



# HHS Public Access

Author manuscript

*Stigma Health*. Author manuscript; available in PMC 2023 November 01.

Published in final edited form as:

*Stigma Health*. 2022 November ; 7(4): 443–453. doi:10.1037/sah0000404.

## The Association of Perceived, Internalized, and Enacted HIV Stigma With Medication Adherence, Barriers to Adherence, and Mental Health Among Young People Living With HIV in Zambia

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### Abstract

Few studies have examined the independent effects of different manifestations of HIV stigma experiences on health outcomes among youth living with HIV in low- and middle-income countries. We examined the association of internalized, enacted, and perceived HIV stigmas with medication adherence, self-esteem, depression, and barriers to adherence. Young people living with HIV aged 18–21 years ( $N = 120$ ) were purposively sampled from two health facilities in Eastern Province, Zambia, and completed self-report measures. Results indicated heterogeneous associations. Internalized HIV stigma was positively associated with depression and negatively associated with adherence, adherence motivation, behavioral adherence skills, and self-esteem. Perceived stigma was negatively associated with self-esteem. No significant association was observed between enacted stigma and health outcomes. The complexity of HIV stigma requires a precise explication of the associations among different HIV stigma experiences and outcomes, which can inform the development of stigma reduction interventions targeting one or more stigma experiences.

### Keywords

internalized stigma; enacted stigma; perceived stigma; adherence; mental health

### Introduction

HIV remains a highly stigmatized illness in many communities in Zambia, particularly among young people (Krishnaratne et al., 2020; Ministry of Health Zambia, 2016). HIV

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All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the University of North Carolina at Chapel Hill IRB (Study # 17–3329) and the University of Zambia Biomedical Research Ethics Committee (Ref 008-01-18).

stigma manifests through various experiences and practices (Earnshaw et al., 2013; Stangl et al., 2019). A recent study conducted in Zambia revealed the persistence of internalized stigma, defined as self-endorsement of negative views about HIV and people living with HIV, and perceived stigma, or the perception that the community devalues those living with HIV (Biemba et al., 2020). In the same study, about one-third of people living with HIV reported experiencing internalized and perceived HIV stigma, whereas more than 60% of health care providers remarked that stigma was a barrier to HIV testing, treatment initiation, and adherence. These stigma experiences result from various practices perpetuating HIV stigma through stereotypes, prejudice, stigmatizing behaviors, and discriminatory attitudes (Stangl et al., 2019). Another study in Zambia reported high levels of judgmental attitudes among healthcare workers toward young people living with HIV (YPLH) and other key population groups affected by HIV (Krishnaratne et al., 2020). Young people's unique physiological and psychological characteristics may heighten their vulnerability to stigma experiences and their adverse effects. The high levels of stigmatization experienced by YPLH have contributed to their lower antiretroviral therapy (ART) initiation and retention rates compared to children and older adults living with HIV in Zambia and elsewhere in southern Africa (Denison et al., 2015; Maskew et al., 2019; Mesic et al., 2019; Rueda et al., 2016; Sweeney et al., 2016).

In addition to suboptimal treatment and care outcomes, evidence suggests an association of HIV stigma with other adverse health and social outcomes, including high levels of anxiety and depression and low levels of self-efficacy among adults living with HIV, and dropping out of school among YPLH (Kane et al., 2019; Kimera et al., 2019; Rueda et al., 2016). However, studies on various HIV stigma experiences and health outcomes involving youth populations remain limited. In a 2019 scoping review of HIV and other health-related stigma research in low- and middle-income countries (LMICs), Kane et al. (2019) reported that less than 5% of included studies involved youth populations. Additionally, internalized stigma was assessed as the most common stigma experience, whereas fewer studies focused on enacted, anticipated, or perceived stigma (Kane et al., 2019). In other words, research is needed to examine which HIV stigma experiences affect health outcomes among YPLH and to identify whether there are consistent or conflicting relationships between different HIV-related stigma experiences and health outcomes. Maughan-Brown and Nyblade (2014) reported that different dimensions of HIV-related stigma might have opposite effects on HIV testing, with perceived and enacted reducing the odds of having had an HIV test, whereas symbolic stigma, or the belief that people living with HIV are less valuable or productive than others, increasing the odds of having had an HIV test. Another study identified that different types of HIV-related discrimination affect retention in care among YPLH differently, with discrimination due to a family member's HIV status directly affecting retention in care (Pantelic et al., 2020). In contrast, discrimination due to the adolescent's HIV status only indirectly affects retention in care. Similar studies that examine the association of different types of HIV stigma experiences with YPLH's health outcomes remain lacking, particularly in LMICs, though studies involving adults are available (Sweeney et al., 2016).

Evidence linking HIV stigma to various health outcomes has contributed to research examining potential pathways or mediators that might explain the relationship between

stigma and health outcomes among people living with HIV (Haines et al., 2019; Kane et al., 2019). Several prior studies involving YPLH in LMICs identified depression and increased risk of other mental health challenges as a mechanism linking HIV stigma to suboptimal treatment outcomes (Ashaba et al., 2019; Earnshaw et al., 2018; Luseno et al., 2021). Other psychosocial pathways that may link HIV stigma experiences to adverse treatment and health outcomes among YPLH are under-researched (Sweeney et al., 2016), though studies involving non-youth populations have identified additional pathways such as individual resilience and self-efficacy (Zhang et al., 2015; Zhou et al., 2020). Well-documented intra- and inter-personal correlates of treatment adherence and retention in care among YPLH, such as motivation and behavioral adherence skills (Fisher et al., 2008; Peh et al., 2021; Rongkavilik et al., 2010), may provide conceptual support to explore other plausible pathways.

