The Impact of Shame on Health-Related Quality of Life Among HIV-Positive Adults with a History of Childhood Sexual Abuse

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Abstract

Childhood sexual abuse is prevalent among people living with HIV, and the experience of shame is a common consequence of childhood sexual abuse and HIV infection. This study examined the role of shame in health-related quality of life among HIV-positive adults who have experienced childhood sexual abuse. Data from 247 HIV-infected adults with a history of childhood sexual abuse were analyzed. Hierarchical linear regression was conducted to assess the impact of shame regarding both sexual abuse and HIV infection, while controlling for demographic, clinical, and psychosocial factors. In bivariate analyses, shame regarding sexual abuse and HIV infection were each negatively associated with health-related quality of life and its components (physical well-being, function and global well-being, emotional and social well-being, and cognitive functioning). After controlling for demographic, clinical, and psychosocial factors, HIV-related, but not sexual abuse-related, shame remained a significant predictor of reduced health-related quality of life, explaining up to 10% of the variance in multivariable models for overall health-related quality of life, emotional, function and global, and social well-being and cognitive functioning over and above that of other variables entered into the model. Additionally, HIV symptoms, perceived stress, and perceived availability of social support were associated with health-related quality of life in multivariable models. Shame is an important and modifiable predictor of health-related quality of life in HIV-positive populations, and medical and mental health providers serving HIV-infected populations should be aware of the importance of shame and its impact on the well-being of their patients.

Introduction

WITH THE AVAILABILITY OF highly active antiretroviral therapy (HAART), HIV/AIDS has been transformed from a progressive fatal disease to a manageable chronic one.¹ Consequently, health-related quality of life (HRQoL), which encompasses perceived health and well-being across multiple domains (e.g., physical functioning, cognitive functioning, emotional status, social role performance), has become a clinically meaningful outcome in HIV-infected populations.²⁻⁴ Childhood sexual abuse (CSA) has been identified as a significant predictor of HRQoL and is associated with a range of psychological, behavioral, and medical ramifications in adulthood.⁵⁻⁷ However, few studies have been published examining HRQoL among seropositive individuals with a history of CSA, despite people living with HIV reporting

disproportionately high rates of CSA.^{8,9} CSA has been linked to risky sexual and substance use behavior, as well as with sexual revictimization, placing both men and women with a history of CSA at greater risk for contracting or transmitting HIV.¹⁰⁻¹² Additionally, among those living with HIV, traumatic stress is associated with medication nonadherence, pain intensity, and interference of pain in daily functioning.¹³⁻¹⁵ Finally, shame is a common consequence of CSA and has been associated with symptoms of posttraumatic stress disorder (PTSD).¹⁶⁻¹⁹ Taken together, these findings suggest that the physical and psychological sequelae of CSA contribute to diminished HRQoL among those living with HIV. In the current study, the independent influence of shame regarding sexual abuse and shame regarding HIV-infection on HRQoL will be examined in a sample of adults living with HIV who have experienced childhood (under age 18) sexual abuse.

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Prior research has explored the impact of demographic, clinical, and psychosocial factors on HRQoL among people living with HIV.²⁰ The literature is inconsistent with regard to the association between demographic factors and HRQoL, although some studies have found associations with gender, income, and employment status.^{4,21,22} With respect to clinical factors, studies have consistently revealed that number and severity of HIV symptoms are linked to HRQoL.^{21,23,24} Additionally, a number of psychosocial factors, including social support, coping skills, perceived stress, grief, and psychological distress, have been found to predict HRQoL.^{2,4,25,26} Finally, HIV-related stigma and discrimination have been shown to have a negative impact on HRQoL,^{20,23,27,28} above and beyond even the severity of HIV symptoms and depression.²⁰

While numerous studies have examined the impact of clinical, demographic, and psychosocial factors, including HIV-related stigma, on HRQoL, research on the association between shame and HRQoL is notably absent from the literature. Many researchers regard shame as distinct from stigma.^{29–31} A stigma is a mark or characteristic of disease, defect, or disgrace, and HIV-related stigma is typically conceptualized as the negative social response to either or both (1) HIV as a life-threatening, chronic illness or (2) behaviors associated with HIV transmission (injection drug use, homosexuality, sexual promiscuity, etc.).³² On the other hand, shame is a painful emotion that typically results from negative evaluation following conduct or circumstances that damage self-respect.^{33,34} While shame and internalized stigma are sometimes considered equivalent, we prefer to conceptualize them as related but distinct constructs. As with most theorists, we view stigma as being socially constructed and contextualized, based on culturally embedded power structures, and resistant to change.^{35–37} Shame, on the other hand, is an internally derived emotional response that may be influenced, but not controlled, by stigmatizing attitudes perceived to be present in the community or internalized by the individual. Thus shame, unlike stigma and discrimination, is amenable to change through psychosocial interventions.^{29,34} We recognize and applaud efforts of some theorists to capture the social impact of stigma on the individual through the cognitive construct of internalized stigma, which has been construed to consist of emotional and behavioral responses (including shame) to perceived or experienced stigma.^{36,38} However, we prefer the linguistic clarity of defining stigma as a sociocultural power structure and shame as a potentially changeable, individually created emotional and behavioral response.

