



# HIV-Related Shame, Stigma and the Mental Health Functioning of Adolescents Living with HIV: Findings from a Pilot Study in Uganda

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## Abstract

This study examined the relationship between HIV-related shame, stigma and the mental health of adolescents (10–14 years) living with HIV in Uganda. Cross sectional data from a 2-year pilot study for adolescents living with HIV (N=89) were analyzed. Multiple linear regression analyses were conducted to determine the relation between HIV-related shame, as measured by the Shame Questionnaire, stigma, and adolescents' mental health functioning, including depressive symptoms, hopelessness, PTSD symptoms, loneliness and self-concept. The average age was 12.2 years, and 56% of participants were female. HIV-related shame was associated with higher levels of depressive symptoms ( $p < 0.05$ ), hopelessness ( $p < 0.001$ ), PTSD symptoms ( $p < 0.001$ ), loneliness ( $p < 0.01$ ), and low levels of self-concept ( $p < 0.01$ ). HIV stigma was not associated with any of the outcomes. Findings support the need for the development of strategies to help adolescents overcome the shame of living with HIV and mitigate the effects of shame on adolescents' mental health and treatment outcomes.

**Keywords** HIV-related shame · Stigma · Adolescent mental health · Child PTSD · Depressive symptoms

## Introduction

Shame—defined as a self-conscious emotion resulting from negative self-evaluation following a perceived deviation from a social or moral code [1, 2], is a public health concern. Shame is characterized by a painful internalized emotion encompassing feelings that the self is damaged and defective [3, 4], and is accompanied by feelings of worthlessness, rejection, isolation and the desire to disappear [5]. Compared to stigma—which involves experiences of blame, exclusion and rejection due to other people's negative social judgement [6–8], shame is an internally constructed emotional response that may be influenced by stigmatizing attitudes, especially once internalized [9]. Given that adolescence is a developmental period of multiple vulnerabilities marked by the onset of physical and emotional maturity [10], as

well as the rise in social evaluations and self-consciousness concerns [11–14], adolescents living with HIV (ALHIV)—a highly stigmatized disease, are more prone to shame during this period.

Shame has been documented as a barrier to combating the spread of HIV, as well as undermining HIV treatment outcomes [15, 16]. Specifically, shame prevents individuals from disclosing their HIV status to family members, friends, sexual partners and service providers [15]. It prevents individuals from getting tested, including pregnant women—limiting them from engaging in prevention of mother to child transmission of HIV programs [17]. Moreover, shame prevents caregivers from disclosing HIV status to their perinatally infected children [18] and can prevent people from engaging in care and or being retained in care, which exacerbates the psychological impact of living positively with HIV [15].

Studies have documented the negative impact of shame on the behavioral, physical, clinical and psychosocial outcomes [1, 9]. Specifically, HIV-related shame has been associated with mental health challenges, including depressive symptoms [6, 19, 20], anxiety and post-traumatic stress disorder symptoms [6, 21–23]. In terms of care and treatment outcomes, HIV-related shame has been associated with non-disclosure, fear of HIV testing [15], non-adherence to

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medication [24] and a barrier to participating in HIV-related clinical trials [25]—pointing to reduced health care service utilization and lower quality of life [9, 26]. Studies have also linked shame to increased production of cortisol—a stress hormone [1], which in turn, is associated with higher viral load among people living with HIV, severe fatigue, depression and anxiety traits [27, 28]. Moreover, HIV-related shame has been associated with increased HIV risky sexual behaviors and linked to continued transmission of HIV among adult populations [5, 29]. In non-HIV related studies, shame has been documented to mediate the relationship between stigmatizing experiences (such as abuse and maltreatment) and internalizing symptoms in children and adolescents [30, 31].

Even with these documented negative effects of shame, fewer studies have investigated shame among people living with HIV in Sub-Saharan Africa (SSA), especially among children and adolescents [32]. Most studies have focused on HIV-related stigma and its impact on mental health functioning [7, 8, 33–36]. Yet, compared to stigma, shame is considered a more proximal predictor of mental health challenges [37]. Moreover, shame is usually examined as a component of internalized stigma, making it difficult to disentangle the specific components that are strongly associated with mental health outcomes [4]. Thus, this study contributes to the limited literature by examining the relationship between HIV-related shame, stigma and the mental health functioning of ALHIV in Uganda. Given that shame is a modifiable predictor through individually focused interventions [1, 38], findings may inform interventions aimed at addressing shame within this young vulnerable population as they transition through adolescence and into young adulthood.

