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A Psychometric Evaluation and a Framework Test of the HIV Stigma Mechanisms Scale Among a Population-Based Sample of Men and Women Living with HIV in Central Uganda

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Abstract

HIV stigma is a critical barrier to HIV prevention and care. This study evaluates the psychometric properties of the HIV Stigma Mechanisms Scale (HIV-SMS) among people living with HIV (PLHIV) in central Uganda and tests the underlying framework. Using data from the PATH/Ekkubo study, (n = 804 PLHIV), we assessed the HIV-SMS' reliability and validity (face, content, construct, and convergent). We used multiple regression analyses to test the HIV-SMS' association with health and well-being outcomes. Findings revealed a more specific (5-factor) stigma structure than the original model, splitting anticipated and enacted stigmas into two subconstructs: family and healthcare workers (HW). The 5-factor model had high reliability ($\alpha = 0.92$–0.98) and supported the convergent validity ($r = 0.12$–0.42, $p < 0.01$). The expected relationship between HIV stigma mechanisms and health outcomes was particularly strong for internalized stigma. Anticipated-family and enacted-family stigma mechanisms showed partial agreement with the hypothesized health outcomes. Anticipated-HW and enacted-HW mechanisms showed no significant association with health outcomes. The 5-factor HIV-SMS yielded a proper and nuanced measurement of HIV stigma in central Uganda, reflecting the importance of family-related stigma mechanisms and showing associations with health outcomes similar to and beyond the seminal study.

Keywords HIV · Stigma · Scale · Uganda · Sub-Saharan Africa

Introduction

HIV-related stigma is a major challenge worldwide for people living with HIV (PLHIV) and a significant risk factor for poor HIV testing and treatment outcomes [1–3]. It has been linked to delayed presentation for care [4], poor physical and mental health [5, 6], lowered CD4 count [1] and poor ART adherence [1, 6, 7] and access to treatment [1, 6]. Therefore, addressing HIV stigma is of paramount importance to achieving UNAIDS goals of ending the HIV epidemic by 2030 [8], especially in Uganda, where there are 1.4 million PLHIV and the number of PLHIV increased 27% over the past decade [9].

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Despite Uganda's extensive efforts to combat HIV, such as through free universal HIV testing and treatment, HIV-related stigma continues to contribute to poor HIV outcomes among PLHIV. Duff et al. [10] observed that HIV stigma is responsible for Ugandan women's non-disclosure to partners, creating barriers to HIV care and treatment. Bogart et al. [11] showed that fisherfolk living with HIV in Uganda experienced stigma differently depending on whether or not they were linked to care, with those not linked expressing fear of social isolation. Additionally, Bogart et al. [11] and Buregyeya et al. [12] noted that fear of being seen in HIV health facilities was a barrier to accessing health care among PLHIV in Uganda, sometimes leading them to travel long distances to access care.

While there is consensus that reducing stigma is essential to ending the HIV epidemic, the literature's diversity of scales has led to different operationalizations of HIV stigma. This, in turn, obscures the identification and comparison of how PLHIV experience stigma and how stigma affects their health. Understanding specific facets of stigma and its health implications are essential for well-designed and efficacious HIV interventions targeting prevention, viral load suppression, and well-being.

Scales that measure HIV stigma have been documented since 1988 [13]. However, a 2009 literature review highlighted the need to understand and measure how HIV stigma is experienced by both PLHIV and people not living with HIV [14], leading to the development of the HIV stigma mechanisms framework. The framework proposes three distinct HIV stigma mechanisms (internalized, anticipated, and enacted stigma) by which PLHIV process deleterious experiences and hypothesizes that each type of stigma is associated with unique health outcomes. Specifically, internalized stigma or "the degree to which PLHIV endorse the negative beliefs and feelings associated with HIV/AIDS about themselves" [14] is associated with affective and behavioral health and well-being outcomes (e.g., helplessness and medical care visits) [15]. Enacted stigma, or "the degree to which PLHIV believe they have experienced prejudice and discrimination from others in their community" [14] is associated with physical health outcomes (e.g., CD4 count) [15]. Anticipated stigma, or "the degree to which PLHIV expect they will experience prejudice and discrimination from others in the future" [14] is associated with behavioral and physical health outcomes (e.g., antiretroviral adherence and chronic illness) [15].

In 2013, Earnshaw et al. advanced the HIV stigma mechanisms framework by developing the HIV Stigma Mechanisms Scale (HIV-SMS) to measure HIV stigma among PLHIV. However, to date, we are aware of only three published studies that have evaluated this scale's psychometric properties [15–17], all analyzing samples of PLHIV

from high-resource countries (i.e., the USA and Sweden). Therefore, we seek to add to the HIV stigma measurement literature by (a) evaluating the psychometric properties of the HIV-SMS and (b) testing the HIV stigma mechanisms framework in a sample of PLHIV in central Uganda. By doing so, we aim to broaden the spectrum of the scale's applicability, especially among East African populations disproportionately affected by HIV [18]. This study's findings have the potential to support HIV practitioners, researchers, and policymakers in understanding the types of stigmas underlying their patients/populations and fostering tailored interventions to positively impact PLHIV's health and well-being.

Methods

First, we sequentially evaluated the psychometric properties of the HIV-SMS among PLHIV in Uganda, assessing its (a) face and content validity, (b) construct validity, (c) reliability, and (d) convergent validity. Second, we tested the HIV stigma mechanisms framework by investigating the associations between each HIV-SMS subconstruct and their hypothesized health and well-being outcomes (affective, behavioral, and physical).

Study Population and Data Source

We used data collected between November 2015 and March 2020 as part of the PATH (Providing Access to HIV Care)/Ekkubo study, a cluster randomized controlled trial of an enhanced linkage to HIV care intervention. PATH/Ekkubo was conducted in central Uganda (Butambala, Mpigi, Mityana, and Gomba districts) in the context of community-wide home-based HIV testing. Villages (cluster unit) were randomized and allocated to the intervention or standard-of-care (control) arms.

All participants were verbally screened for eligibility: speaking Luganda (the most frequently spoken language in the study districts) or English, being *18 to 59 years old or an emancipated minor, accepting HIV testing, and being a resident of the household. Then they provided written (or thumb-printed) informed consent and completed the baseline questionnaire* [19]. The current study used baseline data from participants who reported being previously diagnosed with HIV and were confirmed HIV-positive.