The literature on shame, particularly as it relates to HRQoL is scarce, although a few studies have examined the impact of shame on health-related outcomes. For example, the experience of shame has been shown to increase proinflammatory cytokine activity and produce HIV disease-relevant immunologic changes.³⁴ In qualitative studies, shame (although viewed as a component of internalized stigma) has been cited as a reason for medication nonadherence³⁹ and as a barrier to participating in HIV/AIDS clinical trials,⁴⁰ suggesting that shame may be associated with decreased utilization of health care services. Finally, HIV-related shame has been linked to continued HIV-transmission behavior among HIV-infected adults.⁴¹

The primary aim of this study was to examine the impact of shame regarding both sexual abuse and HIV infection on HRQoL among seropositive adults with a history of CSA.

Hierarchical linear regression was used to examine the effects of shame on HRQoL, while controlling for traumatic stress symptoms, as well as other factors traditionally linked to HRQoL (e.g., demographic variables, HIV-related stress, HIV symptoms, social support, and perceived stress).

Method

Study design and sample

Data comes from the baseline interview of a large randomized controlled trial of HIV-positive adult men and women (18 years or older) with histories of CSA that were recruited from community-based organizations and medical clinics serving individuals with HIV/AIDS in New York City.^{42,43} Potential participants were recruited through provider-referral and recruitment materials advertising a group intervention for people living with HIV who had experienced CSA. A total of 333 potential participants were screened for inclusion using a structured clinical interview, which ascertained demographics, sexual abuse history, depression, posttraumatic stress, and risk to self or others. Participants were included if they had a history of CSA, were HIV positive, and were 18 years or older. CSA was defined as sexual abuse (any unwanted touching of a sexual nature) in childhood (under the age of 13), or adolescence (between the ages of 13 and 17) by an adult or someone 5 years or older than the participant when the abuse occurred. Exclusion criteria were: (1) acute distress due to sexual revictimization in the past month, (2) impaired mental status, and (3) severe psychological distress, as indicated by suicidal intent or a score of 30 or greater on the Beck Depression Inventory (BDI).⁴⁴

Of the 333 potential participants who were screened for eligibility, 21 did not meet the aforementioned criteria (7 had not been sexually abused, 1 had experienced sexual revictimization in the past month, 6 were cognitively impaired, and 7 were severely depressed) and 41 participants were not enrolled in the study for assorted reasons (23 could not be located; 13 declined or were unable to continue due to health, employment or childcare; 3 were incarcerated; and 2 died). Of the remaining 271 participants, 5 had incomplete assessments, and an additional 13 heterosexual men were excluded due to insufficient numbers for randomization. Four transgendered participants were categorized according to their self-identified gender. The final sample included 256 participants. For the current study, 9 participants were missing data on study variables, thus 247 participants were included in the data analysis.

After screening, eligible participants were administered a baseline assessment using a computer-assisted personal interview (CAPI). All assessments were conducted in English, and participants with low literacy had assessments read aloud to them. Research assistants were always available in an adjacent office to provide assistance. Participants received \$35 upon completion of this assessment. All participants provided written informed consent and all study procedures were approved by Institutional Review Boards at all affiliated organizations.

Measures

Outcome measures

HRQoL. The revised Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) was used to assess

participants' HRQoL.⁴⁵ The FAHI assesses general life quality, as it relates to chronic illness, as well as HIV-specific life quality. The revised FAHI is a 44-item measure with 5 subscales: physical well-being, function and global well-being, emotional well-being/living with hiv, social well-being, and cognitive functioning. Respondents rate each item in regard to his or her illness in the past week on a Likert scale ranging from 0 (not at all) to 4 (very much). For the primary data analysis, the 44 FAHI items were summed into a total score, with higher scores indicating greater HRQoL. Secondary analyses were conducted on each of the five subscales. The revised FAHI has demonstrated good reliability and validity, with a Chronbach α of 0.94 for the total score in the current sample. Subscale α were 0.69 (cognitive functioning), 0.87 (social well-being), 0.89 (emotional well-being), 0.90 (physical well-being), and 0.90 (function and global well-being) in the current sample.⁴⁵

Predictive measures

Block 1—demographic factors. Gender was reported as male, female, or transgender. This variable was further dichotomized as male or female, with transgendered participants self-identifying as one gender or the other. Race was reported in multiple categories (non-Hispanic white, Hispanic, non-Hispanic black, Asian or Pacific Islander, Alaskan Native, more than one race/ethnicity), and dichotomized as black or non-black. Annual income was reported in four categories: (1) Less than \$10,000; (2) \$10,000 to \$20,000; (3) \$20,000 to \$30,000; or (4) greater than \$30,000. Annual income was further dichotomized as <\$10,000 or $\geq$ \$10,000. Age and education were reported continuously in years.