The current study was conceptualized to fill gaps in the literature. We examined the association of different HIV stigma experiences (i.e., internalized, enacted, and perceived) with treatment adherence and mental health outcomes among YPLH in Eastern Province, Zambia. This study adds to our understanding of HIV stigma in youth populations by exploring the independent effects of different manifestations of HIV stigma experiences. We also examined the association of HIV stigma experiences with self-esteem, adherence motivation, and behavioral skills to perform adherence-related tasks. These psychosocial factors, alongside depression, may be additional pathways linking stigma to adverse outcomes among YPLH. However, their association with stigma experiences among YPLH in LMICs is unknown.

## Methods

### Design and Sample

This study analyzed cross-sectional baseline data collected from YPLH ( $N = 120$ ), who participated in an asset-based intervention study to improve treatment adherence. The asset-based intervention comprised a 10-session socioemotional skills training and access to a youth-friendly account offered by a local bank with branches in the study sites. Eligibility criteria included: age (between 18 and 21 years old), awareness of HIV positive status, and receiving outpatient HIV treatment and care at either one of two hospitals. The two hospitals were selected due to their comparability based on accessibility for participants, access to ART, and availability of support services for youth living with HIV and their families, such as adherence counseling and home visitations. The ART enrollment list was used to purposively select youth who met the eligibility criteria. Project staff met with prospective participants at the participating hospitals during the youth's scheduled hospital visits to explain the study and to discuss and obtain consent. Each prospective participant was asked if they would like to consider further participating in the study to minimize coercion. In such cases, project staff sought oral consent to contact the youth by phone no sooner than three days after the first consent discussion. Recruitment continued until 60 youth per hospital were enrolled.

Discussions with prospective participants and informed consent procedures were conducted in private. Written informed consent was obtained from all study participants. Study

materials, including the participant information sheet and consent form, were in English and Chewa. The project staff was also fluent in Tumbuka to accommodate participants who preferred to speak in Tumbuka. Study procedures were submitted to and approved by the institutional review boards at the University of Zambia and the University of North Carolina at Chapel Hill. Additionally, a research clearance was obtained from the National Health Research Authority in Zambia.

## Setting

The study was conducted in Chipata and Lundazi districts in Eastern Province. Eastern Province is predominantly rural, with 87% of the population living in rural areas. Chipata and Lundazi districts were selected as they were within the service area of the Rising Fountains Development Program, the project's community-based organization partner with offices in Chipata and Lundazi. Chipata District, the provincial capital, had an estimated population of 566,157 in 2020 (Zambia Statistics Agency [ZSA], 2020). Lundazi District, adjacent to Chipata District, had an estimated population of 442,300 in 2020 (ZSA, 2020). An equal proportion of each district's population was male and female. Additionally, an estimated 20% of each district's population was young people aged 15 to 24 years old.

Consistent with the national trend, HIV prevalence in Eastern Province was higher for females than males among youth aged 15–19 and 20–24. In 2019, HIV positivity rates for females aged 15–19 and 20–24 were 1.7 and 3.2, respectively. Males from the same age groups had HIV positivity rates of 0.8 and 1.9. HIV positivity rates among youth in Eastern Province remained lower than the national averages (ZSA, 2020). An estimated 91% of people (aged 15 years old) living with HIV in Eastern Province knew their status and were on antiretroviral therapy in 2019. Further, 80% were virally suppressed. The most recent data indicated that 81,000 residents of Eastern Province were living with HIV (Ministry of Health Zambia, 2019).

Two health facilities were selected as study sites – Chipata Central Hospital (CCH) and Lundazi District Hospital (LDH). CCH is a third-level or specialty hospital. It serves the entire Eastern Province, with a catchment population of 1.96 million people, including 455,000 residents of Chipata District. CCH offers the most comprehensive medical services in the Eastern Province. LDH is a first-level hospital serving Lundazi District, with an estimated population of 324,000. Both hospitals are government-run and offer services, such as HIV counseling and testing, prevention of mother-to-child transmission, and HIV treatment and care. CCH and LDH are 180 kilometers apart.

## Data Collection

Data were collected between August 2018 and March 2019 using an interviewer-administered survey questionnaire. The questionnaire gathered data on participants' demographics, household economic status, food security and dietary diversity, health behaviors and treatment adherence, social support, social and emotional skills, and experiences of stigma and discrimination. All interviewers trained to administer the survey questionnaire were community members who have worked with young people living with HIV. The interviewers were fluent in English, Chewa, and Tumbuka.