Measures

Data were collected by trained interviewers using interviewer-administered questionnaires [19]. All questions were translated from English into Luganda, back-translated into English, and then modified to ensure equivalence in

meaning. Appendix A provides a table with the HIV-SMS questions in English and Luganda.

The HIV Stigma Mechanisms Scale (HIV-SMS)

The HIV-SMS is a 24-item instrument designed to measure stigma among PLHIV. The scale conceptualizes three distinct mechanisms by which PLHIV process deleterious experiences, measured by a set of items rated along a 5-point Likert scale. Six items with responses ranging from "strongly disagree" to "strongly agree" cover *internalized stigma* and are preceded by the question: "How do you feel about being HIV-positive?" Nine items with responses ranging from "very unlikely" to "very likely" describe *anticipated stigma* and are preceded by the question: "How likely is it that people will treat you in the following ways in the future because of your HIV status?" Nine items with responses ranging from "never" to "very often" cover *enacted stigma* and are preceded by the question: "How often have people treated you this way in the past because of your HIV status?" Table 3 presents all HIV-SMS items.

Sociodemographic

Sociodemographic characteristics included age, gender, marital status, education, religion, and wealth status (measured by an index of participants' household components and possessions).

HIV Status and Health-Related Outcomes

Self-reported HIV status was confirmed with HIV testing, following the 2015 World Health Organization's (WHO) algorithm for high-prevalence HIV settings [20]. Participants' HIV-related clinical characteristics included measures of affective, behavioral, and physical health.

Affective Health and Well-Being The Centre for Epidemiological Studies Depression Scale (CES-D-10) [21] was used to test the hypothesized association between affective health and internalized stigma [15] and evaluate convergent validity. Previous studies have considered depression theoretically associated with HIV stigma among PLHIV [22–24] and used this variable to test convergent validity in Uganda [25]. The CES-D-10 has been validated in South Africa [26] and used with PLHIV in Uganda [27]. It is a 10-item, self-rating scale with responses ranging from 0 (rarely or none of the time/less than 1 day) to 3 (mostly or all of the time/5–7 days) and a threshold sum score of 10 or higher, indicating the presence of significant depressive symptoms [28]. The CES-D-10 presented high reliability in our sample (Cronbach's alpha = 0.9; McDonald's Omega = 0.9).

Behavioral Health and Well-being We calculated two behavioral health measures: (1) months since the last HIV clinic visit, based on the question "When was the last time you attended the HIV clinic?" and baseline/enrollment date, and (2) the Alcohol Use Disorders Identification Test Consumption (AUDIT-C) index [29]. Studies have shown that alcohol use is a behavior associated with HIV stigma [30, 31], and the AUDIT-C has been validated in Namibia [32] and used with PLHIV in Uganda [33]. It is a 3-item, self-rating scale with responses ranging along a 5-point Likert scale. A sum score of 4 for men and 3 for women indicates alcohol misuse [29]. The AUDIT-C presented high reliability in our sample (Cronbach's alpha = 0.7; McDonald's Omega = 0.7). Both measures were used to evaluate the hypothesized association between behavioral health and internalized and anticipated stigma [15].

Physical Health We included three physical health measures: (1) self-reported CD4 levels, grouped as: "less or equal to 500 cell/mm³" and "greater than 500 cell/mm", (2) the number of significant health problems, based on the question: "How many times in the past 6 months have you experienced significant physical medical problems?," and (3) the number of hospitalizations, based on the question "How many times in the past 6 months have you been admitted/hospitalized for physical medical problems?" Each measure was used to test the hypothesized association between physical health and anticipated and enacted stigma [15].

Analytic Approach: Psychometric Analysis of the HIV-SMS

All statistical analyses were performed in R environment v.4.0.2 [36] using the following packages: psych v.2.0.12 [37], ltm v.1.1.1 [38], KernSmoothIRT v.6.4 [39], and lme4 v.1.1.26 [40]. Analyses were considered statistically significant at the $p < 0.05$ level.

Face and Content Validity

The HIV-SMS was analyzed by a multicultural (American and Ugandan) team of experts. They reviewed and evaluated the scale for comprehensiveness, redundancy, and cultural appropriateness. The Ugandan experts lived in Uganda and were aware of the local culture.

Construct Validity

We used exploratory data analysis to identify patterns of missing values, the correlation between items, item-level means, and standard deviation. We used exploratory

factor analysis (EFA) to examine the HIV-SMS latent structure, given it has only been evaluated in three developed countries outside of Sub-Saharan Africa [15, 16, 41].

The optimal EFA solution was selected based on the following statistics: Parallel Analysis [42], Velicer's Minimum Average Partial criterion (MAP) [43], and the goodness of fit statistics [corrected root mean square of the residuals (RMSR), root mean square error of approximation (RMSEA), and the Bayesian Information Criterion (BIC)]. Ultimately, we used a bifactor model (omega hierarchical statistic) to check the selected model assumptions versus the theoretical mechanisms proposed by the scale's authors. The choice of the optimal factor solution considered the proposed HIV stigma mechanisms' theoretical subconstructs, regional culture, and statistical findings. We used polychoric correlations in our EFA and the oblique rotation method to allow the factors to correlate. Only HIV-SMS items with a minimum factor loading of 0.30 were included in the selected solution.

We used a Non-parametric Item Response Model (NP-OCC) to examine the ability of the HIV stigma mechanism items to discriminate across the 5 response options. The Parametric Item Response Model (P-OCC) was used to estimate the discrimination and severity of each item within its assigned subscale.

Reliability

We calculated Cronbach's alpha [44] and McDonald's Omega [45] to assess how closely related the HIV-SMS items were as a group. Correlations among the originally HIV-SMS hypothesized subconstructs (internalized, anticipated, and enacted) were also evaluated.

Convergent Validity

Convergent validity was evaluated by calculating Pearson correlations (r) between the HIV stigma subscales unveiled by EFA and depressive symptoms (CES-D-10).

HIV Stigma Mechanisms Framework: Testing the Associations with Health and Well-Being Outcomes

We used bivariate correlations and multivariate multiple linear regression models to test the hypothesized associations between the three health outcomes (affective, behavioral, and physical health) and specific mechanisms of HIV stigma among PLHIV [15]. Each model controlled for social demographic characteristics.

Ethics

Approval for the PATH/ Ekkubo study was obtained from the institutional review boards of San Diego State University and Makerere University School of Public Health. Clearance was obtained from the Uganda National Council for Science and Technology.