Block 2—HIV-related factors

HIV-related stress. A 15-item measure adapted from other studies was used to measure HIV-specific stressors (e.g., AIDS discrimination, drug regimen, HIV illness of friends or relatives).⁴⁶ Respondents rated how often they felt stressed by each of these items during the past 4 months on a 5-point Likert scale ranging from 1 (not at all) to 5 (always). A total score was calculated by summing the score for each item. In the current sample the internal consistency for this measure was adequate (Chronbach α = 0.81).

HIV symptoms. A 20-item scale was used to assess the presence of HIV symptoms (e.g. skin rash, nausea, diarrhea).⁴⁷ Participants indicated whether each symptom was present or not present. A score was computed by summing the number of symptoms present. This scale exhibited strong internal consistency (Chronbach α = 0.93).

Block 3—traumatic stress symptoms

Impact of event scale. The Impact of Event Scale (IES) is a 15-item scale measuring the psychological impact of traumatic experiences.⁴⁸ For the current study, items were answered in reference to sexual abuse. It has 2 subscales: intrusion and avoidance. Individuals rate how often they experience distress in relation to a specified traumatic experience on a 4-point scale (0 = not at all, 1 = rarely, 3 = sometimes, or 5 = often) during the past week. Because these subscales are highly correlated (r = 0.66, current sample), they were summed into a combined traumatic stress variable for the current analyses (Chronbach α = 0.94).

Block 4—psychosocial factors

Perceived availability of social support. Perceived availability of social support (PASS) was measured using a subscale (7 items) of the Social Relationship Scale.⁴⁹ The PASS assesses whether an individual believes he or she would have support from others given various scenarios, such as inability to get out of bed for several weeks. Responses are given on a 5-point Likert scale, ranging from 1 (definitely no) to 5 (definitely yes). Good internal consistency was observed in the current sample (Cronbach α = 0.85).

Perceived Stress Scale. The Perceived Stress Scale (PSS) has 10 items, which evaluates how often the respondent deems situations stressful in the past month.⁵⁰ The respondent rates how often he/she felt a certain way about a situation on a scale of 0 (never) through 4 (very often), with certain items coded in the reverse direction. Scores range from 0 to 40, with a higher score indicating higher perceived stress. The PSS demonstrated adequate internal consistency in the current sample (Chronbach α = 0.77).

Block 5—shame regarding sexual abuse and HIV infection. A 31-item measure with 3 subscales was used to assess sexual abuse-related shame, hiv-related shame, and the impact of hiv-related shame on behavior.⁴¹ The current study used the sexual abuse-related shame and the hiv-related shame subscales as independent indicators of shame.

Sexual abuse-related shame. Shame concerning CSA was assessed with the 9-item sexual abuse-related shame subscale. This subscale contained items such as: "I struggle with feeling worthless because I've been sexually abused/raped," "I hide my sexual abuse or rape experience(s) from others" and "Having been sexually abused/raped makes me want to hide, disappear, or even die." For each item, participants rate their agreement on a 5-point Likert Scale ranging from 0 (not at all) to 4 (very much). The Sexual Abuse-Related Shame subscale had good internal consistency in the current sample (Chronbach α = 0.93).

HIV-related shame. Shame concerning HIV infection was assessed using the 13-item HIV-related shame subscale. This subscale contained items such as: "Being HIV-positive makes me feel defective, like there's something wrong with me," "I am ashamed that I'm HIV+" and "I hide my infection from others." For each item, participants rate their agreement on a 5-point Likert Scale ranging from 0 (not at all) to 4 (very much). The HIV-Related Shame subscale had good internal consistency in the current sample (Chronbach α = 0.93).

Statistical analyses

Bivariate analyses were performed to test for associations between covariates and the FAHI total score and subscales. Pearson, Spearman, or ϕ correlations were computed to examine associations between continuous, ordinal, and nominal predictors, respectively.