## Measures

**Stigma experiences**—Stigma experiences referred to three manifestations of HIV stigma experiences among YPH. First, internalized HIV stigma was defined as the acceptance of negative societal characterizations, labels, and thoughts about people living with HIV and applying them to the self (Earnshaw and Chaudoir, 2009). Internalized stigma was measured using a 5-item negative self-perception scale ( $\alpha = 0.81$ ) (Holzemer et al., 2007). Youth were asked whether and how frequently in the past three months (never/once or twice/several times/most of the time) they felt worthless, ashamed, no longer a person, brought a lot of trouble to their family, and did not deserve to live, because of their HIV positive status.

Second, enacted HIV stigma referred to actual experiences of discrimination, devaluation, and prejudice by others because of one's HIV-positive status (Earnshaw and Chaudoir, 2009). Enacted stigma was measured using an 8-item verbal harassment scale ( $\alpha = 0.80$ ) (Holzemer et al., 2007). Youth were asked whether and how frequently in the past three months (never/once or twice/several times/most of the time) they experienced being blamed for their HIV status, being scolded, being insulted, being called bad names, being told that they have no future, being mocked, being told that God is punishing them, and hearing offensive songs when passing by.

Third, perceived stigma pertained to awareness of public stigma or a belief that others hold stigmatizing thoughts about people living with HIV (Quinn and Chaudoir, 2009). Perceived stigma was measured using a 3-item public attitude toward HIV scale ( $\alpha = 0.73$ ) (Wiklander et al., 2013). Youth were asked about their level of agreement/ disagreement (strongly disagree/disagree/agree/strongly agree) with the public's stigmatizing beliefs about HIV. Youth were asked about the following three items: "Most people think a person with HIV is disgusting," "Most people with HIV are rejected when others learn about their status," and "Most people believe a person who has HIV is dirty." Scale items comprising each stigma experience were summed to create stigma scores. Higher scores indicated higher levels of stigma.

**Adherence**—Adherence to antiretroviral therapy was measured using two self-reported methods: the visual analog scale (VAS) and the Center for Adherence Support Evaluation (CASE) Adherence Index. We included two measures of adherence to increase the validity of findings. The VAS assessed adherence during the past seven days. Youth were asked to place an "X" inside the box above the point showing the best guess about how much of their current antiretroviral (ARV) medications had been taken in the past seven days. Despite their limitations, patient self-assessments of ART adherence have been shown to perform well (i.e., no evidence of significant overestimation) compared to other more objective adherence measures such as pharmacy records (Kabore et al., 2015; Simon et al., 2014). Two binary adherence variables based on VAS were created. The primary adherence variable operationalized adherence as taking 100% of scheduled doses during the past seven days. Youth were adherent if they took 100% of prescribed doses and nonadherent if they took <100% of prescribed doses. The additional adherence variable operationalized adherence as taking 90% of scheduled doses during the past seven days. Similarly, youth were adherent if they took 90% of scheduled doses and nonadherent if they took <90% of prescribed

doses. Due to the highly skewed nature of continuous self-report measures, we set the adherence cutoff at 100% (Simoni et al., 2006). The other adherence cutoff at 90% is consistent with evidence suggesting that 90% adherence is associated with a lower risk of virologic failure (Bezabhe et al., 2016; O'Halloran Leach et al., 2021).

The CASE Adherence Index is a composite measure of three self-reported ART adherence questions (Mannheimer et al., 2006). The first question asks about the frequency of difficulty taking HIV medications on time (never/rarely/most of the time/all of the time). The second question asks about the average number of days per week at least one dose of HIV medications was missed (never/less than once a week/once a week/2–3 days per week/4–6 days per week/every day). The third question asks about the last time youth missed at least one dose of HIV medications (within the past week/1–2 weeks ago/3–4 weeks ago/between one and three months ago/more than three months ago/never). The CASE Adherence Index score was calculated by summing the responses to the three items, with composite scores ranging from three to 16. Higher scores indicate higher levels of adherence. A binary adherence variable was created to examine the association between stigma and the CASE Adherence Index. Youth had good adherence if their composite score was greater than 10 points, whereas youth with composite scores of 10 and lower had poor adherence (Mannheimer et al., 2006).

**Barriers to Adherence**—Barriers to adherence referred to the motivation and behavioral skills constructs in the Information-Motivation-Behavioral Skills (IMB) model of adherence (Fisher et al., 2006). Motivation refers to youth's personal and social motivation to adhere to ART. Motivation was measured using five items adapted from the LifeWindows Information-Motivation-Behavioral Skills ART Adherence Questionnaire (LW-IMB-AAQ; The Life Windows Project, 2006). Each item represents a barrier related to the motivation construct. Four items asked youth about their attitudes and beliefs about adherence, with each item (e.g., "I am worried that other people might realize that I am HIV+ if they see me taking my HIV medications") describing the burden of adherence and its impact on daily life. One item asked youth about their perceptions of social support in taking their HIV medications (i.e., "Most people who are important to me know I am HIV positive support me in taking my HIV medications"). Youth responded using a 4-point Likert-type scale (strongly agree/agree/disagree/strongly disagree). Item scores were summed to create a total motivation score, with higher scores indicating higher motivation levels to adhere to ART ( $\alpha = .73$ ).