## Methods

### Sample and Setting

Baseline data from adolescents participating in the Suubi4Stigma study (2020–2022), a 2-year pilot study aimed at addressing HIV related stigma among adolescents living with HIV and their caregivers in Uganda, were analyzed. The study recruited 89 child-caregiver dyads ( $N = 178$ ) from 9 comparable health care clinics across four political districts of Masaka, Kyotera, Kalungu and Lwengo—with an HIV prevalence of 11.7% compared to 5.4% of the national average [39]. Inclusion criteria for adolescents: (1) living with HIV and aware of their status; (2) between 10 and 14 years; (3) enrolled on antiretroviral therapy in participating clinics; and (4) living within a family, including with extended family. All health care clinics were comparable in terms of number of adolescents served, facility level and

availability of adolescents' friendly services e.g., adolescent clinic days.

### Participant Recruitment

Study participants were identified and recruited from government HIV health clinics providing HIV-related services within the study region. A clinic staff created a list of all eligible families from medical records, noting their eligibility to participate. Next, the clinic staff presented the project idea to adult caregivers of eligible children during appointments. If caregivers were interested, verbal consent to be contacted by research staff who was on site during the adolescent clinic days was requested. Following a meeting with the research staff, interested caregivers were taken through informed consent after which they provide written consent for themselves and for their child to participate. A total of 147 adolescents together with their caregivers from 9 health care clinics turned up for screening, 89 met the study inclusion criteria and were recruited into the study. Detailed description of the study is provided in the study protocol [40].

### Ethical Considerations

All study procedures were approved by Washington University in St. Louis Institutional Review Board (IRB # 202009185), the Uganda Virus Research Institute (GC/127/20/10/792), and the Uganda National Council for Science and Technology (SS632ES). Prior to study participation, informed written consent and assent were obtained from caregivers and adolescents respectively. The study is registered in the Clinical trials.gov database (Identifier #: NCT04528732).

### Data Collection

Data were collected using a 90-min interviewer-administered questionnaire. All study related materials were translated into Luganda—the widely spoken language in the study region, and back translated into English to ensure consistency. A certificate of translation was obtained from Makerere University. All interviewers received training in human subjects' protection and completed Good Clinical Practice (GCP) trainings prior to engaging with study participants.

### Measures

All measures utilized in this study have been adapted and tested among adolescents affected by HIV in the study region [32, 41–43]. Measures of mental health functioning include depressive symptoms, hopelessness, loneliness, child PTSD and self-concept. *Depressive symptoms* were assessed using the 14-item Child Depression Inventory

(CDI) [44]. Items were adapted from the original long version scale, which measures both emotional and functional problems that correspond with depression in children, and have been tested in the study region among adolescents living with HIV [40, 43]. Respondents were asked to mark a statement that best described their feelings during the past 2 weeks, with three response options that correspond to varying levels of symptomology for clinical depression (Cronbach's alpha 0.61). *Hopelessness* was measured using the Beck Hopelessness Scale (BHS) [45]. The 20-item scale measures children's hopelessness and pessimistic attitudes toward the future, with *true/false* responses, with higher scores indicating higher levels of hopelessness (Cronbach's alpha 0.68). *Loneliness* was assessed using the UCLA Loneliness Scale [46]. The 20-item scale measures one's subjective feelings of loneliness as well as feelings of social isolation (3 = *I often feel this way* and 0 = *I never feel this way*), with high scores indicating higher levels of social isolation (Cronbach alpha = 0.88). *Child PTSD* was measured using 31 items from the abbreviated Childhood post-traumatic Stress Reaction Index (CPTS-RI) [47]. Participants were asked about reactions people sometimes have after very bad things happen and how this was applicable to them in the past month (0 = *none (never)* and 4 = *Most (almost every day)*), with higher scores indicating higher levels of child PTSD symptoms (Cronbach alpha = 0.92). *Self-concept* was measured using the Tennessee Self-Concept Scale [48], a 20-item scale that measures children's perception of identity, self-satisfaction and other behaviors (1 = *Always False*, and 5 = *Always True*), with higher scores indicating higher levels of child self-concept (Cronbach's alpha = 0.81).