Results

Sample Characteristics

As indicated in Table 1, participants' average age was 37.96 years (SD = 10.28); 78.23% (n = 629) were women versus 21.77% (n = 175) men. Many were married or living together most of the time (42.04%) or divorced (31.22%). The majority reported primary-level education (68.91%).

The average level of depressive symptoms (CES-D-10) was low (M = 7.36, SD = 6.81; range 0–30). Similarly, the average HIV stigma score (possible range from 1–5) for each mechanism was low: the internalized stigma mechanism presented an average of 2.16 (SD = 0.86), the anticipated stigma averaged 1.86 (SD = 0.62), and the enacted stigma mechanism average was 1.54 (SD = 0.62).

Correlations Between HIV-SMS Items

Within the enacted and anticipated stigma HIV-SMS subscales, we observed higher correlations among items related to family and healthcare workers. Items also presented higher overall correlations when within the same subscale. The minimum correlation was between the enacted stigma item "healthcare workers have treated me with less respect" and the anticipated stigma item "Family members will avoid me" (r = 0.27, p < 0.01). The maximum correlation was between the enacted stigma items "Family members have looked down on me" and "Family members have avoided me" (r = 0.99, p < 0.01). All correlations are displayed in Fig. 1.

Psychometric Analysis of the HIV Stigma Mechanisms Scale

Face and Content Validity

The PATH/Ekkubo study's multicultural team of experts (from the USA and Uganda) reviewed the HIV-SMS for instrument meaningfulness and relevance to the central Ugandan cultural context. Seven of the twenty-four HIV-SMS items were trimmed for not being relevant in the Uganda setting. These items were excluded before data collection and, therefore, are not included in the analyses.

Table 1 Sample characteristics

Characteristics	% (n)	Average (SD)
Age		37.96 (10.28)
Gender		
Male	21.77 (175)	
Female	78.23 (629)	
Marital status		
Married and living together most of the time	42.04 (338)	
Married and separated most of the time	13.06 (105)	
Widowed	11.32 (91)	
Divorced	31.22 (251)	
Never married	2.36 (19)	
Education		
No education	11.19 (90)	
Primary	68.91 (554)	
Secondary	17.54 (141)	
University/tertiary	2.36 (19)	
Religion		
None	0.13 (1)	
Protestant	21.64 (174)	
Catholic	53.73 (432)	
Moslem	15.05 (121)	
Seventh Day Adventist	1.99 (16)	
Saved/Pentecostal	7.46 (60)	
Wealth index (range: 0–10)		8.21 (1.37)
Depressive symptoms CES-D-10 (range: 0–30)		7.36 (6.81)
Months since last HIV clinic visit		2.08 (4.02)
Alcohol use AUDIT-C (range: 0–12)		1.59 (2.45)
CD4 counting		
Less or equal to 500 cell/mm^3	59.23 (170)	
Greater than 500 cell/mm^3	40.77 (117)	
Number of significant health problems		0.59 (1.27)
Number of hospitalizations		0.12 (0.46)
HIV stigma (range: 1–5)		
Internalized stigma mechanism		2.16 (0.86)
Anticipated stigma mechanism		1.86 (0.62)
Enacted stigma mechanism		1.54 (0.61)

Specifically, three items were excluded from the anticipated and enacted mechanisms because they asked about community/social workers, and such providers do not exist in the Ugandan context: (1) "Community/social workers will not take [have not taken] my needs seriously"; (2) "Community/social workers will discriminate [have discriminated] against me"; (3) "Community/social workers will deny [have denied] me services." One item was excluded from the internalized stigma mechanism ("Having HIV is disgusting to me") because the team did not understand or interpret the item as having an equivalent meaning or expression in Luganda as in English.

The interviewers read the questions to participants to avoid possible misunderstandings. Each section was introduced with explaining statements, for example: "Next, I want you to tell me how much you agree with the statements I read", before the internalized items.

Construct Validity

Exploratory Factor Analysis (EFA) All HIV stigma mechanism items included in our EFA are presented in Table 2. The underlying structure of the HIV-SMS was originally grouped into three factors: internalized, enacted, and anticipated stigma [15]. However, based on the statistics used to evaluate the model goodness of fit, we selected a 5-factor model. The Velicer's MAP, BIC, cumulative explained variance, and RMSEA criteria suggested a 5-factor solution,
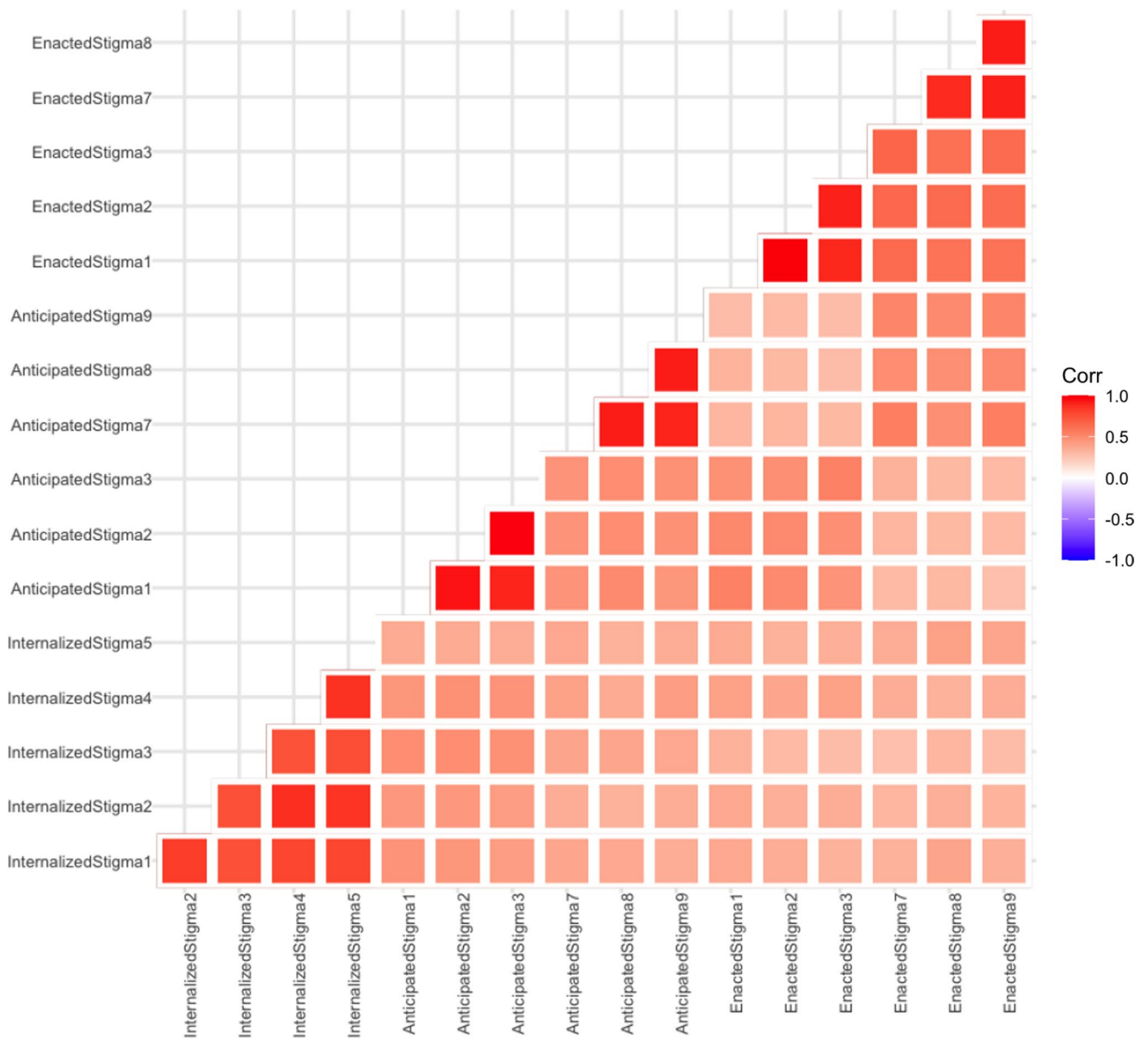
Fig. 1 Correlation (r) between items