Behavioral skills refer to youth's objective ability to perform necessary adherence-related tasks and their perceived self-efficacy for these tasks (Fisher et al., 2006). Behavioral barriers to adherence were measured using seven items adapted from LW-IMB-AAQ. Each item represents a barrier related to the behavioral skills construct in the IMB model of adherence. Youth were asked how hard or easy it was for them to perform various adherence-related tasks, including support for taking HIV medications, on-time medication refills, strategies to minimize side effects of ARV medications, and self-reinforcement for adherence over time and across different events. Youth responded using a 5-point Likert scale (very hard/hard/sometimes hard, sometimes easy/easy/very easy). Item scores were summed to create a total behavioral skills score, with higher scores indicating higher

perceived self-efficacy levels and lower difficulty levels in performing adherence-related behaviors ( $\alpha = .85$ ).

**Depression**—Depression was measured using the short form of the Children’s Depression Inventory (CDI-S). The CDI-S comprises ten items adapted from the original 27-item CDI (Kovacs, 1985). The CDI-S asks youth to rate the severity of different symptoms of depression. Each symptom is presented as a series of three phrases, and youth are asked to select the phrase that best represents how they feel (e.g., “I have plenty of friends”/“I have some friends but wish I had more”/“I do not have any friends”). Item scores were summed to create a total depressive symptomatology score, with higher scores indicating more depressive symptomatology ( $\alpha = .74$ ). Research has identified the similarity of CDI-S to the original CDI concerning sensitivity and specificity in detecting depression (Allgaier et al., 2012).

**Self-esteem**—Self-esteem was measured using the Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965). This 10-item scale measures global self-worth. Youth were asked about their level of agreement/ disagreement (strongly disagree/disagree/agree/strongly agree) with items describing positive and negative feelings about the self. Item scores were summed to create a total self-esteem scale score, with higher scores indicating higher self-esteem ( $\alpha = .81$ ). The RSES is a widely used instrument for evaluating individual self-esteem and has been reported to have acceptable reliability and validity with youth in sub-Saharan Africa, including young people living with HIV (Agyemang, et al., 2020; Mwakanyamale & Yizhen, 2019).

**Covariates**—Covariates included gender (male/female), age (in years), currently in school (yes/no), worked in the last 30 days (yes/no), geographic residence (Chipata District/ Lundazi District), and attitudes toward living at home. Attitudes toward living at home were measured using a 6-item, 4-point Likert scale (Amato, 1988). Youth were asked about their level of agreement or disagreement (strongly disagree/disagree/agree/strongly agree) with positive or negative evaluations of one’s family and home environment. Item scores were summed to create an attitudes-toward-living- at-home scale score, with higher scores indicating positive views about living at home ( $\alpha = .79$ ). Research has identified that these covariates affect stigma and health and treatment outcomes (Akaturkwaswa et al., 2021; Logic & Gadalla, 2009; MacLean & Wetherall, 2021).

## Analysis

Bivariable and multivariable analyses were conducted to examine the association of internalized, enacted, and perceived HIV stigma with treatment adherence, adherence barriers, and mental health outcomes. Data analyses were conducted using logistic regression for binary dependent variables (adherence) and linear regression using the ordinal least squares method for continuous dependent variables (adherence motivation, adherence-related behavioral skills, depression, and self-esteem). The significance level was set at  $p .05$ , two-tailed test.

Before estimation, we performed multiple imputation (MI) to address missing data issues. We conducted MI after our missing data patterns met the criteria Jakob and colleagues (2017) recommended for determining when to use MI. For example, our missing data were not negligible (above 5% missingness), were not substantial (below 40% missing data), and met neither the missing completely at random (MCAR) nor the missing not at random (MNAR) assumptions. First, missing data patterns were described. Study variables with missing values included both measures of adherence (2%), enacted stigma (7%), internalized and perceived stigma (6%), depression (20%), self-esteem (8%), adherence motivation (4%), and adherence behavioral skills (6%). We explored the differences between youth with complete and incomplete data to examine the validity of the missing-at-random (MAR) assumption. Youth with complete and incomplete data did not differ significantly on all independent and dependent variables in our models. Second, diagnostic tests were conducted to compare the distributions of the observed, imputed, and completed values (Eddings & Marchenko, 2012; Nguyen et al., 2017). The distributions obtained using *middiagplots* did not differ considerably, indicating that our imputation model was appropriate (Eddings & Marchenko, 2012). Third, we built an imputation model based on best practices suggested in the literature (Enders, 2010; White et al., 2011). For example, all variables in the MI model were minimally associated with the variables containing the missing values. We also created a more general imputation model than a specific analytical model to capture more associations between the variables (Enders et al., 2006). Our imputation model comprised all variables in our analytic models, including all outcome and stigma variables and auxiliary variables, such as household food insecurity and social and emotional skills. These auxiliary variables were not included in our analytic models but were added to the imputation model to increase statistical power and plausibility of the MAR assumption (Johnson & Young, 2011; White et al., 2010). We determined auxiliary variables based on our review of the literature. Fourth, MI datasets were created by imputation using the chained equations approach (White et al., 2011). We also used regression with augmented data to avoid problems associated with perfect prediction in multiple imputations of categorical variables (White et al., 2010). Continuous variables with nonnormal distributions were imputed by predictive mean matching (Morris et al., 2014). Last, we created our primary MI model with 100 imputed data sets to yield accurate statistical results and improve power (Graham et al., 2007).

