

HIV-related shame and health-related quality of life among older, HIV-positive adults

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Abstract This study investigated how HIV-related shame is associated with health-related quality of life (HRQoL) in older people living with HIV (PLHIV). Structural equation modeling tested whether HIV-related shame was associated with three dimensions of HRQoL (physical, emotional, and social well-being) and whether there were significant indirect associations of HIV-related shame with the three HRQoL dimensions via depression and loneliness in a sample of 299 PLHIV ≥ 50 years old. Results showed that depression and loneliness were key mechanisms, with depression at least partially accounting for the association between HIV-related shame and both emotional and physical well-being, respectively, and loneliness accounting for the association between HIV-related shame and social well-being. HIV-related shame appears to be an

important correlate of HRQoL in older PLHIV and may provide a promising leveraging point by which to improve HRQoL in older PLHIV.

Keywords HIV/AIDS · Aging · Quality of life · Shame · Depression · Loneliness

Introduction

Antiretroviral therapy (ART) and improved clinical care have increased survival rates for people living with HIV (PLHIV; CDC, 2015; Figuero et al., 2011). Nearly 50% of adults currently living with HIV in the United States are 50 years of age or older (Bhavan et al., 2008; Justice, 2010; Kirk & Goetz, 2009). In light of increasing survival, the treatment of HIV increasingly focuses on patients' quality of life—not just physical well-being (Figuero et al., 2011).

Health-related quality of life (HRQoL) encompasses physical, functional, emotional and social aspects of living with a chronic health condition (Cella et al., 1996). As such, HRQoL is not limited to the experience of physical symptoms and side effects (Cella et al., 1996; Figuero et al., 2011). Older PLHIV face unique psychosocial challenges in addition to numerous physical difficulties. For example, as the population of PLHIV ages, many members of this group will contend with the stigma of being perceived as “too old” to have HIV (e.g., due to its association with risky sexual behavior) in addition to maintaining their physical health (Emlet, 2006).

Stigma is the degree to which the public holds negative attitudes about a group because of a devalued characteristic they possess, such a HIV; these negative attitudes affect how members of the devalued group view themselves (Goffman, 1963; Herek et al., 2013; Parker & Aggleton,

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2003). This conceptualization of stigma highlights the role of factors outside of the control of the stigmatized individual, such as the hierarchical power structure between different groups in society (Neufeld et al., 2012; Persons et al., 2010). Whereas stigma may include social and institutional processes that discredit a group or class of people, shame can be understood as a consequence of internalizing stigmatizing messages resulting in an affective manifestation of stigma among stigmatized persons (Kemeny et al., 2004; Neufeld et al., 2012; Persons et al., 2010). Shame can be understood as “a painful, self-conscious emotion in which one perceives the self to be defective” (Bennett et al., 2016, p. 88). Whereas one may experience shame if one “makes stable and global attributions for negative events,” guilt, which is itself a symptom of depression (American Psychiatric Association, 2013), is typically in response to “unstable, specific attributions for negative events” (Bennett et al., 2016, p. 88). Because shame may be more modifiable via behavioral interventions than stigma, shame is an appropriate focus of behavioral research (Neufeld et al., 2012; Persons et al., 2010).

HIV-related shame is associated with lower HRQoL in PLHIV. In a sample of 247 HIV positive adult men and women with histories of childhood sexual abuse, HIV-related shame was negatively associated with HRQoL, even when controlling for HIV-related symptoms, psychological distress, and shame associated with childhood sexual abuse (Persons et al., 2010). Given that older adults as a group are not typically associated with HIV infection, the impact of HIV-related stigma may present unique challenges for older PLHIV (Emlet, 2006). Thus, the affective response of shame and the underlying mechanisms of its associations with HRQoL may be an area of study and intervention that requires further examination.

Empirical studies and theoretical examinations have described shame as “the bedrock of psychopathology” (De Rubeis & Hollenstein, 2009) and a precipitant of psychological distress (Matos & Pinto-Gouveia, 2014; Mills, 2005; Tangney & Dearing, 2003). This fits within a stigma-focused framework of understanding how a uniquely affective response to stigma and associated psychological distress may be linked to HRQoL. Two indicators of psychosocial distress, depression and loneliness, may explain the consistent finding that shame is associated with health-related outcomes in PLHIV. Depression, which is common in older PLHIV, is linked to poor quality of life (Chesney et al., 2003; Heckman et al., 2002; Rodriguez-Penney et al., 2013). One study found that 25% of older PLHIV reported moderate to severe levels of depression (Heckman et al., 2002), and a second found that 39% of older PLHIV had been diagnosed with major depressive disorder (Heckman et al., 2002; Rodriguez-Penney et al., 2013). Furthermore,