with the five factors explaining 85% of the sample variance (Fig. 2).

As indicated in Table 2, in the 5-factor model, all internalized stigma items loaded strongly on the expected theoretical subconstruct, with loadings ranging from 0.77 ("I feel ashamed of having HIV") to 0.95 ("Having HIV makes me feel unclean"). However, the anticipated and enacted stigma items split into two subconstructs related to "family" and "healthcare workers." We defined these new subconstructs as (1) anticipated-family; (2) anticipated-healthcare workers (anticipated-HW); (3) enacted-family; (4) enacted-healthcare workers (enacted-HW).

The *anticipated-family* stigma subscale, with factor loadings ranging from 0.87 to 1.01, encompassed items related to PLHIV's expectations on how their families *will treat them* because of their HIV. Whereas the *anticipated-HW* stigma subscale, with factor loadings ranging from 0.93 to 0.98, comprised items related to PLHIV's expectations of how healthcare workers *will treat them* because of their HIV status. The mean score for anticipated-family stigma anticipated-HW stigma was 2.02 (SD = 0.88) and 1.69 (SD = 0.62), respectively.

The *enacted-family* subscale encompassed items related to PLHIV's experiences of how they *were treated* by their

Table 2 Five-factor model loadings

Items from the HIV SMS for PLHIV	Internalized	Anticipated-family	Anticipated-healthcare workers	Enacted-family	Enacted-healthcare workers
I1. Having HIV makes me feel like I'm a bad person	**0.84**	0.07	− 0.01	− 0.03	0.06
I2. I feel I'm not as good as others because I have HIV	**0.93**	0.01	− 0.02	0.03	− 0.03
I3. I feel ashamed of having HIV	**0.77**	0.16	0.04	− 0.08	− 0.01
I4. I think less of myself because I have HIV	**0.89**	− 0.01	0.06	0.10	− 0.07
I5. Having HIV makes me feel unclean	**0.95**	− 0.10	− 0.02	− 0.01	0.08
A1. Family members will avoid me	0.04	**0.87**	0.05	0.08	− 0.06
A2. Family members will look down on me	0.00	**1.01**	− 0.01	− 0.01	0.02
A3. Family members will treat me differently	− 0.01	**0.96**	0.00	− 0.01	0.04
A7. Healthcare workers will not listen to my concerns	0.02	− 0.02	**0.93**	0.00	0.04
A8. Healthcare workers will avoid touching me	− 0.02	0.02	**0.98**	0.03	− 0.04
A9. Healthcare workers will treat me with less respect	0.02	0.01	**0.93**	− 0.04	0.05
E1. Family members have avoided me	0.03	− 0.01	0.03	**0.99**	− 0.04
E2. Family members have looked down on me	− 0.01	− 0.01	0.01	**1.00**	0.01
E3. Family members have treated me differently	0.01	0.09	− 0.08	**0.78**	0.16
E7. Healthcare workers have not listened to my concerns	− 0.02	− 0.01	0.07	0.10	**0.85**
E8. Healthcare workers have avoided touching me	0.04	0.03	− 0.03	− 0.01	**0.94**
E9. Healthcare workers have treated me with less respect	0.00	− 0.01	0.03	0.00	**0.96**

Items I6, E4–E6, and A4–A6 were excluded. The way this concept is expressed in English did not have an equivalent meaning and expression in Luganda

Bold values indicate the factor on which the item loaded most strongly and therefore which factor the item loaded on in the 5 factor model

Fig. 2 Parallel Analysis Scree plot for the HIV Stigma Mechanisms Scale
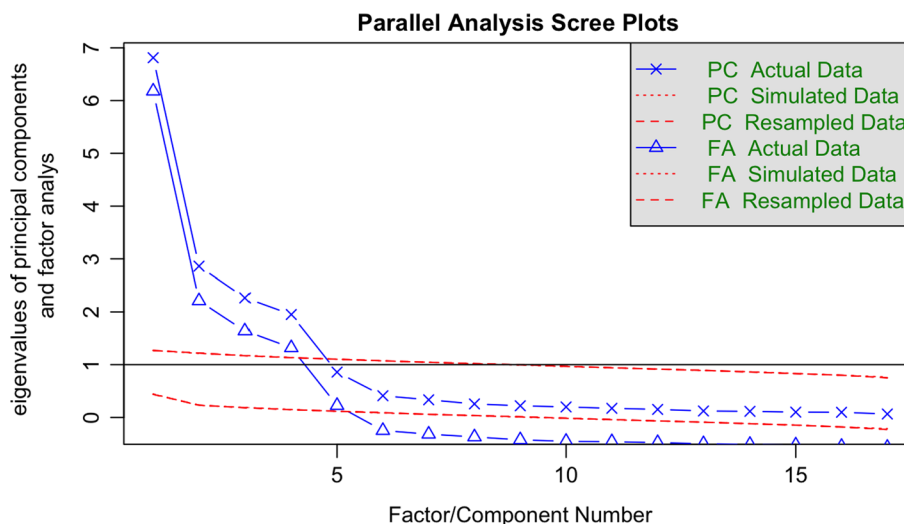
families because of their HIV status and presented loadings ranging from 0.78 to 1.00. Conversely, the *enacted-HW* subscale comprised items related to PLHIV's experiences of how healthcare workers *treated them* because of their status; with factor loadings ranging from 0.85 to 0.96. The mean enacted-family and enacted-HW stigma scores were 1.63 (SD = 0.78) and 1.46 (SD = 0.63), respectively.