Using MI data sets, we estimated seven multivariable models. These seven models examined associations of enacted, internalized, and perceived HIV stigma with treatment adherence (models 1–3), adherence motivation (model 4), adherence-related behavioral skills (model 5), depression (model 6), and self-esteem (model 7). The three treatment adherence models represented different measures and operationalizations of treatment adherence (i.e., Case Adherence Index and VAS, with two adherence thresholds at 100% and 90%). We also compared the results based on complete-case analysis and MI; the results were similar. While complete case results had larger coefficient sizes, the direction of associations did not change when using complete-case analysis or the MI method. All analyses were conducted using Stata 17 (Stata, 2021).



## Results

### Sample Characteristics and Bivariable Results

Table 1 presents sample characteristics and results of bivariable tests examining the association of each manifestation of HIV stigma experience with treatment and health outcomes. The sample included more females (63%) than males. Average age was 19 years old. At the time of data collection, most participants were attending school (62%), whereas 22% reported working in the last 30 days. More youth were from Chipata (55%) than Lundazi. Youth positively perceived their home environment as illustrated by the high attitudes toward living at home scale scores (see Table 1). On average, youth reported lower internalized and enacted stigma levels than perceived stigma, with a mean score twice the minimum possible score. Most youth were adherent to ART. The proportion of adherent youth based on the CASE Adherence Index was 86%, whereas 79% reported taking 100% of their medications within the past seven days.

Bivariable results indicated that higher levels of perceived HIV stigma were significantly associated with lower self-esteem, higher levels of depressive symptomatology, lower adherence motivation, and lower levels of behavioral adherence skills. Higher levels of internalized HIV stigma were significantly associated with poor treatment adherence (as measured by the CASE Adherence Index), lower self-esteem, higher levels of depressive symptomatology, lower adherence motivation, and lower behavioral adherence skills. Higher levels of enacted HIV stigma were also significantly associated with poor treatment adherence (as measured by the CASE Adherence Index), lower self-esteem, and higher levels of depressive symptomatology. The three manifestations of HIV stigma experiences were significantly and positively associated with each other. For example, higher levels of perceived stigma were associated with higher internalized and enacted stigmas. Young men reported significantly lower perceived HIV stigma than young women. Youth in Lundazi reported significantly higher perceived HIV stigma than youth in Chipata. Positive attitudes toward living at home were significantly associated with lower perceived, internalized, and enacted HIV stigma scores. Table 1 lists the point estimates and 95% confidence intervals for each bivariable association tested.

### Perceived HIV Stigma, Adherence, and Mental Health Outcomes

Table 2 presents multivariable associations of different stigma experiences with medication adherence. Table 3 includes multivariable associations of different stigma experiences with adherence barriers and mental health outcomes. In the multivariable models, the relationship between higher levels of perceived HIV stigma and lower levels of self-esteem was statistically significant ( $\beta = -0.63$ ,  $p = .001$ ). None of the other significant bivariable associations remained statistically significant at  $p < .05$ .

### Internalized HIV Stigma, Adherence, and Mental Health Outcomes

Internalized HIV stigma remained significantly associated with adherence, barriers to adherence, and mental health outcomes after controlling for enacted and perceived HIV stigma, in addition to the model covariates. Higher levels of internalized HIV stigma were associated with a lower likelihood of ART adherence, measured by the CASE Adherence

Index (OR = 0.64,  $p = .008$ ). Similarly, for every one-unit increase in internalized HIV stigma, youth's self-esteem score decreased by 0.36 points ( $p = .024$ ). Higher levels of internalized HIV stigma also remained significantly associated with higher levels of depressive symptomatology ( $\beta = 0.19$ ,  $p = .018$ ), lower levels of adherence motivation ( $\beta = -0.52$ ,  $p < .001$ ), and lower levels of adherence-related behavioral skills ( $\beta = -0.72$ ,  $p = .002$ ). Although statistically nonsignificant, higher levels of internalized stigma were associated with a lower likelihood of ART adherence regardless of the VAS adherence threshold, i.e., 100% or 90% of all ARV medications taken.

### Enacted HIV Stigma, Adherence, and Mental Health Outcomes

The association of enacted HIV stigma with treatment adherence, self-esteem, and depression became statistically nonsignificant when our models controlled for the two other types of HIV stigma (internalized and perceived) and six covariates. Although the relationship was nonsignificant, higher levels of enacted stigma remained associated with a lower likelihood of treatment adherence (OR = 0.84) and higher levels of depressive symptomatology ( $\beta = 0.03$ ).

We conducted additional analyses to examine whether adding depression as a covariate affected our main findings. The significant association of stigma experiences with medication adherence, self-esteem, adherence motivation, and behavioral adherence skills remained statistically significant. Additionally, higher levels of depressive symptomatology were significantly associated with lower self-esteem and lower levels of adherence motivation and adherence-related behavioral skills. Depression was not significantly associated with medication adherence.

## Discussion

Our findings are consistent with prior research linking HIV stigma to adverse health outcomes among youth in LMICs. Additionally, our results indicate that the association of HIV stigma with adherence and health outcomes appears to be conditional on the type of stigma experience. Internalized stigma, defined as acceptance of negative societal characterizations, labels, and thoughts about people living with HIV and applying them to the self (Earnshaw & Chaudoir, 2009), was consistently associated with poor health outcomes, including medication nonadherence, higher levels of depressive symptoms, lower self-esteem, lower adherence motivation, and lower levels of adherence behaviors. In contrast, perceived stigma was associated with self-esteem, whereas enacted stigma was not significantly associated with adherence and health outcomes.