depression is consistently, positively associated with loneliness (Groß et al., 2010; Luanaigh & Lawlor, 2008). Loneliness is the negative affective state experienced when social and intimacy-related needs go unmet and is distinct from depression (Peplau, 1987) and is consistently linked to physiological and self-rated, physical health measures in older adults (Luanaigh & Lawlor, 2008; Wen et al., 2006). While shame, depression, and loneliness are interrelated, these variables are well-established as being reflective of separate constructs (Adams et al., 2004; Matos & Pinto-Gouveia, 2014; Mills, 2005). In prior studies, correlations between various forms of shame, depression, and loneliness ranged from 0.48 to 0.62 (Herek et al., 2013; Matos & Pinto-Gouveia, 2014; Shim et al., 2013).

Additional research is needed to characterize associations among shame, depression, loneliness, and HRQoL in older adults, particularly older PLHIV. The experience of HIV-related stigma is associated with depression (Herek et al., 2013; Lee et al., 2002). Given that shame may represent an affective response to stigma, and also exacerbate depression and loneliness, these three affective consequences (shame, depression, and loneliness) may help to explain how HIV-related stigma is linked to poor health outcomes. Although related, depression and loneliness may differentially explain the associations among HIV-related shame and various dimensions of HRQoL. For example, poor social well-being may be more likely to result from the subjective experience of loneliness than from depressed mood, but loneliness may have less of an impact on physical well-being. It is also important to determine if HIV-related shame has direct associations with various aspects of HRQoL when accounting for these other forms of psychosocial distress (i.e., depression, loneliness), suggesting multiple pathways.

Current study

HRQoL in older PLHIV is influenced by HIV-related shame. However, other factors, particularly depression and loneliness, may help to explain the psychological mechanisms via which HIV-related shame is linked to HRQoL. To address these gaps in the literature, the present study tested the hypotheses that, among older PLHIV, higher levels of HIV-related shame will be associated with lower HRQoL, and this link will be mediated via depression and loneliness.

Method

Sample recruitment

From November 2004 to February 2007, adults ≥ 50 years old living with HIV/AIDS in New York City; Columbus,

Ohio; and Cincinnati, Ohio were recruited into a randomized, controlled trial (RCT) that tested the depression treatment efficacy of a coping group intervention for HIV-infected older adults (Heckman et al., 2011). The present study is a secondary data analysis of pre-intervention data from this RCT. Four-hundred and five were recruited through AIDS service organizations, local care providers, and print and online media. Study investigators purposefully recruited three subgroups into the RCT: men who have sex with men (MSM), heterosexual men, and women. Eligible individuals for the RCT were: (a) ≥ 50 years old; (b) self-reported living with HIV/AIDS; (c) scored ≥ 10 on the Beck depression inventory-II (BDI-II; a commonly used cutoff indicating at least mild depression); (d) scored ≥ 75 or higher on modified mini mental state examination; and (e) provided written informed consent. A BDI cutoff of ten was used to ensure that there was at least a minimum of psychological distress to show an effect of the intervention among older PLHIV who would most likely need it. After screening, 349 HIV-positive men and women satisfied eligibility screening criteria. Of those participants, 299 fully completed all pre-intervention measures and were included in present study's data analyses.

Measures

The following measures were administered via audio computer-assisted self-interviews.

Demographics

Participants provided the following demographic information that was adjusted for in the in primary and post hoc analyses: age, location (coded as [0] New York City, [1] cities in Ohio), race (Black, non-Black), ethnicity (Hispanic, non-Hispanic), education (less than high school diploma, high school diploma or greater), and income up to \$10,000, greater than \$10,000).

HIV-related shame

Items used to assess HIV-related shame were drawn from a HIV-related shame subscale of the HARS, a 31-item measure of shame (Neufeld et al., 2012; Sikkema et al., 2009). This subscale included 13 HIV shame items (e.g., "Being HIV-positive makes me feel defective, like there's something wrong with me," "I hide my infection from others"). For each item, participants rate their agreement on a five-point Likert scale ranging from 0 (not at all) to 4 (very much). Higher scores indicated greater HIV-related shame. The HIV-related shame subscale had excellent reliability (Cronbach's $\alpha = 0.93$, current study).

Psychosocial distress

Two dimensions of psychosocial distress, depression and loneliness, measured as follows:

Depression The Geriatric Depression Scale (Yesavage et al., 2000) asks thirty *yes* or *no* questions (e.g., "Do you often feel downhearted and blue?" "Do you feel that your life is empty?"). A *yes* answer endorses a symptom of depression. Higher scores indicated greater depression. The GDS demonstrated strong reliability (Cronbach's $\alpha = 0.92$).

