	6.7	32.4	8.6

Pearson χ^2 (36) = 390.8708 Pr ≤ 0.000, Cramér's V=0.1387.
IDP, internally displaced people.

Table 3 Change in incomes among vulnerable women and girls in Nigeria

Groups	Total (n=3442)	Lost all their income (%)	Reduced by more than half (%)	Reduced by about half (%)	Reduced by less than half (%)	No change (%)	Increased (%)	Missing (%)
On the move	700	8.7	24.4	18.0	9.4	33.6	3.4	2.4
Migrants	46	2.2	8.7	13.0	2.2	50.0	23.9	–
Refugees	82	22.0	22.0	12.2	8.5	31.7	2.4	1.2
Asylum seekers	3	–	–	–	–	100	–	–
Returning migrants	139	6.5	18.0	12.2	8.6	47.5	5.0	2.2
IDPs	430	7.7	28.8	21.6	10.7	27.2	0.9	3.0
NOT on the move	2637	7.1	26.2	15.7	12.8	30.6	4.7	3.0
Did not know	105	10.5	29.5	2.9	10.5	37.1	6.7	2.9

Pearson χ^2 (30) = 145.7046 Pr ≤ 0.000, Cramér's V=0.0934.
IDP, internally displaced people.

than 4 in 10 (42.7%) reporting a reduction in their income and more than a fifth (22.0%) having lost all their income since the COVID-19 crisis started. Finally, a third (33.6%) of women and girls on the move reported no change in their income, essentially because most of those reporting no change (64.4%) had no prior income (see online supplement S5).

Table 4 shows that more than a quarter (27%) of women and girls on the move reported disrupted access to HIV services when needed during COVID-19. This percentage is lower than among other vulnerable women not on the move (43.9%). Similarly, women and girls on the move reported lower disruption in their access to SRH services when needed during COVID-19 (13.8%) compared with other vulnerable but not on the move (32.1%). Migrant women living with HIV reported higher disruption in their access to HIV activities (45.5%) and SRH services (38.6%) compared with vulnerable women and girls not on the move. Returning migrants and IDPs reported lower rates of disruption. Returning migrants reported more symptoms of anxiety and depression than the reference category.

Inferential statistics on the socioeconomic determinants of inequality.

Our preliminary analysis of socioeconomic determinants of inequality showed that, on the first hand, there are no differences among women and girls on the move who were HIV-negative, HIV-positive, and who did not know their HIV status, as shown in online supplement S6. On the other hand, we found substantial differences in the determinants of inequality when comparing women and girls on the move who were HIV-positive and women and girls not on the move who were HIV-positive. These differences are presented in table 5. Each adjusted OR (aOR) reflects the probability of meeting a said outcome measure (first column of table 5) for the women and girls on the move that of those not on the move, adjusting for the other outcome measures.

In terms of health inequity, table 5 shows that women and girls on the move and living with HIV have lower odds of reporting disrupted access to HIV services (aOR 0.54, 95% CI 0.36 to 0.82), disruption of access to SRH services (aOR 0.55, 95% CI 0.34 to 0.90), reporting

Table 4 Disrupted access to HIV and SRH services when it was needed during the COVID-19

	Disrupted access to HIV services	Disrupted access to SRH services	Symptoms of anxiety and depression
	N = (2571)	N = (2552)	N = (20407)
	X² (6) 71.5390 Pr≤0.001 Cramér's V=0.1468	X² (6) 103.3465 Pr≤0.001 Cramér's V=0.1771	X² (6) 15.5767 Pr=0.016 Cramér's V=0.0703
Women and girls NOT on the move (n=2637)	43.9%	32.1%	41.9%
Women and girls on the move (n=700)	27.0%	13.8%	38.4%
Migrants (n=46)	45.5%	38.6%	23.8%
Refugees (n=82)	19.5%	9.8%	25.9%
Asylum-seekers (n=3)	0.0%	33.3%	0.0%
Returning migrants (n=139)	30.7%	19.3%	45.0%
Internally displaced people (n=430)	25.7%	10.2%	40.6%
Missing or did not know (n=195)	44.6%	31.0%	45.3%

SRH, sexual and reproductive health.

Table 5 Logistic regression of different markers of inequality among women and girls on the move and living with HIV when compared with women and girls not on the move living with HIV

HIV-positive women and girls on the move	aOR	P value	95% CI	
Age groups				
Adolescent girls and young women (15–24)	0.64	0.047	0.41	0.99
Adults (25–44)	Base			
Older adults (45+)	1.22	0.485	0.70	2.15
Education level				
From none to primary education	2.76	0.000	1.85	4.12
Secondary education	Base			
Post secondary or university degree	0.55	0.070	0.28	1.05
Health inequity				
Disrupted access to HIV services	0.54	0.003	0.36	0.82
Disrupted access to SRH services	0.55	0.017	0.34	0.90
Symptoms of anxiety and depression	0.91	0.002	0.86	0.96
HIV stigma index	0.94	0.000	0.91	0.97
Socioeconomic inequality				
Subjective social standing status				
Lower tercile	2.16	0.001	1.36	3.43
Middle tercile	Base			
Higher tercile	1.36	0.309	0.75	2.48
Economic precarity	6.08	0.002	1.94	19.03
Skip meals	5.96	0.001	2.16	16.50
Macrosocial categories of vulnerability				
Survivor of gender-based violence				
I am not experiencing any violence	Base			
Less violence than before COVID-19	1.77	0.142	0.83	3.81
The same level of violence as before COVID-19	4.93	0.000	2.79	8.71
More violence than before COVID-19	5.61	0.000	3.01	10.47
Engaged in sex work	0.44	0.022	0.21	0.89
Engaged in transactional sex	0.85	0.632	0.44	1.64
Interaction eco precarity # skipmeals	0.18	0.005	0.05	0.60
Interaction sex work # transactional sex	Empty			
Constant	0.45	0.291	0.10	1.97
N	946			
Log-likelihood	–361.76			
LR χ^2 (18)	285.59			
prob>χ^2	0.000			

SRH, sexual and reproductive health.

symptoms of anxiety and depression (aOR 0.91, 95% CI 0.86 to 0.96) and lower odds of reporting high HIV stigma index (aOR 0.94, 95% CI 0.91 to 0.97) compared with HIV-positive women and girls not on the move. In other terms, there are weak associations[44] between the four measures of health inequity for women and girls on the move and living with HIV compared with the association of health inequity among women and girls living with HIV but not on the move.