We used bi-factor analysis to examine if the "family" and "healthcare workers" items within the enacted and anticipated stigma subscales could be grouped into two subscales: (1) "family," comprising items related to treatment that PLHIV received from family and based on past experiences (enacted) and expectations (anticipated); (2) "healthcare workers," comprising items related to treatment

that PLHIV received from healthcare workers and based on past experiences (enacted) and expectations (anticipated). The Omega-hierarchical of the tentative "family" subscale was 0.68 and 0.70 for the tentative "healthcare workers" subscale, suggesting that, in both cases, a single subconstruct was insufficient to organize the items, reinforcing the 5-factor HIV-SMS solution for the current study population.

Item Response Model The items' response frequency showed that all response options were used by participants to describe their HIV stigma, with "Strongly disagree" to "Disagree," "Very unlikely" to "Unlikely," and "Never" to "Not-often" as the most frequent options chosen (Table 3). The internalized stigma items had the highest percentage of "Strongly Agree," reflecting the overall highest mean score among the three hypothesized mechanisms of the HIV stigma scale (Table 1).

The Nonparametric Option Characteristic curves for the 5-factor solution suggested no substantial evidence for regrouping any response option for any item (Online Appendix B). The discrimination and severity thresholds estimated by the Parametric Item Response model suggested that the items distinguished well between participants across the different HIV-SMS stigma subscales, with high discrimination estimates (above 1.4) for all items (Table 4).

Reliability

The Cronbach's alpha of the HIV-SMS 5-factor solution ranged from 0.92 (internalized) to 0.98 (anticipated-family), while the McDonald's Omega ranged from 0.95 (internalized) to 0.98 (anticipated-family). Table 3 presents all of Cronbach's alpha and McDonald's Omega statistics. We also computed Cronbach's alpha for each subscale, after excluding items one by one. This analysis did not suggest a need to drop any items (Table 3). The overall reliability of the 5-factor HIV-SMS was analogously high (Cronbach's alpha = 0.90; McDonald's Omega = 0.91).

Convergent Validity

The Pearson correlation between the full 5-factor HIV-SMS and the CES-D-10 was 0.39 (p < 0.01). The maximum correlation was between the internalized HIV stigma mechanism and CES-D-10 (r = 0.42, p < 0.01), followed by enacted-family (r = 0.25, p < 0.01), anticipated-family (r = 0.24, p < 0.01), and anticipated and enacted-HW (both r = 0.12, p < 0.01).

Bivariate Analyses Among the HIV-SMS 5-Factor Solution

Bivariate analyses among the HIV-SMS 5-factor solution showed a maximum Pearson correlation of 0.47 (p < 0.01)

between anticipated-HW and enacted-HW, followed by enacted-family and enacted-HW and anticipated-family and enacted-family (both r = 0.46, p < 0.10). The association between anticipated-family and enacted-HW presented the minimum correlation of 0.19 (p < 0.01; Table 5).

HIV Stigma Mechanisms Framework: Testing the HIV Stigma Subconstructs Associations with Health Outcomes

The multiple regression models testing the hypothesized associations between each HIV stigma mechanism and health outcomes are presented in Table 6. Many of the findings confirmed the bivariate association presented in Table 7. A comparison between the USA-based seminal work and our results is in Fig. 3, and our findings for the HIV-SMS framework hypothesized associations are detailed below:

a. *Internalized stigma & affective and behavioral health* As hypothesized, internalized stigma was positively associated with depressive symptoms. An increase of 1 unit in internalized stigma (range 1–5) was associated with an increase of b = 3.27 (95% CI 2.59–3.94, p < 0.01) in depressive symptoms (range 0–30) and b = 0.46 (95% CI 0.08–0.84, p < 0.01) in "months since the last visit to an HIV clinic." No statistically significant association between internalized stigma and with alcohol use was found. However, non-hypothesized associations involving the internalized stigma were also present. When examining associations between internalized stigma and physical health outcomes we found that higher levels of internalized stigma were associated with having a lower CD4 count (< 500 cell/mm^3, aOR = 0.66, 95% CI 0.48–0.90, p < 0.01) and more significant health problems (b = 0.32, 95% CI 0.21–0.44, p < 0.01).

b. *Anticipated stigma & behavioral and physical health* The hypothesized association between anticipated stigma and physical health outcomes was found, but only when examining the anticipated-family stigma mechanism. *Anticipated-family stigma* was positively associated with number of hospitalizations, such that a one-unit increase in anticipated-family stigma (range 1–5) was associated with an increase of b = 0.06 in the number of hospitalizations (95% CI 0–0.11, p < 0.05). Regarding behavioral health, *anticipated-HW stigma* was uniquely associated with alcohol use. However, different than hypothesized, higher levels of anticipated-HW stigma were linked to less alcohol use (b = − 0.66, 95% CI − 1.02–0.29, p < 0.01).

c. *Enacted stigma & physical health* As hypothesized, *enacted-family stigma* was positively associated with number of hospitalizations (b = 0.09, 95% CI 0.02–