Loneliness A 10-item version of the UCLA Loneliness Scale assessed loneliness (e.g., "I feel in tune with the people around me," "I feel part of a group of friends"; Russell et al., 1980). Each item used a four-point response scale ranging from 1 ("Never") to 4 ("Often"). Higher scores indicated greater feelings of loneliness. The scale showed very good reliability ($\alpha = 0.89$).

Health-related quality of life (HRQoL)

Health-related quality of life (HRQoL) was assessed using the functional assessment of human immunodeficiency virus infection (FAHI; Cella et al., 1996). The FAHI is a 47-item measure that yields a total score of overall HRQoL as well as five subscales physical well-being (e.g., "I am bothered by side effects of treatment"; 13 items), emotional well-being (e.g., "I worry that my condition will get worse"; 10 items), and social well-being (e.g., "My family has accepted my illness"; eight items). The functional and global well-being and cognitive functioning subscales were not included due to concerns regarding the possibility of confounding with age (e.g., older adults may be more likely not to work outside the home; interests and activities may change with age; natural, neurocognitive declines occur among some older adults). Participants rated each item in reference to their illness in the prior week using a five-point Likert scale ranging from 0 (*not at all*) to 4 (*very much*). Higher scores represented better HRQoL. The Cronbach's alpha values for the subscales based on current study data were 0.90 (physical well-being), 0.88 (emotional well-being), and 0.87 (social well-being).

Data analysis plan

Descriptive statistics consisted of means and standard deviations for continuous variables and counts and percentages for categorical variables. The primary data analytic strategy was structural equation modeling (SEM), conducted using Mplus 6 (Muthén & Muthén, 2010) to identify significant indirect associations of HIV shame with three dimensions of HRQoL (i.e., physical, emotional, and

social well-being) via two indicators of psychosocial distress (i.e., depression and loneliness). Robust maximum likelihood estimation was used to yield a Satorra–Bentler Scaled χ^2 (SB χ^2) test statistic and robust standard errors that account for non-normality in the data. Good model fit was assessed using any two of the following three criteria: root mean square standard error of approximation (RMSEA) with 90% confidence intervals (CI) and a RMSEA value of 0.08 or less within the CI; a Tucker–Lewis index (TLI) value of at least 0.95; and a standardized root mean square residual (SRMR) criterion of 0.08 or less (Hu & Bentler, 1999; Kline, 2015; MacCallum et al., 1996). Direct and indirect associations were estimated using bias-corrected bootstrapping. The model was adjusted for race, location, ethnicity, education level, and income.

Latent variables of each study measure (HIV shame, depression, loneliness, and physical, emotional, and social well-being) were created to account for measurement error (Fuller, 2009; Kline, 2015). Modification indices were obtained via Mplus and used to determine what correlations between residuals of item-level indicators to allow within, but not between, latent factors. Upon establishing that each latent variable model adequately fit the data, an omnibus model that included all latent variables was tested to determine correlations among latent variables (e.g., whether variables were sufficiently distinct to retain them as separate factors in SEM). For highly correlated variables, discriminant validity was assessed using SB χ^2 difference testing (Satorra & Bentler, 2010; Steiger et al., 1985) to compare (a) a two-factor model of each pair of correlated latent variables to (b) a one-factor model with the indicators of the two latent variables loading onto a single factor instead of their original two, separate factors.

Next, upon demonstrating discriminant validity, the primary analysis was conducted using a structural regression model of outcome variables (physical, emotional, and social well-being) regressed onto the predictor variable (HIV shame) and mediator variables (depression, loneliness) and mediator variables regressed onto the predictor variable. The structural regression model was adjusted for covariates. Unstandardized regression coefficients (*b*), their standard errors (SE), and *p* values were reported. Item parceling by averaging (Coffman & MacCallum, 2005; Little et al., 2002, 2013) was used so that the structural regression model in the primary and post hoc analyses would converge given the small sample and subsample sizes. For each variable, two to three parcels were used except for depression, which had eight parcels.

A post hoc three-group analysis between the three recruitment groups, MSM and heterosexual men and women, yielded models that could not converge due to the small subsample sizes. Thus, separate two-group analyses

were conducted by gender (i.e., [0] men; [1] women) and by self-identified sexual orientation/behavior (i.e., [0] MSM; [1] heterosexual men and women) to determine if the direct and indirect associations via depression and loneliness of HIV shame with the three dimensions of HRQoL differed by these factors. Due to small subsample sizes and the exploratory nature of these post hoc analyses, a more liberal alpha criterion of 0.10 instead of 0.05 was used for SB χ^2 difference testing between the groups.