Regarding socioeconomic inequality, table 5 shows that HIV-positive women and girls on the move had more than twice higher odds (aOR 2.16, 95% CI 1.36 to 3.43) of being among the lower tercile in terms of subjective social standing; more than six-time higher odds of facing economic precarity (aOR 6.08, 95% CI 1.94 to 19.03) and almost six-time higher odds of having to skip meals because there was not enough money since the COVID-19 pandemic started (aOR 5.96, 95% CI 2.16 to 16.50) when compared with vulnerable women living with HIV but not among the people on the move. In other terms, there are medium to very large associations between the three measures of socioeconomic inequality for women and

girls on the move and living with HIV compared with the association of health inequity among women and girls living with HIV but not on the move.

In terms of macrosocial categories of HIV vulnerability, table 5 shows that women and girls on the move and living with HIV had almost five times higher odds (aOR 4.93, 95% CI 2.79 to 8.71) of facing gender-based violence and more than five and half times higher odds (aOR 5.61, 95% CI 3.01 to 10.47) of facing more gender-based violence since the COVID-19 crisis started compared with those vulnerable HIV-positive women not on the move. They also had lower odds (aOR 0.44, 95% CI 0.21 to 0.89) of engaging in sex work when compared with HIV-positive women not on the move. We found no statistical difference between the two groups regarding transactional sex, even after controlling for interactions between transactional sex and sex work. In other words, there are very large associations between being a woman or girl on the move living with HIV and gender-based violence compared with those women and girls living with HIV but not on the move.

DISCUSSION

This study aimed to assess whether HIV-positive women and girls who are on the move experience greater health inequities and socioeconomic inequalities than other vulnerable women and girls living with HIV in Nigeria during the COVID-19 pandemic. To our knowledge, this study is the first attempt to examine the syndemics of HIV and COVID-19 among women and girls on the move, explicitly focusing on socioeconomic inequality and health disparities within an African country. The study yielded five key findings that can inform targeted and effective interventions for this highly vulnerable group of women and girls living with HIV.

First, there were no disparities in health inequities and socioeconomic inequalities between HIV-negative vulnerable women on the move and not on the move. However, we found important differences between women and girls living with HIV who were on the move and those not on the move. This suggests that the combination of being on the move and living with HIV exacerbates individual vulnerabilities, and the COVID-19 pandemic may have further intensified existing inequalities.

Second, women and girls on the move and living with HIV seem less likely to have experienced health inequity compared with women living with HIV but not on the move. There were, however, disparities in access to HIV services between the categories of women on the move living with HIV: migrant women and girls reported higher health inequities than IDPs and returning migrants. Our findings may reflect the positive effect of the specific assistance provided to IDPs to minimise the impact of the lockdown and other COVID-19 public health preventive measures.[46 47] We postulate that women and girls on the move and living with HIV were less likely to face disrupted access to health services because they had learnt to navigate challenges associated with poor health service access before the COVID-19 pandemic.[48]

Third, HIV-positive women and girls on the move were more likely to belong to the lowest tercile in social standing. They were exposed to additional socioeconomic shock during the COVID-19 crisis, being more likely to skip meals because they were cash-strapped and to rely on sources of income that put them in economic precarity, such as being in survival mode (eg, recycling and selling in slums, or begging), depending on assistance from charitable or CSOs, engaging in transactional sex, relying on remittances or not having any source of income. In addition, very few of them reported access to social transfers, including food transfers. These findings corroborate previous findings[49 50] on socioeconomic inequalities experienced by IDPs in Nigeria and alert to the intersection of gender, socioeconomic and HIV-related inequalities exacerbated by future health crises such as COVID-19.

Fourth, the study highlighted the high risk of gender-based violence faced by women and girls on the move living with HIV since COVID-19 started. Our findings provide additional evidence on the increased level of gender-based violence faced by women and girls on the move,[51] by HIV-positive women in sub-Saharan Africa,[52] as well as the increment of gender-based violence during the COVID-19 pandemic.[53] The exceptionally high risk for gender-based violence faced by women and girls on the move during this pandemic cannot all be explained by theories that frame patriarchal structures of power as the root cause of gender-based violence.[4 54] The observed disproportional impact of gender-based violence among people on the move living with HIV when compared with peers not living with HIV needs further analysis. These findings call for a better gender-based violence surveillance system and urgent feminist interventions[55] that promote women's safety, health, positive lifestyles, personal strength, competence and resilience. It underlines the need for targeted interventions to prevent and protect the survivors of gender-based violence, with particular attention to vulnerable women and girls.

Lastly, the study found that symptoms of anxiety and depression and HIV self-stigma were high among all HIV-positive women and girls. Nonetheless, women and girls on the move and living with HIV reported fewer symptoms of mental distress and a lower HIV-stigma score than their HIV-positive peers not on the move. These findings are interesting and open the way for more studies to explore what appears as a strong resilience capacity of people on the move and how the involvement of HIV-positive people on the move in HIV programmes and activities could contribute to reinforcing and strengthening the resilience of other vulnerable communities.