For the primary data analysis, a hierarchical linear regression model was constructed to examine the association between predictors and the FAHI total score. Variables were entered into the regression model in blocks. The first block contained demographic variables (gender, race, income, age,

education). The second block contained HIV-related factors (HIV-related stressors, HIV symptoms). The third block contained an indicator of traumatic stress symptoms (IES total score). The fourth block contained the predictors perceived social support and stress (PASS, PSS). The fifth and final block contained the variables sexual abuse-related shame and HIV-related shame. Secondary analyses repeated these steps for each of the five FAHI subscales to examine predictors for specific components of HRQoL.

Results

Participant characteristics

Table 1 displays descriptive statistics for study variables by gender. The mean age of the 247 participants included in this study was 42 years. Slightly greater than half the sample was female (51%). The majority of the sample was African American/Black (69%), while 17% of the sample was Hispanic, 10% were White, and the remaining 5% were of other race/ethnicity. More than half of the sample earned less than \$10,000 per year (66%). Approximately 25% of the sample earned between \$10,000 and \$20,000 per year. The remaining 8% of the sample earned \$30,000 per year or greater. Slightly more than half of the sample graduated from high school (52%). Thirty-one percent had not completed high school, and 16% attained at least some college education. With respect to sexual orientation, almost half (45%) of the sample identified as gay/homosexual, and 16% identified as bisexual. The remaining 40% of the sample identified as straight/heterosexual.

As shown in Table 1, the sample differs significantly by gender with regard to a number of demographic characteristics. The proportion of blacks was higher among females (76%) than males (60%). Overall, females were poorer than males, with the majority of females (80%) earning less than \$10,000 a year, while only slightly more than half of males earned less than this amount (52%). In addition, females were less educated. Almost half of females (46%) had less than a high school education, as opposed to 17% of males. Finally, with respect to sexual orientation, the majority of females were straight or heterosexual (77%), while all of the men engaged in sex with men (17% bisexual, 83% homosexual).

Bivariate analyses

Table 2 displays a correlation table of the bivariate associations between predictor variables and HRQoL (FAHI total score and subscale scores). Demographic variables were not associated with HRQoL. However, HIV-related stress, HIV symptoms, traumatic stress symptoms, perceived stress, and shame regarding sexual abuse and HIV infection were each moderately to strongly associated with lower HRQoL. Conversely, perceived availability of social support was associated with higher HRQoL. Patterns of correlations with predictor variables were similar for the FAHI subscales, with the exceptions that social well-being was not significantly associated with HIV-related stress, HIV symptoms, or traumatic stress; and Cognitive Functioning was not significantly associated with social support.

Hierarchical linear regression analyses

The results from the primary data analysis using hierarchical regression analysis are presented in Table 3. The de-

TABLE 1. DESCRIPTIVE STATISTICS OF STUDY VARIABLES BY GENDER

Variable	Female (n = 129)		Male (n = 118)		
Block 1—Demographic Factors					
Categorical Variables	n	%	n	%	χ^2
Race/ethnicity					7.16 ^b
African American/black	99	76.7%	72	61.0%	
White, Hispanic or other	30	23.3%	46	39.0%	
Annual income					20.58 ^b
<\$10,000	102	79.1%	61	51.7%	
≥\$10,000	27	20.9%	57	48.3%	
Sexual orientation					148.60 ^b
Straight/heterosexual	98	76.0%	0	0.0%	
Gay/bisexual	31	24.0%	118	100%	
Continuous Variables	Mean	SD	mean	SD	t test
Age (years)	43.3	7.1	41.1	6.7	2.11 ^a
Education (years)	11.6	2.1	13.1	2.5	5.00 ^b
Block 2—HIV-Related Factors					
HIV-related stress	30.4	11.1	32.7	11.6	1.64
HIV symptoms	12.8	11.5	10.5	8.3	1.77
Block 3—Traumatic Stress Symptoms					
Impact of Events Scale	35.9	19.0	30.7	17.7	2.21 ^a
Block 4—Psychosocial Factors					
Perceived availability of support	28.8	6.0	28.1	5.2	0.95
Perceived stress	18.3	5.8	18.2	6.5	0.03
Block 5—Shame Regarding Sexual Abuse and HIV Infection					
Sexual abuse-related shame	14.1	11.6	14.6	10.7	0.35
HIV-related shame	15.7	13.0	17.0	12.7	0.81
Health-Related Quality of Life					
FAHI Total Score	105.0	32.2	104.8	28.3	0.07
Physical well-being	25.9	9.2	27.8	8.5	1.69
Emotional well-being	24.2	9.9	23.3	9.5	0.68
Function and global well-being	29.0	12.3	28.6	10.1	0.30
Social well-being	18.9	8.8	17.7	8.2	1.07
Cognitive functioning	7.1	3.0	7.5	2.7	1.14

^aValue significant, $p < 0.05$.

^bValue significant, $p < 0.01$.