Results

The majority of the sample was aged 50–59 years (74.8%) and had an annual household income of \$10,000 or less (86.6%). Most participants graduated from high school or earned a GED (76.3%). The sample was racially and ethnically diverse, with half of participants identifying as Black (49.2%), 29.1% identifying as non-Hispanic White, and 15.7% identifying as Hispanic (see demographics in Table 1). The majority (81.5%) reported currently taking antiretrovirals (ART) and 59.8% reported ever being diagnosed with AIDS at baseline. MSM were predominantly White, whereas as heterosexual men and women were predominantly Black. On average, MSM reported more years of formal education and higher income than heterosexual men and women, which likely reflected socioeconomic disparities observed between Blacks and Whites in the general population. Clinical scale scores are also presented in Table 1.

Measurement and structural regression models

Fit statistics for the measurement models, including an omnibus measurement model of all latent variables, were adequate to good (see Table 2). SB χ^2 difference testing for discriminant validity showed that all latent variables were distinct (see Table 2). A structural regression model was hypothesized such that HIV-related shame was associated with two indicators of psychosocial distress, depression and loneliness. In turn, depression and loneliness were associated with three dimensions of HRQoL, physical, emotional, and social well-being. HIV-related shame was hypothesized to be indirectly associated with physical, emotional, and social well-being via depression and loneliness. The structural regression model (Fig. 1) adjusting for covariates fit the data adequately: χ^2 (392, *N* = 299) = 860.25, *p* < 0.001; RMSEA = 0.060 (90% CIs 0.054–0.066); TLI = 0.92; SRMR = 0.06. This model accounted for 43.9, 78.6 and 67.7% of the variance in physical, emotional and social well-being, respectively. HIV shame accounted for 36.0% of the variance in depression and 29.3% of the variance in loneliness.

Table 1 Participant characteristics with comparisons by gender and sexual orientation

Characteristic	Total sample <i>N</i> = 299	MSM <i>n</i> = 137	Heterosexual men <i>n</i> = 62	Heterosexual women <i>n</i> = 95	<i>p</i> value
Mean current age (<i>SD</i>)	55.23 (4.84)	55.96 (5.26) _a	54.16 (3.77) _b	54.88 (4.70) _{a,b}	0.036
Mean years living with HIV (<i>SD</i>)	12.41 (5.31)	13.50 (5.69) _a	12.24 (4.70) _{a,b}	10.94 (4.76) _b	0.001
Race/ethnicity, <i>n</i> (column %)					<0.001
Black, non-Hispanic	147 (49.2)	40 (29.0) _a	42 (65.6) _b	65 (67.0) _b	
White, non-Hispanic	87 (29.1)	74 (53.6) _a	11 (17.2) _b	2 (2.1) _c	
Black Hispanic/Latino	26 (8.7)	11 (8.0) _a	3 (4.7) _a	12 (12.4) _a	
White and other Hispanic/Latino	21 (7.0)	7 (5.1) _a	6 (9.4) _a	8 (8.2) _a	
Native American	7 (2.3)	0 (0.0) _a	1 (1.6) _{a,b}	6 (6.2) _b	
Other	11 (3.7)	6 (4.3) _a	1 (1.6) _a	4 (4.1) _a	
Highest level of education, <i>n</i> (column %)					<0.001
8th grade or less	8 (2.7)	0 (0.0) _a	4 (6.3) _b	4 (4.1) _b	
Some high school	63 (21.1)	12 (8.7) _a	17 (26.6) _b	34 (35.1) _b	
12th grade	78 (26.1)	25 (18.1) _a	19 (29.7) _{a,b}	34 (35.1) _b	
Some college or vocational school	88 (29.4)	50 (36.2) _a	19 (29.7) _{a,b}	19 (19.6) _b	
Bachelor's degree	30 (10.0)	25 (18.1) _a	2 (3.1) _a	3 (3.1) _b	
Higher than bachelor's degree	32 (10.7)	26 (18.8) _a	3 (4.7) _b	3 (3.1) _b	
Annual household income, <i>n</i> (column %)					0.001
\$0–\$10,000	160 (53.5)	55 (39.9) _a	44 (68.8) _b	61 (62.9) _b	
\$10,001–\$20,000	99 (33.1)	57 (41.3) _a	15 (23.4) _b	27 (27.8) _{a,b}	
\$20,001–\$30,000	20 (6.7)	11 (8.0) _a	3 (4.7) _a	6 (6.2) _a	
\$31,001–\$40,000	6 (2.0)	3 (2.2) _a	1 (1.6) _a	2 (2.1) _a	
Over \$40,000	12 (4.0)	12 (8.7) _a	0 (0.0) _b	0 (0.0) _b	
Declined to answer	2 (0.7)	0 (0.0) _a	1 (1.6) _a	1 (1.0)	
HIV-related shame, Mean (<i>SD</i>)	17.84 (13.13)	18.57 (13.17) _a	19.98 (13.03) _a	15.41 (12.89) _a	0.065
Depression, mean (<i>SD</i>)	12.30 (7.90)	13.54 (8.09) _a	12.06 (7.86) _{a,b}	10.69 (7.41) _b	0.023
Loneliness, mean (<i>SD</i>)	21.22 (6.01)	22.17 (6.28) _a	20.83 (6.12) _{a,b}	20.13 (5.35) _b	0.031
Physical well-being, mean (<i>SD</i>)	35.77 (9.72)	35.86 (9.80) _a	36.88 (8.32) _a	34.93 (10.44) _a	0.458
Emotional well-being, mean (<i>SD</i>)	25.37 (8.84)	24.71 (8.71) _a	24.44 (9.00) _a	26.93 (8.81) _a	0.106
Social well-being, mean (<i>SD</i>)	18.35 (8.02)	17.24 (8.28) _a	18.76 (7.60) _a	19.64 (7.78) _a	0.070