One of the study's strengths is the large sample size that allowed for robust subgroup analysis. Nevertheless, the findings should be considered in the context of several limitations. First, the recruitment strategies combined non-probabilistic sampling methods with a risk for selection

biases.[56 57] However, these methods are reputed to be appropriate for recruiting hard-to-reach and stigmatised population groups.[58 59] To reduce the risk of selection bias, CBOs and CSOs involved in the design and implementation of this study helped reach out to vulnerable adolescent girls and women with diverse profiles to participate in the study. Second, we used self-reported measures, such as self-reported HIV status, which may increase the risk for overestimation or underestimation. We used validated instruments and performed the appropriate tests to minimise this risk. Finally, the prevailing COVID-19 control measures at the time of the survey led to several restrictions which may have impacted the recruitment of participants. The geopolitical and insecurity situation in Adamawa State, as well as the interreligious tensions, kidnapping and killings by unknown gunmen in Akwa-Ibom, Benue and Lagos States, required additional security measures. The survey security protocol and the close involvement of local organisations and specialised organisations working hand in hand with the data collectors enabled the team to securely address these challenges and recruit people on the move in most geopolitical zones.

CONCLUSIONS

This study showed that being on the move and living with HIV compounded increased socioeconomic inequalities and gender-based violence for adolescent girls and women. The COVID-19 crisis appeared to have exacerbated these inequalities, leading to further economic precarity and food insecurity. These findings raise concerns over the pandemic's medium-term to long-term impact on women and girls on the move and call for two urgent interventions in conflict zones and migration routes: First, the need for more feminist and bold interventions to protect HIV-positive women on the move. Second, to actively involve HIV-positive women and girls on the move in HIV and humanitarian programmes to benefit from their impressive resilience. These findings can enhance programmes' design to address people's needs and preparedness for future pandemics.

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Contributors EL and MOF conceptualised the study and drafted the manuscript. EL developed the econometric models and conducted the data analysis. MOF, EL, HYN, AE, AS, AM, RMA, HO, VU, PO, OA, and OAA contributed to the study design and the data collection. All authors contributed to the reviewing and editing of subsequent versions of the manuscript for critical intellectual content. All authors read and approved the final version of the manuscript. EL act as the guarantor of this study.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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Ethics approval This study involves human participants and was approved by Ethics approval for the study, including a waiver for parental consent for adolescents 15-17 years old, was obtained from the Institute of Public Health, Obafemi Awolowo University Health Research Committee (IPH/OAU/12/1692) and the ethics committee in Lagos (LS/C.350/S.1/215), Anambra (MH/AWK/M/321/363), Adamawa (ADHEC07/06/2021), Akwa-Ibom (MH/PRS/99/Vol.V/994), Benue (MOH/STA/208/VOL.1/183) and Kaduna (MOD/ADM/774/VOL.1/1008) States. Written informed consent was obtained for all study participants. No identifier data were collected from respondents. All study methods were carried out in accordance with the National Health Research Ethics Code governing research conduct in Nigeria. Participants gave informed consent to participate in the study before taking part.

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PLOS GLOBAL PUBLIC HEALTH

RESEARCH ARTICLE

Facilitators and barriers to community-led monitoring of health programs: Qualitative evidence from the global implementation landscape

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Abstract

Achieving the global HIV, tuberculosis, and malaria targets will require innovative strategies to deliver high quality and person-centered health services. Community-led monitoring (CLM) is a rapidly proliferating health systems strengthening intervention for improving healthcare services and documenting human rights violations, through social empowerment and political accountability. Driven in part by increasing financial support from donors, a growing number of countries are implementing CLM programs. This study aimed to identify early challenges and lessons learned from CLM implementation, with the aim of informing and improving the implementation of CLM programs and ultimately achieving greater impact on the delivery of services. Twenty-five CLM implementors representing 21 countries participated in an interview. Early generation of buy-in from diverse stakeholders was noted as critical for CLM success. Leveraging existing networks of service users and community organizations to implement CLM also helped to maximize program reach and resources. Uncertainty around CLM's purpose and roles among CLM stakeholders resulted in challenges to community leadership and ownership of programs. Respondents also described challenges with underfunded programs, especially advocacy components, and inflexible donor funding mechanisms. Critical capacity gaps remain around advocacy and electronic data collection and use. With the rapid expansion of CLM, this study serves as an important first step in characterizing challenges and successes in the CLM landscape. Successful implementation of CLM requires prioritizing community ownership and leadership, donor commitment to sustainable and reliable funding, and strengthened support of programs across the data collection and advocacy lifecycle.

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1. Introduction

The joint efforts of governments, donors, and civil society have achieved tremendous progress in the fight against HIV, tuberculosis, and malaria as public health threats [1–3]. Yet despite progress in many countries toward elimination and control targets, several countries and populations continue to be left behind [4].

Improving healthcare quality and access is an urgent priority in the fight against the three diseases, one requiring a multi-faceted approach to both identifying and addressing a wide range of clinical, social, and economic health-related barriers and enablers. One proposed avenue for improving service delivery is the strengthening of accountability structures within health systems through community-led monitoring.

Community leadership in identifying gaps and advocating for change is not a new practice. Since the 1970s, a variety of community-based initiatives to monitor health systems have been described, including community scorecards, citizen report cards, and health facility committees [5, 6]. Today, community-led monitoring (CLM) is commonly defined by a service user- and community-driven approach that not only identifies gaps but uses routine data collection and advocacy to apply pressure on decision-makers to improve service delivery, generate political will, and improve accountability [7]. As such, CLM is typically implemented as a routine cycle of information gathering (at the community or facility level), analysis of data to identify gaps and barriers, development of solutions to issues identified in the data, feedback of findings and solutions to stakeholders, and advocacy for changes to policy and practice.