The heterogeneity of association between stigma experiences and health outcomes is consistent with studies that examined the independent effects of different HIV stigma experiences on HIV prevention (Maughan-Brown & Nyblade, 2014; Mukolo et al., 2013). Our findings also add to knowledge about the potential effects of internalized stigma on depression, self-esteem, and barriers to adherence, particularly motivation and behavioral skills, which could be additional and plausible pathways linking internalized HIV stigma to harmful outcomes. However, we did not test mediating pathways due to our cross-sectional data. Future research should examine whether self-esteem and barriers to adherence mediate

the relationship between internalized stigma and medication adherence. We know from the literature that internalized stigma is associated with depression, negatively affecting treatment adherence among young people living with HIV in sub-Saharan Africa (Ashaba et al., 2018; Pantelic et al., 2017). Although depression is an important confounder, it did not change the significant association between HIV stigma experiences and other health outcomes. This finding may indicate that internalized and perceived stigmas, independent of depression, are notable predictors of health outcomes among YPLH.

Our finding suggests a need to further understand the drivers and facilitators of internalized HIV stigma among youth, especially in the context of low perceived and enacted stigmas. We know that internalized HIV stigma may develop independently of enacted stigma or experiences of discrimination (Earnshaw et al., 2013). For example, when YPLH decide not to disclose their status to others due to stigma, this nondisclosure would make youth less susceptible to enacted or overt HIV-related discrimination but not internalized HIV stigma (Madiba & Josiah, 2019). Drivers and facilitators of HIV stigma, including internalized stigma, exist at the individual, household, community, and societal levels. There is a need to understand better the role of social and structural factors in shaping internalized stigma (Pantelic et al., 2017; Pantelic et al., 2019; Stangl et al., 2019). It is plausible that there is less enacted and perceived stigma in communities where HIV prevalence is high. However, HIV stigma may be linked to the preservation of social and power hierarchies (Parker & Aggleton, 1982). Youth in our study have other characteristics or attributes that may intensify (or weaken) internalized HIV stigma, independent of other HIV stigma experiences. These characteristics may reinforce internalized stigma as these other stigmatized attributes put YPLH further to the margins compared to other YPLH without intersecting stigmatized characteristics. For example, in low-resource settings, internalized stigma may be compounded by social and structural factors, such as poverty and gender norms that shape YPLH's beliefs of what is possible for them and access to opportunities and resources within their families and communities. In other words, internalized HIV stigma may operate within mutually reinforcing relationships with other marginalized social statuses (Pantelic et al., 2020).

In our bivariable results, perceived stigma was associated with higher internalized stigma levels than enacted stigma. Perceived stigma may heighten internalized stigma, particularly among groups with multiple stigmatized characteristics. Alternatively, belonging to a dominant (or more valued group) may lessen the experience of internalized HIV stigma. In our study, young men reported lower perceived stigma than young women, while youth in Lundazi District reported higher than those in Chipata District. Being male remains more valued than being female in many communities in Zambia. For example, social norms prioritize allocating resources to boys than girls, which reinforces limited agency and opportunities for mobility among girls (Bermudez et al., 2021). In our study, the proportion of boys in school was higher than girls, even though 63% of the study sample were girls. Living in less prosperous areas with higher poverty rates appears to be also stigmatizing. Chipata, the provincial capital of Eastern Province, is an urban hub that offers more socioeconomic resources and opportunities than Lundazi, which is rural and dominated by agri-based livelihoods. Thus, belonging to a less valued group (i.e., being female and residing in areas with fewer socioeconomic resources and opportunities)

may intensify perceived stigma, which might increase the internalization of perceived HIV-related prejudices and develop negative feelings about themselves.

The lack of significant association between enacted stigma and health outcomes might be surprising given prior research linking enacted HIV stigma to adverse outcomes (Kane et al., 2019; Reuda et al., 2016). However, nondisclosure of HIV status may make youth less susceptible to enacted or overt HIV-related discrimination. This lack of significant association might also indicate resiliency among YPLH. Experiences of discrimination could have an unexpectedly positive effect on the behaviors of YPLH, which could be attributed to youth's resilience or ability to face adversity and navigate stressors. The negative association between HIV stigma and positive beliefs about living at home may indicate strong family support or cohesion, allowing YPLH to successfully navigate stressors despite experiences of enacted stigma or discrimination. However, our findings suggest that resiliency or stigma resistance might operate during experiences of enacted HIV stigma, but such resilience might not have the same effect on internalized stigma. Additionally, the effect of enacted stigma on health outcomes might be captured by the association of internalized HIV stigma with treatment and health outcomes. Prior research has reported a mediating role of internalized stigma in the relationship between enacted stigma or discrimination and treatment outcomes (Pantelic et al., 2020; Turan et al., 2017). For example, Pantelic and colleagues identified internalized HIV stigma as a mediating factor linking discrimination due to family and adolescent HIV to retention in care among adolescents in South Africa (Pantelic et al., 2020).