Table 3 Reliability and frequency statistics

Items from the HIV SMS for PLHIV	Cronbach's alpha excluding the item	Frequency				
Internalized (Cronbach's alpha = 0.92, omega = 0.95)		Strongly disagree (1) (%)	Disagree (2) (%)	Neither disagree nor agree (3) (%)	Agree (4) (%)	Strongly agree (5) (%)
I1. Having HIV makes me feel like I'm a bad person	0.91	23.13	58.38	7.75	9.25	1.50
I2. I feel I'm not as good as others because I have HIV	0.90	22.75	54.50	7.00	13.00	2.75
I3. I feel ashamed of having HIV	0.92	19.38	54.62	7.75	14.37	3.88
I4. I think less of myself because I have HIV	0.90	22.12	56.25	7.37	12.25	2.00
I5. Having HIV makes me feel unclean	0.90	23.00	57.38	5.87	11.13	2.62
Anticipated-Family (Cronbach's alpha = 0.98, omega = 0.98)		Very unlikely (1) (%)	Unlikely (2) (%)	Neither unlikely nor likely (3) (%)	Likely (4) (%)	Very Likely (5) (%)
A1. Family members will avoid me	0.98	25.62	56.38	9.88	6.12	2.00
A2. Family members will look down on me	0.97	28.38	52.75	9.88	6.88	2.13
A3. Family members will treat me differently	0.98	27.62	54.12	8.75	7.00	2.50
Anicipated-healthcare workers (Cronbach's alpha = 0.97, omega = 0.97)		Very unlikely (1) (%)	Unlikely (2) (%)	Neither unlikely nor likely (3) (%)	Likely (4) (%)	Very likely (5) (%)
A7. Healthcare workers will not listen to my concerns	0.97	36.00	58.12	3.38	1.87	0.63
A8. Healthcare workers will avoid touching me	0.96	39.00	56.75	2.62	1.00	0.63
A9. Healthcare workers will treat me with less respect	0.97	39.38	55.75	2.75	1.63	0.50
Enacted-family (Cronbach's alpha = 0.97, omega = 0.97)		Never (1) (%)	Not often (2) (%)	Somewhat often (3) (%)	Often (4) (%)	Very often (5) (%)
E1. Family members have avoided me	0.97	49.50	40.62	5.50	3.50	0.88
E2. Family members have looked down on me	0.96	53.25	37.62	4.62	3.62	0.88
E3. Family members have treated me differently	0.98	53.75	36.38	5.00	3.62	1.25
Ena-Healthcare workers (Cronbach's alpha = 0.97, omega = 0.97)		Never (1) (%)	Not often (2) (%)	Somewhat often (3) (%)	Often (4) (%)	Very often (5) (%)
E7. Healthcare workers have not listened to my concerns	0.94	60.19	35.45	1.46	2.38	0.53
E8. Healthcare workers have avoided touching me	0.90	60.58	36.24	1.46	1.06	0.66
E9. Healthcare workers have treated me with less respect	0.89	60.05	36.64	1.06	1.46	0.79
Full HIV stigma mechanism scale (Cronbach's alpha = 0.90, omega = 0.91)						

Items I6, E4–E6, and A4–A6 were excluded because the way these concepts are expressed in English did not have an equivalent meaning and expression in Luganda

0.16, p < 0.01). However, we also found a non-hypothesized positive association between enacted-family stigma and depressive symptoms: a one-unit increase in enacted-family stigma (range 1–5) was associated with an increase of b = 1.15 in depressive symptoms (95% CI 0.31–1.99, p < 0.01). Additionally, contrary to our hypothesis, *enacted-HW stigma* was negatively associated with number of significant health problems (b = − 0.18, 95% CI − 0.35–0, p < 0.05).

Discussion

This study advances previous research on HIV stigma measures by evaluating the psychometric properties of the HIV-SMS. We tested and adapted the HIV-SMS for PLHIV in central Uganda, a country disproportionately affected by HIV. We tested the final scale associations with health outcomes hypothesized in the original HIV stigma mechanisms framework [15]. Interestingly, we found comparable rates

Table 4 Discrimination and severity estimates according to parametric item response model

HIV stigma mechanism scale: results according to P-OCC	Discrimination	Severity			
		b1	b2	b3	b4
Internalized					
I1. Having HIV makes me feel like I'm a bad person	2.06	− 0.34	1.91	2.39	3.56
I2. I feel I'm not as good as others because I have HIV	3.39	− 0.43	1.05	1.49	2.71
I3. I feel ashamed of having HIV	1.76	− 0.46	1.44	2.06	3.51
I4. I think less of myself because I have HIV	3.57	− 0.47	0.76	1.32	2.43
I5. Having HIV makes me feel unclean	1.44	− 0.24	0.85	1.67	3.42
Anticipated-family					
A1. Family members will avoid me	3.50	− 0.79	1.23	1.87	2.66
A2. Family members will look down on me	3.27	− 0.44	1.21	1.90	2.78
A3. Family members will treat me differently	3.41	− 0.46	1.18	1.78	2.67
Anticipated-Healthcare workers					
A7. Healthcare workers will not listen to my concerns	7.51	0.19	0.32	0.43	0.56
A8. Healthcare workers will avoid touching me	3.18	0.95	1.26	1.52	1.82
A9. Healthcare workers will treat me with less respect	3.36	0.76	1.05	1.29	1.58
Enacted-family					
E1. Family members have avoided me	3.27	− 0.03	1.49	1.97	2.69
E2. Family members have looked down on me	3.48	0.12	1.38	1.97	2.71
E3. Family members have treated me differently	3.43	0.10	1.37	2.00	2.70
Enacted-Healthcare workers					
E7. Healthcare workers have not listened to my concerns	3.46	0.04	0.90	1.12	1.69
E8. Healthcare workers have avoided touching me	3.79	0.37	1.09	1.35	1.67
E9. Healthcare workers have treated me with less respect	3.73	0.34	1.41	1.64	2.01

Items I6, E4–E6, and A4–A6 were excluded. The way this concept is expressed in English did not have an equivalent meaning and expression in Luganda

Table 5 Correlation (r), part I

	Internalized	Anticipated-family	Anticipated-health-care workers	Enacted-family	Enacted-healthcare workers
Internalized	–				
Anticipated-family	0.37***				
Anticipated-healthcare workers	0.26***	0.35***			
Enacted-family	0.27***	0.46***	0.20***		
Enacted-healthcare workers	0.23***	0.19***	0.47***	0.46***	
Age	− 0.10***	− 0.08**	− 0.01	0.01	0
Education	0.08**	0.01	− 0.02	− 0.04	0
Wealth Index	0.02	− 0.03	− 0.08**	− 0.08**	− 0.07**

***p value < 0.01; **p value < 0.05, and *p value < 0.10

of HIV stigma as reported in the seminal work conducted in the USA [15]. On average, overall rates of self-reported HIV stigma were low, with enacted stigma being the least reported and internalized stigma the most reported.