This central focus on advocacy and community ownership also differentiates the CLM model from traditional monitoring and evaluation techniques. While the accuracy of community data is important, the CLM model intentionally prioritizes context-specific knowledge, participatory methodologies, and local decision-making over commonly held standards for monitoring and evaluation (M&E). Indicators are developed based on the expertise and perspectives of the communities most familiar with the challenges in the healthcare system, and often capture aspects of patient centered healthcare like understanding why service users are lost to follow up and documenting human rights violations. This approach prioritizes responsiveness and adaptability, allowing communities to define their own monitoring indicators and methodologies. Additionally, CLM programs are typically operated out of small, local civil society organizations with support from international donors, and as such the breadth and depth of monitoring is typically limited by institutional capacity and funding levels.

Recent years have seen growth in CLM implementation, particularly HIV-focused programs. With increasing recognition that global HIV targets will not be achieved without innovative strategies to deliver high-quality patient-centered services, CLM has sparked donor interest and has been highlighted as relevant to pandemic preparedness efforts. Since 2020, PEPFAR has required CLM in all countries receiving PEPFAR funding [8] and the Global Fund currently supports CLM through allocation funding, Strategic Initiatives, [9] and the COVID-19 Response Mechanism (C19RM).

Despite increased awareness and donor support, many funded CLM programs have faced significant challenges to initial implementation and there exists little formalized research on CLM to date. Social accountability mechanisms like CLM remain an understudied approach to health systems strengthening, and assessments of impact on services delivery have been mixed in both health and development more broadly [10, 11]. These variable results have been attributed to broad definitions of social accountability and evaluations that lack nuanced consideration of the complex and highly-context dependent nature of social accountability work

[12, 13]. Accordingly, understanding the potential impact of social accountability work is not just about asking if it works, but seeking to understand the conditions that facilitate success [12].

As several CLM programs conclude their first year (or more) of implementation, and with a rapid growth in CLM implementation anticipated in the near-term, a critical moment has emerged to elucidate the key facilitators and barriers to success emerging from CLM work. This study aims to identify the challenges and associated lessons learned from early implementation of CLM, with the aim of ensuring that investments in CLM implementation are likely to achieve impact and improvements in the quality of care.

2. Materials and methods

2.1 Data collection

Participants were recruited through a two-stage process. First, respondents participated in a brief screening survey that gathered informed consent and data on key parameters of the participants' CLM programs. Participants consented simultaneously to the screener and interview process. The screening survey was distributed in five ways: 1) directly to CLM programs identified by the authors or funders; 2) via research and advocacy networks; 3) via social media; 4) on electronic notice boards of global public health institutions and universities; and 5) through snowball sampling in which respondents were encouraged to share contact information of other individuals and/or programs who may be interested in participating in the project and were able to forward the link to the screening questionnaire. The screening questionnaire was administered through Qualtrics and was available in English, French, Portuguese, Russian, and Spanish (S1 Text).

The screening process was designed to limit the sample and findings specifically to CLM programs, while excluding other community systems strengthening interventions and classic M&E programs. Participants that self-reported being part of a CLM program and met two out of three inclusion criteria were included in the study: 1) implementation is led by a local civil society organization, key, vulnerable, or priority populations, or people living with or impacted by HIV, tuberculosis, or malaria; 2) activities include collecting data on healthcare quality and access; and 3) activities include advocating for solutions and working with decision-makers for change. In addition, participants from programs operating with a regional or global focus (i.e. not implementing in one country) were excluded.

Participants who met the inclusion criteria were invited to participate in an in-depth interview. In cases where multiple respondents from the same CLM program responded (based on the program name) only the first respondent to complete the survey was invited to participate in an interview. In-depth interviews guides were semi-structured and explored key aspects of their program, with a particular focus on challenges, successes, key learnings, and recommendations for best practices (S2 Text).

Interview guides were developed through consultations with CLM implementors and contained five key sections: governance and structure; financing; data collection, analysis, and reporting; advocacy; and engagement with external stakeholders. Interviews were conducted on recorded Zoom calls in the respondent's preferred language and translated to English and transcribed verbatim. Interviews were conducted by two researchers outside of the community, with positionality shaped by their expertise in public health research and evaluation.

An initial 97 respondents began the screening survey, of whom 59 completed the entire survey and 48 were eligible to participate in an interview and 25 completed an interview (Fig 1). Of these, 25 (100%) self-identified as being involved in a CLM program or other initiative to