The Shame Questionnaire [49], an 8-item scale, was used to measure adolescent's *feelings of shame*, on a 3-point scale (0 = *Not true* and 2 = *Very True*). Higher scores indicate higher levels of HIV-related shame. The scale has been adapted and validated to measure HIV-related shame among Ugandan ALHIV, with high internal consistency (Cronbach's alpha = 0.84) [32]. *HIV-related stigma* was assessed by 9-items from the Berger Stigma Scale measuring both internalized and anticipated stigma [50], on a 4-point scale (1 = *Strongly Disagree* and 4 = *Strongly Agree*) with a higher score indicating higher levels of internalized and anticipated stigma. The scale demonstrated an acceptable internal consistency (Cronbach's = 0.74) among Ugandan ALHIV [42]. Based on previous literature, variables included in the model as control variables include participants' age, gender, orphanhood status, number of people in the household, and family cohesion.

## Analysis Procedures

Data analysis was performed using STATA version 17. We analyzed participants' demographic characteristics, as well

**Table 1** Sample characteristics (N = 89)

Variable	Total sample (N = 89)
Gender (%)	
Age (min/max: 10–14)	12.21 (1.41)
Orphaned child (n, %)	40 (44.9)
Number of people in the household (min/max: 2–14)	6.42 (2.66)
Family cohesion (min/max: 12–35)	24.90 (6.30)
Shame and Stigma	
Shame (min/max: 0–11)	2.80 (3.05)
HIV Stigma (min/max: 9–33)	16.96 (5.52)
Psychosocial measures	
Loneliness (min/max: 20–62)	33.28 (10.77)
Depressive symptoms (min/max: 0–16)	5.02 (3.58)
Hopelessness (min/max: 0–12)	5.89 (3.19)
Child PTSD Index (min/max: 0–94)	30.2 (22.07)
Self-concept (min/max: 48–100)	76.04 (12.25)

as the independent and outcome variables. We conducted multiple linear regression models to ascertain the relationship between HIV-related shame, stigma, and measures of adolescents' mental health functioning, specifically, depressive symptoms, hopelessness, PTSD, loneliness and self-concept. Statistical significance was set a priori at the 5% level. To adjust for alpha inflation, Robust Huber–White standard errors and test statistics were used for all models. For each linear regression model, standardized residuals were predicted, and diagnostic tests examined to check the distribution of residuals for non-normality and/or inequality of residuals over levels of predicted values for linear regression models. Specifically, the histogram (i.e., P–P and Q–norm plots) of the standardized residuals with the normal curve overlaid and a scatterplot of the standardized residuals by predicted values were visually examined for each linear regression model. Additionally, we examined multicollinearity for each model and concluded that number of children in the family was highly correlated with number of people in the family and hence dropped from all models. All models were single-level models.

## Results

Sample characteristics are presented in Table 1. The majority of participants were female (56%), the average age was 12.2 years and about 45% identified as orphans i.e., had lost a biological father or mother. The average household size was 6 people, with 3 children. Overall, participants reported moderate scores on HIV-related shame, stigma, and all mental health measures.

Bivariate correlation results are summarized in Table 2 and regression results are presented in Table 3. Controlling for participants' and household characteristics, HIV-related shame was associated with higher levels of depressive symptoms ( $b = 0.24$ , 95% CI = 0.04, 0.44,  $p < 0.05$ ) in model 1, hopelessness ( $b = 0.35$ , 95% CI = 0.15, 0.55,  $p < 0.001$ ) in model 2, PTSD symptoms ( $b = 3.04$ , 95% CI = 1.72, 4.36,  $p < 0.001$ ) in model 3, loneliness ( $b = 0.97$ , 95% CI = 0.21, 1.73,  $p < 0.01$ ) in model 4, and low levels of self-concept ( $b = -1.08$ , 95% CI =  $-1.88$ ,  $-0.28$ ,  $p < 0.01$ ) in model 5. In addition, gender i.e., being a female child, was associated with higher levels of hopelessness ( $b = 1.82$ , 95% CI = 0.60, 3.05,  $p < 0.01$ ), PTSD symptoms ( $b = 11.37$ , 95% CI = 3.35, 19.39,  $p < 0.01$ ), and low self-concept ( $b = -8.67$ , 95% CI =  $-13.03$ ,  $-4.31$ ,  $p < 0.001$ ). HIV stigma was not associated with any of the outcomes.