However, unlike prior research, findings from our analyses exploring the HIV-SMS' latent structure pointed to more nuanced HIV stigma mechanisms among PLHIV in central Uganda. Specifically, our analyses unveiled that the HIV-SMS' enacted and anticipated stigma subscales should split into two: one subscale related to family members and the other associated with healthcare workers. This finding resulted in a newly configured HIV-SMS composed of five (versus three) stigma subscales: internalized, anticipated-family, anticipated-HW, enacted-family, and enacted-HW.

Within the resultant 5-factor model, the subscales with higher correlations were associated with the same source

Table 6 Multiple Associations between the health outcomes with the 5-factor solution for the HIV-Stigma Mechanism Scale

Estimate (b and aOR with 95% CI below)

	Depressive symptoms[a] (b)	Months since last HIV clinic visit[a] (b)	Alcohol use AUDIT-C[a] (b)	CD4 count[+] (aOR)	Number of significant health problems[a] (b)	Number of hospitalizations[a] (b)
Internalized	3.27***	0.46***	− 0.02	0.66***	0.32***	0.01
	(2.59,3.94)	(0.08,0.84)	(− 0.27,0.23)	(0.48,0.90)	(0.21,0.44)	(− 0.03,0.05)
Anticipated-family	0.23	0.21	0.01	1.01	0.04	0.06**
	(− 0.51,0.98)	(− 0.22,0.64)	(− 0.26,0.29)	(0.73,1.40)	(− 0.07,0.16)	(0,0.11)
Anticipated-health-care workers	0.18	− 0.44	− 0.66***	0.97	0	− 0.02
	(− 0.79,1.15)	(− 1.02,0.14)	(− 1.02,− 0.29)	(0.60,1.57)	(− 0.16,0.17)	(− 0.10,0.05)
Enacted-family	1.15***	− 0.22	− 0.11	1.44*	0.1	0.09***
	(0.31,1.99)	(− 0.70,0.25)	(− 0.42,0.19)	(0.95,2.18)	(− 0.03,0.24)	(0.02,0.16)
Enacted-healthcare workers	− 0.63	0.13	− 0.06	0.94	− 0.18**	− 0.01
	(− 1.63,0.36)	(− 0.44,0.72)	(− 0.43,0.30)	(0.54,1.64)	(-0.35,0)	(-0.09,0.07)

[a]Multiple regression coefficients estimates (b) for continuous outcomes

Logistic regression adjusted odds ratio (aOR) estimate for binary outcome[+]: CD4 count (reference category is ≤ 500 cells/mm^3)

In parentheses the 95% confidence intervals

***p value < 0.01; **p value < 0.05; and *p value < 0.10

Table 7 Correlation (r), part II

	Depressive symptoms	Months since last HIV clinic visit	Alcohol use AUDIT-C	CD4 count	Number of significant health problems	Number of hospitalizations
Age	0	− 0.03	0.13***	− 0.05	0	0.01
Education	− 0.05	0.06	− 0.08**	0.11*	0	− 0.03
Wealth index	− 0.06*	0	− 0.05	0.06	− 0.07**	− 0.13***
Internalized	0.42***	0.09**	− 0.07*	− 0.08	0.23***	0.10**
Anticipated-family	0.24***	0.03	− 0.08**	0.01	0.12***	0.19***
Anticipated-healthcare workers	0.12***	− 0.02	− 0.15***	0	0.04	0.04
Enacted-family	0.25***	0.01	− 0.05	0.07	0.11***	0.22***
Enacted-healthcare workers	0.12***	0	− 0.10***	0.03	0	0.05

***p value < 0.01; **p value < 0.05, and *p value < 0.10

agents of stigma: anticipated-family and enacted-family were positively and strongly correlated, as well as anticipated-HW and enacted-HW. These findings suggest that HIV stigma is processed differently among PLHIV in central Uganda and varies depending on the source agent. HIV is a "family disease"; consequently, the family is an essential resource for prevention, care, and wellness [46]. Although some families in Uganda may abandon PLHIV and be a source of discrimination, they may also help PLHIV to develop a more positive sense of themselves [47].

The literature on substance use-related stigma also shows an agent-based structure for anticipated and enacted stigma mechanisms. Thus, our study findings may be generalizable to other stigma types outside of HIV-related stigma. For example, similar to our findings, Smith et al. [48] and

Smith et al. [49] found factor solutions that split anticipated and enacted stigma subconstructs into family and healthcare workers for the Substance Use and Methadone Maintenance Treatment Stigma Mechanisms Scales (SU-SMS and MMT-SMS).