SD, standard deviation; FAHI, Functional Assessment of Human Immunodeficiency Virus Infection.

mographic variables entered in Block 1 were not associated with HRQoL in the multivariable analysis, with the entire block explaining a non-significant 2% of the variance in overall HRQoL. As shown in Table 3, however, each additional block entered into the model after Block 1 (Blocks 2 through 5) did significantly contribute to the overall model above and beyond the combination of blocks entered previously. Block 2, containing HIV-related factors, explained an additional 25.8% of the variance in overall HRQoL. However, in the final adjusted model, only the variable HIV symptoms significantly predicted lower overall HRQoL ($\beta = -0.20$, $p < 0.001$). Block 3, consisting of traumatic stress symptoms,

TABLE 2. BIVARIATE ASSOCIATIONS BETWEEN PREDICTOR VARIABLES AND HEALTH-RELATED QUALITY OF LIFE

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Gender ^a												
2. Race/ethnicity ^b	-0.17^c											
3. Income	-0.29^c	0.15 ^c										
4. Age	0.13 ^d	0.07 ^d	0.08 ^d									
5. Education	-0.31^d	0.19^d	0.27^d	0.11								
6. HIV-related stress	-0.10 ^d	0.03 ^d	0.05 ^d	-0.10	0.08							
7. HIV symptoms	0.06 ^d	0.06 ^d	-0.16 ^d	-0.02	-0.06	0.33						
8. Impact of Events Scale	0.14 ^d	-0.10 ^d	-0.12 ^d	-0.09	-0.06	0.36	0.34					
9. Perceived availability of support	0.11 ^d	-0.02 ^d	0.11 ^d	0.02	-0.01	-0.06	-0.13	-0.12				
10. Perceived stress	0.01 ^d	-0.04 ^d	-0.08 ^d	-0.17	-0.03	0.36	0.37	0.52	-0.27			
11. Sexual abuse-related shame	-0.04 ^d	-0.06 ^d	0.08 ^d	-0.02	0.04	0.35	0.29	0.64	-0.14	0.41		
12. HIV-related shame	-0.06 ^d	-0.02 ^d	0.03 ^d	-0.11	0.06	0.49	0.23	0.44	-0.15	0.38	0.56	
13. Health-related quality of life	-0.01 ^d	-0.04 ^d	0.01 ^d	0.10	-0.07	-0.40	-0.44	-0.47	0.36	-0.64	-0.45	-0.57
13a. Physical Wellbeing	-0.11 ^d	-0.02 ^d	0.07 ^d	0.09	-0.02	-0.33	-0.59	-0.43	0.14	-0.44	-0.36	-0.32
13b. Emotional well-being	0.06 ^d	0.01 ^d	-0.01 ^d	0.13	-0.08	-0.50	-0.34	-0.49	0.19	-0.53	-0.50	-0.65
13c. Function and global well-being	0.02 ^d	-0.01 ^d	-0.04 ^d	0.01	-0.07	-0.22	-0.23	-0.33	0.33	-0.52	-0.33	-0.44
13d. Social well-being	-0.07 ^d	-0.13 ^d	0.02 ^d	0.08	-0.08	-0.10	-0.12	-0.09	0.45	-0.32	-0.14	-0.23
13e. Cognitive functioning	-0.06 ^d	0.01 ^d	-0.01 ^d	0.04	0.05	-0.32	-0.42	-0.36	0.11	-0.58	-0.30	-0.43

Note: Numbers in bold font signify a significant relationship, $p < .01$.

^aMale is the referent value.

^bAfrican American/black is the referent value.

^cPhi coefficient.

^dSpearman correlation coefficient; otherwise Pearson correlation coefficient.

explained an additional 7.7% of the variance in overall HRQoL. However, traumatic stress was not a significant predictor of HRQoL in the final adjusted model ($\beta = -0.05$, $p < 0.445$). The psychosocial factors entered in Block 4 explained 18.3% of the variance in HRQoL over and above that explained by the previous blocks entered in the model, with perceived availability of social support predicting higher levels of HRQoL ($\beta = 0.19$, $p < 0.001$), and perceived stress predicting lower levels of HRQoL ($\beta = -0.36$, $p < 0.001$). Last, Block 5 explained an additional 7.3% of the variance above that of the other blocks entered in the model. However, sexual

abuse-related shame did not remain a significant predictor of HRQoL, while HIV-related shame was a strong predictor of poorer overall HRQoL ($\beta = -0.33$, $p < 0.001$).