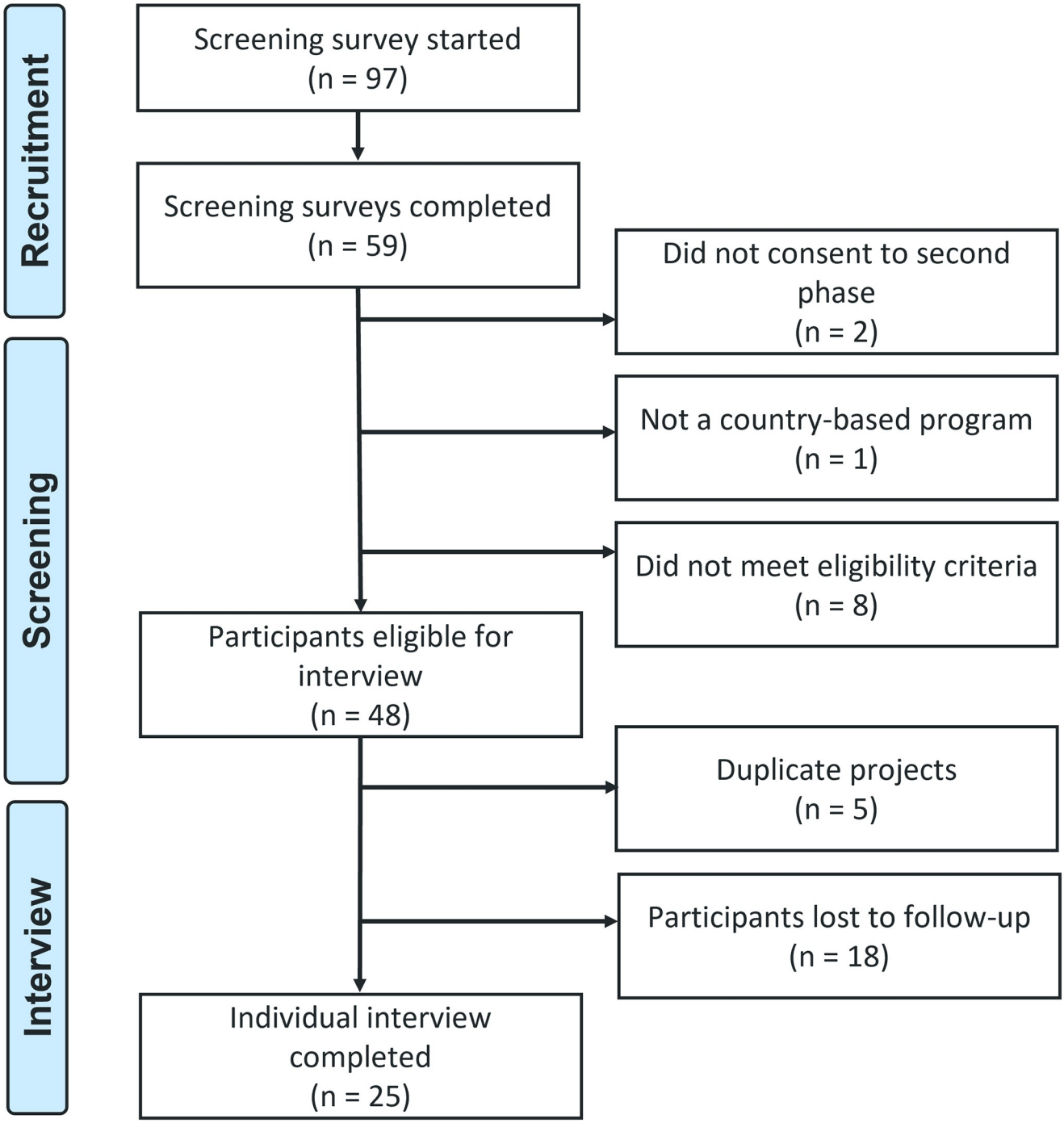

Fig 1. Participant recruitment flowchart.

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use monitoring data to advocate for better healthcare services (Table 1). Among the final sample that participated in the interviews, 18 (72%) fulfilled all three eligibility criteria; four (16%) were part of programs not led by a local civil society organization, key populations, and/or people living with affected by the three diseases; two (8%) were part of programs without advocacy activities; and one (4%) did not report collecting health facility data.

Table 1. Participant characteristics (N = 25).

Characteristic	Total	N	%
Currently working on a CLM program*	25		
Yes		25	100%
No		0	0%
Respondent's position in the CLM program	25		
Staff at an organization involved in implementing the monitoring project		17	68%
Community member involved in the project		11	44%
Other		8	32%
Advisor / consultant / technical assistance provider		6	24%
International donor		1	4%
Government / Ministry of Health		0	0%
UN Organization		0	0%
Focus of the CLM program	25		
HIV/AIDS		23	92%
Tuberculosis		18	72%
Human rights		17	68%
COVID-19		14	56%
Malaria		7	28%
Other		5	20%
Geographic region of CLM program	25		
Western Africa		8	32%
Eastern Africa		7	28%
Middle Africa		3	12%
Central Asia		2	8%
Caribbean		1	4%
Eastern Europe		1	4%
South-eastern Asia		1	4%
Southern Africa		1	4%
Southern Asia		1	4%
Types of activities performed by CLM program	25		
Collecting data on healthcare quality and access at facility and/or community level*		24	96%
Developing an advocacy strategy to resolve issues identified in the data		23	92%
Advocating for solutions and working with decision-makers to implement change*		23	92%
Disseminating the data to key stakeholders		22	88%
Identifying service-related needs and deficits impacting the community		21	84%
Analyzing and interpreting data to find solutions and key action points		20	80%
Monitoring changes over time, looking for trends and impact		19	76%
Other		2	8%
None of the above		0	0%
Who is leading CLM implementation*	25		
Local civil society organizations		17	68%
Key, vulnerable, or priority populations		12	48%
People living with, and communities impacted by HIV, malaria, or TB		12	48%
Nonprofit healthcare organization		9	36%
Other		5	20%
The program donor (for example, the Global Fund or PEPFAR)		3	12%
Ministry of Health or other government body		2	8%
International civil society organizations		2	8%

(*Continued*)

Table 1. (Continued)

Characteristic	Total	N	%
A university or academic institution		2	8%
Not yet determined		0	0%
Who is funding the CLM program	25		
The Global Fund to Fight AIDS, Tuberculosis and Malaria		13	52%
U.S. government (PEPFAR, CDC, USAID)		9	36%
Other		6	24%
U.N. Organization (UNAIDS, UNDP, etc)		4	16%
Stop TB Partnership		1	4%
Private foundation or other donor		1	4%
Self-funded		1	4%
Roll Back Malaria		0	0%
Country government / Ministry of Health		0	0%
The project is still in the planning stages and no funding has been acquired		0	0%

* Indicates question used in exclusion criteria

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2.2 Data analysis

Deductive hierarchical coding was used with a multi-level codebook developed from the interview guide. Each interview transcript was reviewed separately by two researchers. Discrepancies within coding were resolved via discussion with the broader research group. The preliminary codebook was iteratively refined through this group coding approach until consensus was reached. Purposeful thematic analysis of the coded data was then conducted, guided by the approach of Nowell et. al. [14]. Thematic analysis relied heavily on researcher triangulation, with researchers discussing identified themes until consensus was reached to support analytic validity [14, 15].