## Discussion

Adolescents living with HIV are at an increased risk of developing poor mental health conditions [51–54]. This study examined the relationship between HIV-related shame, stigma and the mental health functioning of adolescents living with HIV. Findings indicate that HIV-related shame was significantly associated with depressive symptoms, hopelessness, loneliness, PTSD symptoms, as well as low levels of self-concept. These findings are consistent with studies that have documented the negative impact of shame on behavioral and mental health outcomes [6, 19–23].

Contrary to studies that have examined HIV stigma and mental health [34, 35, 55–57], stigma was not associated with any of the outcomes in the current study. Indeed, it has been suggested that shame is a more proximal predictor of mental health challenges than stigma [37]. Given that shame increases avoidant coping [6, 54, 55], it could be that adolescents living with shame utilize more avoidant coping strategies, including withdrawal from social interactions, which in turn, may potentially exacerbate pre-existing psychological distress. In addition, given the high prevalence of HIV in the study region [39], where families have been greatly affected by HIV, it is possible that stigmatizing behaviors, especially towards children are declining. Indeed, the most recent Stigma Index Survey report in Uganda [58] indicate that experiences of externalized stigma have reduced significantly from 4.5% in 2013 to 1.3% in 2019—potentially explaining the minimal association with adolescents' psychosocial wellbeing. Finally, given the young age of adolescents in our study, it could be that they are still developing or forming stigma related perceptions and attitudes [59]. As such, they may be unable to recognize stigmatizing behaviors toward them, reducing the potential negative impact on their psychosocial wellbeing.

Study results also indicate that girls were more likely to experience more negative mental health outcomes compared to boys. These findings are consistent with a small number of studies suggesting that female youth living with HIV are at a higher risk of mental health difficulties compared to males [60, 61]. Other studies have documented differences in sexes—specifically, that being female is a risk factor for internalizing problems, including depression and anxiety, while being male is a risk factor for behavioral problems [62]. Among adult populations, studies have found that women living with HIV are at a higher risk of depression, anxiety, PTSD compared to their male counterparts [63, 64]. Given that mental health disorders negatively influence treatment outcomes and mortality [65, 66], findings point to the integration of gender specific components for addressing mental health among adolescents living with HIV.

Study findings have important implications for the development of effective psychosocial interventions. Indeed, interventions such as cognitive behavioral therapy, mindfulness [67, 68], acceptance and commitment therapy [69], as well as compassion-based interventions [70, 71], show promise of decreasing shame across diverse populations. The current study tests two evidence-based interventions, including group-based cognitive behavioral therapy to address HIV-related stigma among adolescents [40]. Findings, if warranted, will inform the incorporation of shame-reduction components within the current cognitive behavioral therapy intervention.

A few limitations are worth noting. First, we analyzed cross sectional data from a small pilot sample. Second, all outcomes were self-reported and may be impacted by social desirability. Third, data collection was conducted during the Covid-19 pandemic. The associated challenges, including social distancing and disruptions may have been associated with worsening mental health among adolescents.

Overall, study findings contribute to the limited literature examining HIV-related shame and mental health of young people living with HIV in SSA. Future research is needed to understand the mechanisms through which HIV-related shame impacts the mental health of adolescents living with HIV. Findings are in line with the increasing calls to address mental health difficulties to achieve the HIV prevention and treatment outcomes for young people growing up with a highly stigmatized infection.

## Summary

Shame has been documented as a barrier to combating the spread of HIV, as well as undermining HIV treatment outcomes. Shame negatively impacts the behavioral, physical, clinical and psychosocial outcomes of individuals. However, fewer studies have investigated shame among

**Table 2** Bivariate correlation analysis

	Age	Female child	Orphaned child	People in house-hold	Family cohesion	Stigma	Shame	Depressive symptoms	Self-concept	Hopelessness	PTSD	Loneliness
Age	1											
Female child	0.084	1										
Orphaned child	0.072	0.039	1									
People in house-hold	-0.03	-0.064	-0.142	1								
Family cohesion	-0.017	-0.18	-0.119	0.171	1							
Stigma	-0.056	0.032	0.065	0.044	0.117	1						
Shame	-0.291**	0.125	-0.022	-0.082	-0.201	0.215*	1					
Depressive symptoms	-0.098	0.2	-0.102	-0.073	-0.224*	0.029	0.312**	1				
Self-concept	0.036	-0.415***	-0.152	0.103	0.259*	-0.217*	-0.373***	-0.279**	1			
Hopelessness	0.023	0.332**	0.046	0.09	-0.16	0.105	0.347***	0.184	-0.541***	1		
PTSD	0.035	0.311**	0.152	0.084	-0.093	0.228*	0.418***	0.236*	-0.572***	0.391***	1	
Loneliness	0.013	0.124	0.147	-0.044	-0.094	0.217*	0.295**	0.004	-0.346***	0.135	0.529***	1