Our study findings imply that reducing internalized HIV stigma may improve treatment adherence and plausible pathways (i.e., self-esteem, depression, motivation adherence, and behavioral adherence skills) that strengthen the link of internalized stigma to suboptimal treatment outcomes. In other words, stigma-reduction interventions for YPLH may be effective when they purposefully target internalized stigma and its drivers and facilitators, independent of other types of HIV stigma. Different manifestations of stigma experiences necessitate distinct but interrelated intervention components; it is critical to identify whether HIV stigma reduction interventions should target holistic stigma experiences or specific stigma experiences. Interventions may be inadequately conceptualized as they might target different stigma experiences with the same types of activities and tasks, assuming that they share the same drivers, facilitators, and pathways. Although there is limited evidence to date of well-established programs that focus on reducing internalized stigma among YPLH, there are promising interventions that could be adapted for stigma reduction among YPLH. In Ndola, Zambia, Project YES!, which paired YPLH with a trained peer mentor as a strategy to support maintaining or achieving viral load suppression, reported a significant reduction in internalized stigma among intervention youth relative to the comparison youth (Denison et al., 2020).

There are important limitations to our study. First, our data might not generalize to YPLH who are not in treatment or dropped out of treatment. HIV stigma experiences might differ for YPLH who are not receiving treatment or not retained in care than our sample of YPLH who remained in care during our study recruitment. Second, findings are cross-sectional and descriptive and thus do not permit inferences about temporality or causality. We did not

test mediating effects of psychosocial constructs on the relationship between HIV stigma experiences and treatment adherence due to the cross-sectional study design. Third, although our stigma measures have been used in LMICs, our measures of enacted, internalized, and enacted HIV stigmas may not fully represent the lived experiences of YPLH in this study. For example, our measure of enacted stigma did not capture non-verbal forms of harassment and discrimination, such as bullying, physical abuse, and rejection. Fourth, missing data might have biased our results and decreased statistical power. We used multiple imputation to address these missing data issues. Fifth, our study focused on HIV stigma and did not include intersections with other stigmatized characteristics and conditions affecting YPLH.

## Conclusions

In sum, this study indicates that internalized HIV stigma among YPLH is associated with adverse outcomes, including medication nonadherence, higher levels of depression, lower self-esteem, and lower levels of adherence motivation and behavioral adherence skills. Perceived stigma is associated with self-esteem, whereas enacted stigma is not significantly associated with health outcomes. The complexity of HIV stigma requires a more precise explication of the associations among different HIV stigma experiences and outcomes. In turn, interventions can be developed to address a specific type of HIV stigma. Our study implies a need for developing and testing interventions to reduce internalized HIV stigma and its impact on treatment and other health outcomes. More research, including qualitative and mixed-methods studies, is needed to understand the link between internalized HIV stigma and adverse outcomes, independent of enacted and perceived HIV stigmas.

## Acknowledgments

This research was funded in part through Developmental funding from the University of North Carolina at Chapel Hill Center for AIDS Research (CFAR), and NIH funded program P30 AI050410. The authors have no relevant financial or non-financial interests to disclose.

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**Table 1**

Sample characteristics and bivariable results

Variables	% or <i>M</i> (SD)	HIV Stigma Experience					
		Perceived		Internalized		Enacted	
		$\beta$ /O.R.	95% CI	$\beta$ /O.R.	95% CI	$\beta$ /O.R.	95% CI
<i>HIV stigma experiences</i>							
Perceived stigma	6.06 (2.26)	0.43*	0.29, 0.58	0.40*	0.18, 0.63		
Internalized stigma	4.68 (1.88)	0.63*	0.42, 0.84	0.39*	0.12, 0.65		
Enacted stigma	9.39 (2.60)	0.31*	0.14, 0.47	0.22*	0.06, 0.36		
<i>Outcome variables</i>							
Adherence (VAS = 100%)							
Nonadherent <sup>†</sup>	21%						
Adherent	79%	0.95	0.76, 1.18	0.91	0.76, 1.109	0.99	0.81, 1.21
Adherence (VAS 90%)							
Nonadherent <sup>†</sup>	10%						
Adherent	90%	0.91	0.69, 1.21	0.88	0.71, 1.09	0.93	0.74, 1.16
CASE adherence index							
Poor adherence <sup>†</sup>	14%						
Good adherence	86%	0.87	0.69, 1.11	0.73*	0.59, 0.89	0.83*	0.68, 0.99
Self-esteem	28.91 (4.07)	-0.93*	-1.25, -0.62	-0.69*	-0.99, -0.40	-0.40*	-0.72, -0.07
Depression	15.56 (1.81)	0.30*	0.14, 0.46	0.30*	0.16, 0.45	0.17*	0.01, 0.32
Motivational barriers to adherence	14.94 (3.33)	-0.54*	-0.82, -0.27	-0.66*	-0.89, -0.43	-0.25	-0.53, 0.03
Behavioral barriers to adherence	27.61 (4.97)	-0.70*	-1.12, -0.28	-0.85*	-1.21, -0.50	-0.34	-0.78, 0.10
<i>Covariates</i>							
Age (in years)	19.50 (3.25)	0.04	-0.10, 0.18	0.08	-0.08, 0.24	0.10	-0.06, 0.27
Gender							
Female <sup>†</sup>	63.2%						
Male	36.8%	-1.16*	-2.07, -0.25	0.01	-1.03, 1.04	-0.99	-1.99, 0.01
Health facility							