2.3 Ethical approval

This study was approved by the Georgetown University institutional review board. Electronic written informed consent was obtained from all participants as part of the Qualtrics screening survey. All data were collected between January and March 2022.

3. Results

3.1 Participants

Twenty-five respondents participated in individual interviews. Participants were from 21 countries, with representatives primarily from Western Africa, Eastern Africa, and Middle Africa (Table 1). Respondents were primarily staff working for an organization implementing the CLM program and/or community members involved in the project. Implements from CLM projects focusing on HIV/AIDS, tuberculosis, malaria, COVID-19, and human rights were included in the sample.

3.2 Themes

Thematic analysis revealed implementers' perceptions of common facilitators and barriers to successful CLM implementation.

3.2.1 Facilitators to CLM implementation. *Negotiating stakeholder relationships*. Part of maintaining successful relationships with stakeholders frequently required framing CLM as a collaboration between community, funders, and government. This positioning was achieved in several ways. First, many programs noted they had to engage a diversity of stakeholders early, both to explain the CLM model and to convey the program as a non-oppositional partnership.

> *I think the greatest thing that we did was to acquire high political will, which we did through the observation, and the acknowledgement and utilization of the current status quo. . .we have the [Ministry of Health] which is the clinical partner with regards to HIV, TB and malaria; and then, we've got—from a strategic viewpoint—the National AIDS Council. So, we looked at those entities, and we said, what role should they play in CLM? It was also important for us to set-up an entity that will not be viewed as challenging the government. Let's come together and, from the outset, create a platform together.*
>
> *(respondent from Eastern Africa)*

Secondly, respondents described the need to present data in a nuanced way, highlighting successes alongside gaps and ensuring that the program brought community-generated solutions alongside the issues they identified.

> *The other thing is the way you are conducting advocacy, it's like you are not coming to show their mistakes, their wrongs, you are going there to offer more opportunities, you are going there to offer solutions. If you are going there with that angle they can be able to be more open and listen to those kinds of findings or feedback.*
>
> *(respondent from Eastern Africa)*

However, in some cases stakeholders were unconvinced of the collaborative nature of CLM and instead perceived it as an antagonistic civil society tactic. This conception was described as creating challenges with soliciting support from stakeholders and building relationships with clinic staff.

Building on existing community structures. Respondents repeatedly described the value in incorporating community members and key populations into CLM implementation. While a few respondents found it challenging to manage roles and priorities across diverse organizations, respondents overall found a multitude of benefits to leveraging existing networks of community organizations and service users when starting CLM programs. Existing networks were able to expand the reach of CLM programs in less resource-intensive ways, often because they covered a wider geographic area and already had skilled and knowledgeable staff.

> *There's a network of people living with HIV and AIDS, people who use drugs also have their own network [. . .] commercial female sex workers also have their own groups [. . .] then the same thing with the LGBT communities. If we want to collect more data also, we can also leverage [these networks] because with a limited amount of resources and power, we can't reach everybody. But if we can also collect data via this network, it has a wider reach.*
>
> *(respondent from Western Africa)*

In addition to the benefits for data collection purposes, these networks also served as critical pathways for disseminating CLM data back to communities, which was perceived to be a challenging but essential component of CLM.

Employing health service users and representatives of key populations as data collectors and advocates was also noted as essential for legitimizing the programs. Staffing from the community conferred several benefits, including legitimizing the program in the eye of stakeholders, service recipients feeling more at ease discussing challenges during data collection, and the opportunity to draw on firsthand expertise around community needs during data analysis and advocacy. It was also noted that while programs benefited from community staff, the monitors themselves benefited by building a knowledge base about the issues directly impacting them and developing transferable professional skills.

But also, the use of the data collectors who were, you know, people from the communities—people from the districts where the study was taking place—was also an awesome thing because it empowered people to understand what it is when they are talking about COVID, when they're talking about TB or HIV. And also, you would see that the capacity that was built also was that people were able to understand exactly how important data is when you are making programs.

(respondent from Eastern Africa)

3.2.2 Barriers to CLM implementation. *Implementer relationships with stakeholders*. A core tenet of the CLM model is programmatic leadership by civil society organizations and community members. Respondents commonly reported that funders, financial pass-throughs, and governments were leading aspects of implementation that respondents identified as rightfully belonging to the community. For one program, this meant that community members were hired as data collectors with no other participation or leadership in CLM implementation:

So, the donors have the full control over how they want everything done if they're funding them, and it prevents them. . .as the organization—to share those results with who they want to share those results. . .And then after they collect the data, the donors just take the data off their hands and do whatever they want with it.

(respondent from Central Asia)

Similarly at odds with community leadership, donors and financial pass-through organizations also made significant decisions about the populations and topics to be prioritized in monitoring, as well as decisions about how community data could be shared. This included blocking the use of a publicly available data dashboard for one program.

The big issue for [us] now is to use the dashboard to publish all the data we have. We still have the dashboard, [but] we need to have the conversation we PEPFAR [. . .] they really don't accept us to publish it for anyone to see. [. . .] So, if we can address that situation [with] OGAC and PEPFAR [to clarify that] the CLM have the rights to publish the data on their dashboard.