We also found similar results and limitations when testing the relationship between our HIV-SMS 5-factor solution and health outcomes as in the seminal work [15]. Internalized stigma had the strongest positive association with affective health (depressive symptoms) and was the only mechanism positively associated with the behavioral health outcome months since the last HIV clinic visit. Opposite than hypothesized, we found a negative association between internalized stigma and CD4 count (physical health). This counterintuitive finding could be due to recall bias, given that
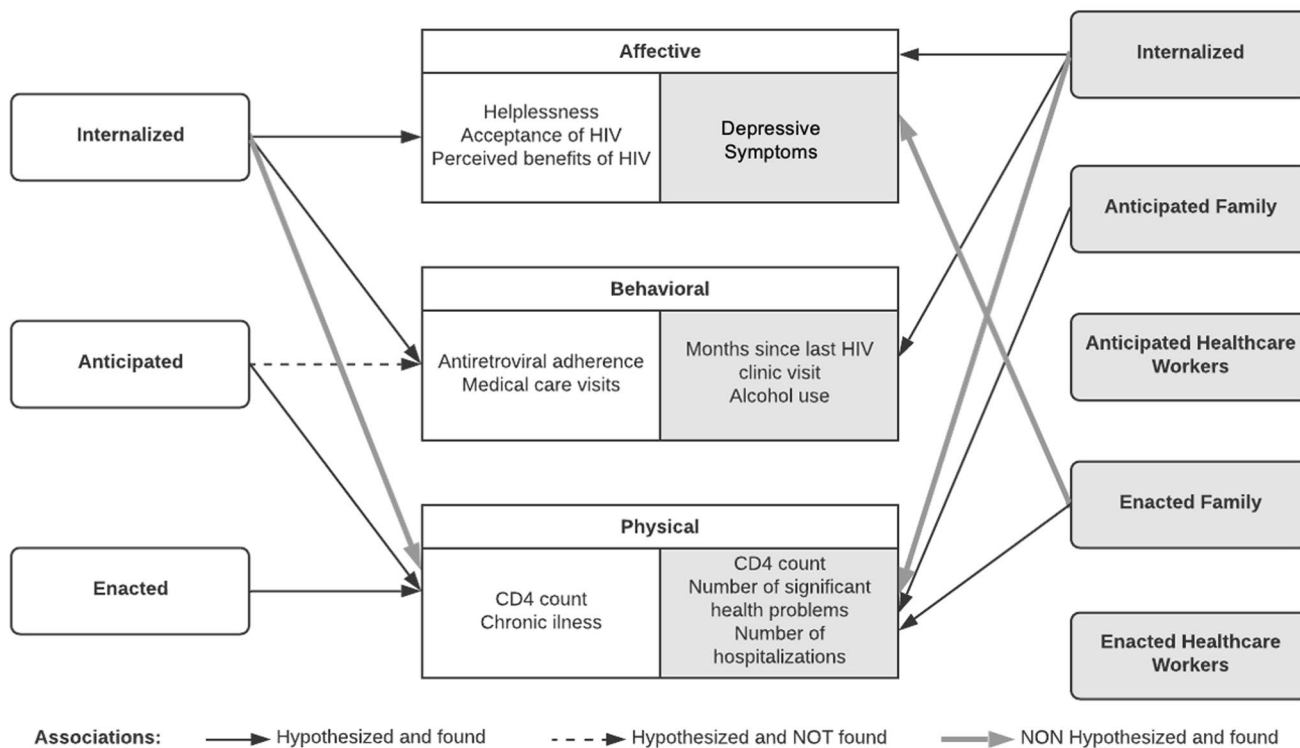
Fig. 3 Associations between HIV Stigma Mechanisms Scale and outcomes in health and well-being. On the left results of the seminal work (USA), on the right results of this study (Uganda)

participants' CD4 count was self-reported and the length of time since participants' last CD4 count was not assessed. We also found a non-hypothesized positive association between internalized stigma and physical health (number of significant health problems), indicating that future research should explore this relationship, as it may parallel findings that depression is associated with chronic illness [50].

Like findings from the seminal HIV stigma mechanisms framework research [15], we found a positive association between anticipated and enacted family stigma and physical health (number of hospitalizations). However, we did not find support for the hypothesized association between anticipated (family or HW) with behavioral health (months since last HIV clinic visit and alcohol use). Researchers have found that PLHIV's fear of disclosing their serostatus to their family is linked to isolation and non-linkage to care [11]. Therefore, "months since last HIV clinic visit" may not be an appropriate measure to use with PLHIV experiencing family-related HIV stigma as they may not be receiving HIV care. Future research should encompass different HIV treatment access and adherence measures representing behavioral health constructs to explore this possibility. Furthermore, as time has evolved with differentiated care approaches in the

Ugandan HIV healthcare system, patients who are stable on treatment may not need to go to the clinic for up to 6 months, making "months since the last clinic visit" as an indicator of potential lapses in care a difficult measure to apply universally to PLHIV in this context.

Anticipated and enacted healthcare worker stigma were not positively associated with any of the health outcomes considered in this study. Interestingly, the average stigma scores in both the anticipated-HW and enacted-HW sub-constructs were, on average, 13% lower than their family counterparts. A possible explanation for this finding is that, given the higher rates of HIV, the duration of the epidemic, and greater initiatives to end the HIV epidemic in Uganda, such as through free universal test-and-treat [51], healthcare workers received more training and experience working with PLHIV. This additional training and exposure to PLHIV may have ultimately reduced discrimination from HIV healthcare workers. The negative association between enacted-HW and the number of significant health problems (physical health outcome) can also result from exposure to the health care system. If someone has more health problems and has sought more (outpatient) health care, they might be less fearful of stigma from healthcare workers.

Finally, we did not find a significant positive association between alcohol use (behavioral health) and any of the stigma mechanisms. This finding could be due to the samples' low rate of alcohol consumption (average of 1.59 on a scale ranging from 0 to 12), indicating that future research in Uganda should oversample PLHIV with high levels of alcohol consumption to ensure adequate representation of this high-risk population.

Strengths and Limitations

The current study has several strengths, including being the first to examine the HIV-SMS psychometric properties using a sample from a resource-limited setting. Additionally, the study analyses were conducted using a representative community-based sample of PLHIV in central Uganda and tested relationships with health measures not explored in prior work. However, the study findings must be interpreted cautiously, given certain limitations.

First, we used cross-sectional data to conduct the analyses. As HIV becomes more familiar to people, the level of HIV stigma experienced may have decreased over time [52]. Thus, to broaden our understanding of the HIV stigma mechanisms framework and specify how each stigma mechanism is associated with health and well-being outcomes, it would be important to consider longitudinal designs, especially with newly diagnosed participants.

Second, this is a secondary analysis of the PATH/Ekkubo study data; the variables used may not be optimal for this specific analysis. For example, because HIV stigma was only measured using the HIV-SMS in the PATH/Ekkubo study, we did not test convergent validity using other HIV stigma measurement instruments. Relatedly, we did not assess other sources of HIV stigma outside of family and healthcare workers, such as HIV stigma from community members. Community-level stigma experienced by PLHIV in Uganda is not uncommon. For example, one study in Uganda found that PLHIV prefer to look for HIV treatment in facilities not close to their home for fear of being stigmatized by their community members [53]. Future HIV stigma research, especially those conducted in central Uganda or similar settings, should include measures of community-level anticipated and enacted stigma, as well as other sources of stigma (e.g., anticipated/enacted stigma from co-workers and faith-based organizations).

Conclusion

Our 5-factor solution for the HIV-SMS is a nuanced, reliable, and valid instrument for measuring HIV stigma among PLHIV in central Uganda and potentially for other sub-Saharan African regions sharing similar cultures. The specificity of the 5-factor model can help inform the growing body of interventions targeting HIV stigma [54, 55] not only by providing improved HIV stigma measurement but also distinguishing the source agents of stigma in the HIV dynamic, specifically families versus healthcare workers. Our psychometric analysis and framework testing reinforce the HIV-SMS' generalizability and the relationship between HIV stigma and PLHIV's health and well-being. It also expands our knowledge of health and well-being outcomes associated with HIV stigma by testing health outcomes not explored in prior research.

Declarations

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