Results from secondary data analyses examining the same set of predictor variables with each of the five FAHI subscales are shown in Table 4. In general, results were similar to what was observed in the primary data analysis. The demographic variables entered in Block 1 were nonsignificant across all FAHI subscales. The HIV-related factors entered in Block 2 explained significant levels of the variance in all components of HRQoL except social well-being. Similarly, Block 3,

TABLE 3. PRIMARY HIERARCHICAL REGRESSION MODEL PREDICTING HRQoL (FAHI TOTAL SCORE)

Variable	R^2	ΔR^2	F Change	df	p	β	p
Block 1—Demographic Factors	0.020	0.02	0.989	5, 241	0.425		
Gender						-0.049	0.288
Race/ethnicity						-0.045	0.289
Income						-0.063	0.164
Age						0.010	0.820
Education						-0.067	0.134
Block 2—HIV-Related Factors	0.278	0.258	42.735	2, 239	<0.001		
HIV-related stress						-0.010	0.841
HIV symptoms						-0.196	<0.001
Block 3—Traumatic Stress Symptoms	0.356	0.077	28.553	1, 238	<0.001		
Impact of Events Scale						-0.045	0.445
Block 4—Psychosocial Factors	0.538	0.183	46.713	2, 236	<0.001		
Perceived availability of support						0.185	<0.001
Perceived stress						-0.362	<0.001
Block 5—Shame Regarding Sexual Abuse and HIV Infection	0.611	0.073	22.008	2, 234	<0.001		
Sexual abuse-related shame						:010	0.870
HIV-related shame						-0.330	<0.001
Final Model Adjusted R^2	0.591						
Final Model N = 247							

HRQoL, health-related quality of life; FAHI, Functional Assessment of Human Immunodeficiency Virus Infection.

TABLE 4. SECONDARY HIERARCHICAL REGRESSION MODELS PREDICTING COMPONENTS OF HRQoL (FAHI SUBSCALES)

Variable	Physical well-being			Emotional well-being			Function and global well-being			Social well-being			Cognitive Functioning		
	R ²	ΔR ²	β	R ²	ΔR ²	β	R ²	ΔR ²	β	R ²	ΔR ²	β	R ²	ΔR ²	β
Block 1	0.03	0.03		0.03	0.03		0.01	0.01		0.03	0.03		0.01	0.01	
Gender			−0.09			−0.01			−0.03			−0.02			−0.06
Race/ethnicity			−0.03			−0.01			−0.01			−0.10			−0.01
Income			−0.01			−0.04			−0.09			−0.02			−0.10
Age			0.05			0.04			−0.07			0.05			−0.06
Education			−0.07			−0.05			−0.04			−0.06			0.05
Block 2	0.38	0.35 ^b		0.30	0.27 ^b		0.08	0.07 ^b		0.05	0.02		0.23	0.22 ^b	
HIV stress			−0.04			−0.15 ^a			0.10			0.06			0.01
HIV symptoms			−0.45 ^b			−0.08			−0.04			−0.02			−0.24 ^b
Block 3	0.42	0.04 ^b		0.39	0.09 ^b		0.14	0.06 ^b		0.05	0.00		0.26	0.03 ^b	
IES			−0.13			−0.11			−0.02			0.11			0.01
Block 4	0.44	0.02 ^a		0.44	0.05 ^b		0.34	0.20 ^b		0.27	0.22		0.41	0.15 ^b	
Perceived Social Support			0.02			0.04			0.19 ^b			0.38 ^b			−0.06
Perceived Stress			−0.16 ^a			−0.21 ^b			−0.38 ^b			−0.23 ^b			−0.45 ^b
Block 5	0.44	0.00		0.54	0.10 ^b		0.40	0.07 ^b		0.29	0.02		0.46	0.05 ^b	
Abuse shame			−0.04			−0.06			0.02			0.01			0.10
HIV shame			−0.05			−0.37 ^b			−0.33 ^b			−0.17 ^a			−0.29 ^b
Final Model															
Adjusted R ²	0.42			0.52			0.37			0.25			0.43		

^aValue significant, $p < 0.05$.^bValue significant, $p < 0.01$.

HRQoL, health-related quality of life; FAHI, Functional Assessment of Human Immunodeficiency Virus Infection.

containing traumatic stress symptoms, explained small but significant amounts of the variance in all components of HRQoL except social well-being, although the Impact of Events Scale was not a significant predictor in any multivariable models. Block 4, containing psychosocial variables, was the only block which contributed significantly to the prediction of all components of HRQoL. Within this block, the variable perceived stress was significant in all multivariable models, while perceived availability of support was significant in the models predicting function and global well-being and social well-being. Finally, Block 5, containing sexual abuse-related shame and HIV-related shame, explained significant amounts of variance across all components of HRQoL except physical well-being. Of the shame variables, only HIV-related shame was a significant predictor, related to all FAHI subscales except physical well-being.