(respondent from Caribbean)

At times, these challenges to community ownership were driven by misunderstandings about the CLM model. Funders and governments were described as unaware of CLM's objectives, methodology, and their role in implementation. These misunderstandings made it difficult to solicit political buy-in. Additionally, some stakeholders urged CLM programs to adopt

standardized, international monitoring indicators, which respondents noted led to survey instruments that were not appropriate for their local context. Where all stakeholders were able to reach consensus around the purpose of CLM early and communities obtained buy-in from the national government, this partnership facilitated engagement with local government and facilities during program implementation. Maintaining these relationships required ongoing communication, regular dissemination of results to stakeholders, and participation in meetings and events.

Improperly-financed and underfinanced for scope of work. Respondents consistently reported challenges funding CLM programs, both due to underfunding and delays in receiving funds from donors. A commonly-reported gap was adequately paying the 'community monitors,' a term referring to CLM frontline staff who collect data in the community or at health facilities. Multiple respondents reported that community monitors needed to pay out-of-pocket for costs related to data collection.

Other common funding gaps were reimbursing transportation costs during data collection, purchasing tablets for electronic data collection, and budgeting sufficiently for advocacy activities. Data collection costs were noted to take priority in budgets, leaving limited resources for advocacy staff, deliverables, and actual engagement with service providers, government, and funders.

One consequence of low salaries was high turnover of community monitors, which exacerbated financial challenges by requiring programs to invest in frequent re-training of staff.

> *One of the key areas that we currently are not sure of is [. . .] are the [community monitors] going to stay long? Are we going to incentivize them enough to stay long and do this work after having invested so much in them? [. . .] Probably the answer is not yes, it's a no, because these are people who can take their skills and capacities somewhere else.*
>
> *(respondent from Eastern Africa)*

Low budgets were described as a consequence of donor-driven requirements, including overall CLM budget ceilings, caps on reimbursing community workers, and declining to pay for electronic data collection tools and advocacy program components. Additional challenges included opacity around funding mechanisms, lack of visibility on available funding, and challenges engaging in budget negotiations.

In addition to the amount of funding available for implementation, the funding disbursement mechanisms themselves were described as a challenge. Many respondents described not receiving indirect costs and overhead in CLM grants, which were perceived as necessary to implementing quality programming. This lack of indirect costs was especially challenging when significant staff capacity was directed toward CLM implementation. In some cases, respondents described donor funding being routed through multiple financial conduits, each deducting indirect costs at the expense of the overall programmatic budget.

The financial intermediaries created additional challenges that extended beyond funding. One report described a financial conduit refusing to release funds.

> *There was an HIV program manager [with the Principal Recipient who would tell us] that no, we have no money for [community] observers, so instead of three you will continue with a single observer. We said "Ah, well, there is no money? How?" And I was forced to write to the Global Fund [. . .] and the Global Fund was forced to balance the approved budget for the country and under the watchdog line, there was money.*
>
> *(respondent from Middle Africa)*

In other cases, financial intermediaries created conflicts of interest, particularly in scenarios where the principal recipient of funding had authority over the programs being monitored.

Respondents suggested that direct funding of the civil society organizations leading CLM implementation, or funding passing through a non-implementing institution like UNAIDS, could mitigate these conflicts of interest. More direct funding of community organizations was additionally described as helping to build organizational capacity of community organizations.

Establishing CLM as distinct from monitoring and evaluation. Another commonly identified challenge was stakeholders conflating CLM with academic research and M&E. Respondents described facing questions about the validity of CLM data, with stakeholders holding CLM programs to technical research standards for sample sizes, sampling, and generalizability, often using this critique to discredit CLM findings and recommendations. However, many of the ways in which CLM can be distinguished from academic research were seen as positives for community members, particularly the timeliness of CLM data and the way in which data is truly reflective of community priorities.

> *[CLM] creates a world apart from the previous world where community-led monitoring was not available, where we had to rely on surveys, where we had to rely on a situational analysis and all sorts of things that are very. . .what I can call very academic, very structured in nature. It's community-led monitoring, where it is functional, where the information is available, and it's stored and packaged in a manner that speaks to what communities want, creates an opportunity for data that is available, that can be shared at any moment.*
>
> *(respondent from Eastern Africa)*

Programs also collected qualitative data that were described as being compelling, but respondents were unsure of how to present the data in a way that would be acceptable to duty bearers.

> *If you pick up qualitative issues [. . .] some of them are critically important for one site, but they are not for another site. But I think people or stakeholders, and even key advocacy players, are interested in things that affect the majority. So how do you transmit that information about the minority so that it makes sense?*
>
> *(respondent from Eastern Africa)*

Capacity gaps remain. The routine cycle of data collection proved to be a significant challenge for multiple programs. This included navigating to remote and sometimes dangerous facilities, keeping data collection tools relevant to the priorities of the community, and figuring out affordable and usable electronic data collection systems. Where data were successfully collected, several programs reported being unable to analyze data and propose evidence-informed solutions quickly enough to be timely for advocacy. This was especially true for programs utilizing paper data collection rather than electronic data collection, which proved to demand inordinate staff effort to successfully manage and analyze.

> *The data analysis takes a lot of time if you want to do it the right way. . .usually this is what happens—they collect data, then for another half a year, they're working on the report. And then the results that are being represented are retroactive, right? So they're not representing what's currently happening.*
>
> *(respondent from Eastern Europe)*

Respondents also noted that there were critical skills gaps among the community monitors. Despite program management staff receiving technical assistance to build capacity around data skills, community monitors often lacked those same opportunities. Providing more professional development opportunities and training for community monitors was perceived as an opportunity to both incentivize staff to stay engaged with the program and to improve the quality of data collection and direct advocacy.