Variables	% or <i>M</i> ( <i>SD</i> )	HIV Stigma Experience					
		Perceived		Internalized		Enacted	
		<i>β</i> /O.R.	95% CI	<i>β</i> /O.R.	95% CI	<i>β</i> /O.R.	95% CI
Chipata Central †	55.1%						
Lundazi General	44.9%	1.27*	0.41, 2.14	0.89	-0.10, 1.88	0.29	-0.75, 1.33
Currently in school							
No †	37.7%						
Yes	62.3%	0.43	-0.49, 1.35	-0.67	-1.70, 0.36	-0.95	-2.02, 0.12
Worked in the last 30 days							
No †	78.1%						
Yes	21.9%	-0.53	-1.61, 0.55	-0.49	-1.71, 0.73	-0.47	-1.76, 0.82
Attitudes toward living at home	20.14 (3.10)	-0.18*	-0.32, -0.04	-0.19*	-0.34, -0.03	-0.19*	-0.35, -0.04

Note. % = categorical variables, *M*=mean and *SD*=standard deviation for continuous variables.

† = reference group.

\* *p* < .05.

**Table 2**

Multivariable logistic regression results of the association between different HIV stigma experiences and adherence

<i>Variables</i>	<b>Case Adherence Index</b>		<b>VAS Adherence (=100%)</b>		<b>VAS Adherence ( 90%)</b>	
	<b>OR</b>	<b>95% CI</b>	<b>OR</b>	<b>95% CI</b>	<b>OR</b>	<b>95% CI</b>
<i>HIV stigma experiences</i>						
Perceived	1.11	0.74, 1.67	1.00	0.73, 1.39	0.93	0.61, 1.43
Internalized	0.64**	0.46, 0.89	0.98	0.77, 1.23	0.95	0.72, 1.27
Enacted	0.84	0.62, 1.14	1.20	0.85, 1.70	1.24	0.79, 1.93
<i>Covariates</i>						
Age	0.90	0.68, 1.18	0.96	0.77, 1.20	0.85	0.64, 1.13
Gender (ref = female)	2.01	0.33, 12.30	0.74	0.22, 2.42	0.58	0.12, 2.70
Health facility (ref = Chipata Central)	2.28	0.28, 18.43	1.10	0.28, 4.36	1.06	0.18, 6.19
Currently in school (ref = no)	0.39	0.03, 4.49	1.42	0.28, 7.21	2.45	0.36, 16.56
Worked in the last 30 days (ref = no)	0.41	0.04, 4.67	1.03	0.20, 5.24	1.88	0.27, 13.21
Attitudes toward living at home	0.99	0.75, 1.31	1.20	0.99, 1.46	1.12	0.88, 1.43

Note. OR = odds ratio, CI = confidence intervals.

\*  $p < .05$ ,

\*\*  $p < .01$ ,

\*\*\*  $p < .001$ .

**Table 3**

Multivariable linear regression results of the association between different HIV stigma experiences and mental health and barriers to adherence.

Variables	Depression		Self-esteem		Motivational Barriers to Adherence		Behavioral Skills Barriers to Adherence	
	$\beta$	95% CI	$\beta$	95% CI	$\beta$	95% CI	$\beta$	95% CI
<i>HIV stigma manifestations</i>								
Perceived	0.15	-0.04, 0.34	-0.63**	-1.01, -0.26	-0.19	-0.52, 0.14	-0.45	-0.99, 0.08
Internalized	0.19*	0.03, 0.35	-0.36*	-0.66, -0.05	-0.52*	-0.79, -0.26	-0.72*	-1.16, -0.27
Enacted	0.03	-0.13, 0.20	0.11	-0.21, 0.44	0.04	-0.25, 0.33	0.06	-0.45, 0.56
<i>Covariates</i>								
Age	-0.03	-0.16, 0.10	-0.09	-0.36, 0.17	-0.22	-0.46, 0.01	-0.01	-0.38, 0.37
Gender (ref = female)	-0.09	-0.80, 0.63	0.82	-0.66, 2.30	0.55	-0.73, 1.82	0.58	-1.48, 2.64
Health facility (ref = Chipata Central)	0.05	-0.79, 0.89	0.47	-1.17, 2.12	-0.22	-1.67, 1.24	0.98	-1.39, 3.35
Currently in school (ref = no)	0.22	-0.84, 1.28	0.15	-1.97, 2.27	-0.33	-2.10, 1.45	0.41	-2.51, 3.35
Worked in the last 30 days (ref = no)	-0.12	-1.13, 0.89	0.16	-1.93, 2.28	-0.61	-2.41, 1.19	-1.41	-4.31, 1.49
Attitudes toward living at home	-0.09	-0.21, 0.02	0.38**	0.15, 0.61	0.19	-0.02, 0.40	0.19	-0.15, 0.52

Note.  $\beta$  = regression coefficient, CI = confidence intervals.

\*  $p < .05$ ,

\*\*  $p < .01$ ,

\*\*\*  $p < .001$