Discussion

This study examined the impact of shame regarding both sexual abuse and HIV infection on HRQoL in HIV-positive adults with a history of CSA. To date, few studies have been published on the impact of shame on people living with HIV. While some studies have been published documenting the negative impact of HIV stigma on HRQoL in HIV-positive populations,^{20,27,28} this appears to be the first study to examine the relationship between sexual abuse-related shame and HRQoL. Both sexual abuse-related shame and HIV-related shame were negatively associated with HRQoL in bivariate analyses. However, the results of this study revealed that HIV-related shame, but not sexual abuse-related shame, was strongly and consistently associated with poorer HRQoL and most of its components, explaining up to 10% of the

variance in multivariable models over and above other predictors for overall HRQoL, as well as emotional, function and global, social well-being, and cognitive functioning components of HRQoL. Sexual abuse and HIV-related shame were negatively linked to physical well-being in unadjusted analyses, although these associations dissipated after controlling for other factors.

While we are unaware of specific theories linking shame to HRQoL, it does not seem implausible to take models of shame-based PTSD⁵¹ an additional step to help explain the impact of shame on HRQoL. Models of shame-based PTSD describe shame as both a primary and a secondary emotion.⁵¹ Psychobiological theories of shame⁵² suggest that shame as a primary emotion serves as a mechanism for establishing and maintaining social rank and status. Thus, the experience of shame is the result of an individual appraising that he or she has lost social value and is at risk for rejection by his or her community. As a result, individuals experiencing primary shame exhibit submissive and avoidant behavior patterns.⁵¹ In contrast, shame as a secondary emotion is seen as the result of cognitive appraisal following an event perceived to be frightening, traumatic, or humiliating and in which one perceives himself or herself as being or acting weak or shameful. An individual's cultural and familial experiences, and the resulting formation of self-schemas, determine what events and behaviors will be perceived as shameful and give rise to secondary shame.⁵¹

Both primary and secondary shame are theorized to impact mental health, particularly traumatic stress and depression.⁵¹ Primary shame leads to submissive and avoidant behavior patterns, and can reinforce perceptions of the self as weak or damaged, which also increases the risk of experiencing secondary shame. Secondary shame, particularly when it rein-

forces underlying negative core beliefs about the self, can lead to intrusive and negative thoughts, and high levels of avoidance, consistent with PTSD and Major Depression. This is also consistent with Social Self-Preservation Theory, which suggests that threats to one's social standing result in feelings of shame and humiliation, which are linked to physiologic changes such as increased cortisol levels.⁵³ Adapting these models of shame-based PTSD⁵¹ and stress⁵³ to sexual abuse and HIV-related shame, it is conceivable that the impact of shame on avoidant behavior, negative self-image, and poor mental health functioning can also lead to avoidance of health care and social support networks, increased substance use, reductions in motivation for self-care, and feelings of submissiveness and inadequacy in managing one's health.

The literature on shame, although sparse, provides support for this theory. For example, one study found that 54% of patients receiving psychotherapy for depression withheld information about their symptoms due to shame, and that nondisclosure of symptoms was related to poorer outcomes.⁵⁵ The authors suggested that facilitating the disclosure of shameful symptoms may improve clinical outcomes. Qualitative research has identified shame as a barrier to utilization of services and medication adherence. In a small sample of predominantly African American HIV-positive adults, shame and social stigma were described as barriers to picking up medication and following their HIV medication regimen.³⁹ In another qualitative study, HIV-positive injection drug users utilizing supervised injection drug use services at an HIV care facility cited feelings of shame and fear of judgment as a drawback to using these services.⁵⁴ However, a limitation of both of these studies is that researchers did not fully differentiate between shame and social stigma.

In addition to revealing a significant negative impact of shame on overall HRQoL and most of its domains, the current study evaluated the impact of other demographic, clinical, and psychosocial factors on HRQoL in an important, but understudied, population of seropositive individuals. Consistent with the literature, this study did not find any of the selected demographic factors (i.e., income, gender, sexual orientation, race) to be associated with HRQoL.^{22,56,57} Furthermore, this study replicated the association between HIV symptoms^{4,20,57} and perceived stress^{58,59} and diminished HRQoL, as well as perceived availability of social support^{4,25} and improved HRQoL. This study also found that HIV-related stress was a significant predictor of emotional well-being/living with HIV, but not overall HRQoL or other domains of HRQoL.