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$

**Table 3** Regression on mental health functioning

Variables	Depressive symptoms		Hopelessness		Child PTSD	
	b (Robust SE)	95% CI	b (Robust SE)	95% CI	b (Robust SE)	95% CI
Age	-0.07 (0.21)	-0.48, 0.35	0.22 (0.21)	-0.20, 0.65	2.14 (1.34)	-0.52, 4.80
Female child	0.88 (0.59)	-0.29, 2.05	1.82 (0.62)**	0.60, 3.05	11.37 (4.03)**	3.35, 19.39
Orphaned child	-0.72 (0.63)	-1.97, 0.52	0.31 (0.60)	-0.89, 1.51	6.94 (3.88)	-0.77, 14.65
Number of people in household	-0.04 (0.14)	-0.31, 0.23	0.19 (0.12)	-0.05, 0.42	1.27 (0.50)**	0.28, 2.25
Family cohesion	-0.07 (0.06)	-0.19, 0.04	-0.03 (0.05)	-0.13, 0.06	0.06 (0.32)	-0.58, 0.70
HIV stigma	-0.01 (0.04)	-0.09, 0.83	0.02 (0.06)	-0.10, 0.13	0.47 (0.42)	-0.36, 1.30
HIV shame	0.24 (0.10)*	0.04, 0.44	0.35 (0.10)***	0.15, 0.55	3.04 (0.66)***	1.72, 4.36
Constant	16.35 (3.19)***	10.01, 22.70	0.23 (3.18)	-6.11, 6.56	-32.16 (20.14)	-72.22, 7.90
R <sup>2</sup>	0.160		0.241		0.321	
F-value (df)	2.97 (7)	0.008	4.41 (7)	<0.001	9.73(7)	<0.001
N	89		89		89	

  

Variables	Loneliness		Self-concept	
	b (Robust SE)	95% CI	b (Robust SE)	95% CI
Age	0.66 (0.73)	-0.79, 2.11	-0.09 (0.79)	-1.68, 1.48
Female child	1.50 (2.35)	-3.17, 6.18	-8.67 (2.19)***	13.03, -4.31
Orphaned child	2.82 (2.24)	-1.64, 7.29	-2.75 (2.22)	-7.16, 1.67
Number of people in household	0.01 (0.31)	-0.60, 0.62	0.12 (0.39)	-0.65, 0.89
Family cohesion	-0.05 (0.18)	-0.41, 0.32	0.28 (0.19)	-0.09, 0.65
HIV stigma	0.30(0.21)	-0.12, 0.72	-0.35 (0.20)	-0.76, 0.05
HIV shame	0.97 (0.38)**	0.21, 1.73	-1.08 (0.40)**	-1.88, -0.28
Constant	16.30 (11.06)	-5.71, 38.30	85.23 (11.99)	<0.001
R <sup>2</sup>	0.146		0.334	
F-value (df)	2.37 (7)	0.029	9.01(8)	<0.001
N	89		89	

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ 

children and adolescents living with HIV sub-Saharan Africa. This study examined the relationship between HIV-related shame, stigma and the mental health of adolescents (10–14 years) living with HIV in Uganda. Cross sectional data from a 2-year pilot study for adolescents living with HIV (N=89 dyads) were analyzed. Multiple linear regression analyses were conducted to determine the relation between HIV-related shame, as measured by the Shame Questionnaire, stigma, and adolescents' mental health functioning, including depressive symptoms, hopelessness, PTSD symptoms, loneliness and self-concept. The average age was 12.2 years, and 56% of participants were female. HIV-related shame was associated with higher levels of depressive symptoms ( $p < 0.05$ ), hopelessness ( $p < 0.001$ ), PTSD symptoms ( $p < 0.001$ ), loneliness ( $p < 0.01$ ), and low levels of self-concept ( $p < 0.01$ ). In addition, girls were more likely to experience more negative mental health outcomes compared to boys. HIV stigma was not associated with any of the outcomes. Findings

support the need for the development of strategies to help adolescents overcome the shame of living with HIV and mitigate the effects of shame on adolescents' mental health and treatment outcomes.

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## Declarations

**Conflict of interest** The authors have no conflict of interest to disclose.

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