> *[Community monitors] are the ones at the front. It's different from the generals who are in the offices. They are theorists where they know war, in theory. But [without capacitation] those who face the enemy, the target. . .they are not armed.*
>
> *(respondent from Western Africa)*

Conducting activities for the advocacy phase was also identified as a challenge, with programs lacking technical advocacy skills and the human resources to allocate to advocacy. CLM programs reported successful advocacy required negotiating challenging political contexts and navigating a complexity of stakeholders responsible for different aspects of service delivery. Challenges included identifying the players capable of addressing specific issues captured by CLM data and developing tailored advocacy the strategies that would effectively reach different levels of government.

> *And the other thing is there are different stakeholders that play different roles at the facility, so sometimes it will be an issue to do with those that have worked with construction. Yet for us, maybe we are trying to approach the Department of HIV and AIDS, it's not affected by that.*
>
> *(respondent from Central Asia)*

Many programs also found that despite sufficient technical assistance (TA) around data collection, TA for advocacy skills was nearly nonexistent. Some programs suggested that more opportunities to learn from CLM programs elsewhere might help to fill advocacy-related capacity gaps.

4. Discussion

The community-led monitoring model is defined by two key characteristics: first, by its emphasis on community ownership of the full cycle of activities, and secondly, that data collection must be followed by evidence-informed advocacy. This study provides an early look into the real-world experiences and challenges facing community implementers.

The reported value of community ownership, collaborative approaches, and using community data for advocacy align with previous evidence [5]. Indeed, the existing evidence base on social accountability for health services has suggested that such strategies often work through 'soft pressure' in which change occurs through positively shifting relationships between community and duty bearers, [16] aligning with the emphasis respondents in this study placed on generating collective buy-in and collaboration. The critical role that allies both within health systems and within civil society can play in further elevating or supporting accountability demands has been well established, further supporting the role that broad stakeholder buy-in can play in successful CLM implementation [12, 17]. Ensuring stakeholders understand the concept and importance of CLM can help to strengthen these ally-ships.

In addition to allies within health systems or donors, respondents here also cited the importance of engaging a broad coalition of civil society in CLM efforts, especially in order to build the reach of CLM efforts in a resource efficient way. The literature suggests that beyond this

particular benefit, social accountability efforts that consist of or engage with a broad variety of community and civil society organizations may help to grow the social capital of the effort and help to increase bargaining power with duty bearers [18]. Interestingly, the need for CLM to representative of broad swaths of community also emerged in this study as it relates to approaches to data collection. Respondents noted that qualitative data was often dismissed by decision makers. The aggregation of voice has been proposed as an important moderator of social accountability success, aligning with challenges CLM projects faced in make the stories of individuals pressing for decision-makers [12].

The importance of hiring impacted communities to serve as data collectors highlighted by respondents in this work aligns with previous literature that suggests decision-makers perception of the legitimacy of citizen groups may play an important role in responsiveness to social accountability [16]. Respondents here highlighted that this also helps service users to build capacity and advocacy skills. Indeed, empowerment of community is a key outcome tied to social accountability in development broadly, though the potential for empowerment may be limited where state structures and processes over dictate the structure of accountability interventions [10].

In this study, participants noted that they were at time challenged by gaps in skills related to both data collection and advocacy. The inclusion of mechanisms that aimed to build capacity for collective action has been noted as an important facilitator of accountability and transparency work that engages community [18]. Respondents in this study made clear that this kind of capacity building is often under-funded within their projects.

While existing literature supports that social accountability work can be limited by challenges related to under-funding, more specific concerns related to funding structure emerged from this study [19]. Donors appear ill-adapted to financing large-scale programs that are led by community organizations, with clear barriers emerging around adequately funding core program costs. Further, traditional funding mechanisms are challenging for community organizations with limited financial capacity, with low budgets or delays in disbursements having knock-on effects on program's abilities to implement programs and retain staff.

These findings have implications for funders, stakeholders, and CLM implementers. Funder policy is needed that emphasizes community ownership of all aspects of CLM and funders can also actively support CLM implementors when other stakeholders are challenging those roles. Such policy should outline roles and limitations of financial passthroughs and technical assistance providers. Where needed, funders may also have to facilitate preliminary meetings between government and CLM programs to build understanding of the CLM model, where community members cannot safely or effectively do so.

As the evidence base on effective CLM grows, grant allocations and structures must grow to accommodate these components like funding for community monitor pay or salary, aspects of CLM advocacy like dedicated staff and technical assistance, and the tools necessary for electronic data collection. Where program implementation is yet to begin, funders should structure requests for applications that facilitate CLM implementation by networks of community organizations to amplify reach and impact of programs.

Existing literature has emphasized the potential of social accountability efforts to improve service provider and service user relationships, quality of care, and healthcare outcomes, [10, 16, 19, 20] and despite the nascency of many of the CLM programs described here, many respondents viewed CLM as a valuable tool for elevating community voice in service delivery where implementers successfully create strong working relationships with stakeholders, service users, and civil society networks. Stakeholders have the opportunity to facilitate the implementation of high quality CLM by addressing the need for flexible, adaptive funding mechanisms and greater consensus to be built around CLM models and roles.

5. Conclusions

Community-led monitoring may play an important role in improving healthcare systems through community and service user empowerment. However, understanding the moderators of successful CLM implementation is critical to improving implementation moving forward. Ensuring impactful CLM implementation will require a concerted effort by international donors, governments, and other stakeholders to financially and programmatically support community organizations with the implementation of large-scale, technically complicated programs.

Supporting information

S1 Checklist. Inclusivity in global research.
(DOCX)

S1 Text. Brief screening tool.
(DOCX)

S2 Text. Interview question guide.
(DOCX)

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