This study also examined the impact of traumatic stress symptoms on HRQoL. Research on the relationship between mental health and HRQoL among people living with HIV has traditionally focused on depression or general psychological distress. However, in one recent study conducted in a sample of men who have sex with men recruited from an ambulatory HIV care center, traumatic stress was significantly associated with poorer general health, greater pain, and functional role impairment.⁶⁰ In another study, conducted in a large sample of both male and female patients recruited from HIV clinics in the rural south, researchers found that PTSD symptoms independently predicted poorer physical, social, and cognitive functioning.⁶¹ In the present study, we found that traumatic stress symptoms were not significantly associated with HRQoL after controlling for other factors. A possible expla-

nation for these somewhat discrepant findings is that in the current study all participants had a history of sexual trauma. The mean level of traumatic stress in our sample was very high compared to normal controls or other samples experiencing traumatic stress, which could have attenuated the actual association between traumatic stress and HRQoL in this sample.⁶² Furthermore, traumatic stress symptoms were explicitly linked to sexual trauma in the questionnaire used, and this variable was highly correlated with sexual abuse-related shame. Without sexual abuse-related shame in the multivariable models, traumatic stress symptoms were significantly related to poorer physical and emotional well-being domains of HRQoL.

This study has a number of limitations, which should be noted. First, because this study is cross-sectional, inferences regarding causality are unwarranted. Second, as the study was conducted in a sample of seropositive individuals seeking entry to an intervention for coping with HIV and a history of sexual trauma, the sample may not be representative of HIV-infected individuals who experienced CSA and who do not seek such treatment. Additionally, all men in the sample were men who have sex with men, and thus findings may not generalize to heterosexual men with histories of CSA. Furthermore, it is unclear whether this study's findings are generalizable to the broader population of HIV-infected individuals without a history of CSA. The measures we used in this study covered differing retrospective periods (from 1 week to 4 months) that could produce inconsistencies in relationships between variables. This study also relied exclusively on participant self-report, including for health-related variables. While the majority of study variables focused specifically on participant perceptions of health, stress, social support, and functioning, information collected using self-report is susceptible to recall error, social desirability bias, and recall bias, which may obscure true associations between a given factor and health status. Finally, while we assessed shame related to sexual abuse and HIV infection, we were reminded by a reviewer that participants in this study had multiple stigmatized identities that were not addressed, such as gay, injection drug user, sex worker, poor, mentally ill, undereducated, and persons of color. These identities may also influence an individual's experience of shame and quality of life.

Despite these limitations, this study has several strengths. The study sample is one of the largest samples available of HIV-positive individuals who have experienced CSA, and is diverse with respect to age, gender, race, and sexual orientation. While all of the men included in the sample were bisexual or homosexual, MSM are the largest group of people living with HIV in the United States, representing 56% of all new HIV infections, and are the only group with an increasing HIV incidence.⁶³ Additionally, this study contributes to the existing literature as it is perhaps the only study to examine the impact of shame regarding sexual abuse and HIV infection, traumatic stress symptoms resulting from sexual trauma, and HIV-specific stressors and symptoms on HRQoL, and identifies HIV-related shame as highly relevant in the health and functioning of those living with HIV.

Since the advent of HAART, HIV has become a largely manageable, chronic condition. Consequently, HRQoL is a clinically meaningful outcome and identifying factors that impact HRQoL, particularly factors that may be modifiable, is

a priority. The consideration of HRQoL is especially important in individuals with a history of sexual trauma, as a history of CSA is common among HIV-positive individuals and such a history is independently associated with poorer physical and mental health status later on in life.^{5,6,8,9} This study revealed that within an HIV-positive population with a history of CSA, HIV-related shame was strongly associated with poorer overall HRQoL above and beyond other variables. Additionally, HIV symptoms and perceived stress were associated with poorer HRQoL, while perceived availability of social support was associated with better overall HRQoL. It is important to note that each of these predictors of HRQoL is modifiable with appropriate intervention. For example, with proper adherence to HIV medication and medical care, HIV symptoms can be successfully managed.¹ Additionally, myriad coping and stress management interventions have been developed for people living with HIV, and consistent with Social Self Preservation Theory,⁵³ these may be particularly salient for people experiencing HIV-related shame. Also, the number of empirically-supported behavioral interventions for people who have experienced childhood abuse is growing, including interventions that address shame and guilt, traumatic stress and sexual risk among HIV-positive adults, and HIV treatment adherence.^{42,43,64-66}

Overall, the present study's findings underscore the importance of HIV-related shame in HRQoL, and future research should focus on the roles of shame and stigma as separate barriers to obtaining and utilizing care. Identifying and addressing patient shame may be critical in eliciting full disclosure of symptoms,⁵⁵ and social service organizations and clinics serving seropositive individuals should be aware of and address HIV-related shame in the services they provide. The present study's findings also confirm and expand upon previous research linking stress to HRQoL in seropositive populations. The results provide evidence to suggest that stress-management interventions, which recognize the importance of managing HIV-specific stressors as well as more generalized stress, may be instrumental in improving HRQoL for seropositive individuals. Last, these results suggest that group interventions, and interventions aiming to improve social support among HIV-positive individuals, may be important, as social support was associated with multiple components of HRQoL.

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