MSM men who have sex with men. Means and standard deviations (*SD*) are reported for continuous variables. Differences between groups on continuous variables were tested using ANOVA with Games–Howell post hoc, pairwise comparisons (equal variance not assumed). Counts and percentages are reported for categorical variables. Differences between groups on categorical variables were based on Pearson Chi square tests. Groups (i.e., MSM; Heterosexual Men; Heterosexual Women) with different subscript letters (i.e., a; b) are significantly different ($p < 0.05$)

Table 3 summarizes the direct and indirect effects in the model. The association of HIV-related shame with physical well-being was fully mediated by depression, as shown by a non-significant direct association of HIV-related shame with physical well-being when accounting for a significant, negative indirect association via depression of HIV-related shame with physical well-being. The association between HIV-related shame and emotional well-being was partially mediated by depression, as indicated by a significant direct association of HIV-related shame with emotional well-being when accounting for a significant, negative indirect association via depression of HIV-related shame with emotional well-being. The association between HIV-related shame and social well-being was partially mediated by loneliness, as evidenced by a significant direct association of HIV-related

shame with social well-being when accounting for a significant indirect association via loneliness of HIV-related shame with social well-being. The indirect association via depression of HIV-related shame with social well-being and the indirect associations via loneliness of HIV-related shame with physical and emotional well-being were accounted for but not significant (see Table 3).

Standardized and unstandardized regression coefficients, standard errors, and *p* values are displayed in Table 3. In regard to indirect associations, there were significant differences between indirect associations via depression and indirect associations via loneliness. The indirect associations via depression of HIV-related shame with physical well-being and with emotional well-being were greater than the indirect associations via loneliness with physical

Table 2 Measurement model with standardized factor loadings and zero-order correlation coefficients among latent variables (N = 299)

	Factor loadings	SB χ^2	df	p	RMSEA	CI _{90, RMSEA}	TLI	SRMR	1	2	3	4	5
1. HIV Shame	0.42–0.91	139.34	58	<0.001	0.068	0.054–0.083	0.95	0.03	1.000				
2. Dep	0.40–0.72	687.24	372	<0.001	0.053	0.047–0.059	0.87	0.06	0.566	1.000			
3. Lon	0.50–0.81	60.99	30	0.001	0.059	0.037–0.080	0.97	0.05	0.488	0.681	1.000		
4. PWB	0.41–0.86	107.64	61	<0.001	0.051	0.034–0.066	0.96	0.04	–0.351	–0.634	–0.475	1.000	
5. EWB	0.46–0.80	60.68	30	0.001	0.058	0.037–0.080	0.96	0.04	–0.805 ^a	–0.742 ^b	–0.556	0.662	1.000
6. SWB	0.41–0.88	47.55	17	<0.001	0.078	0.052–0.104	0.96	0.04	–0.458	–0.519	–0.801 ^c	0.299	0.416

All correlations are statistically significant at $\alpha = 0.05$. Satorra–Bentler Chi squared (SB χ^2) difference testing comparing two-factor models of each pair of highly correlated latent variables to their respective, combined one-factor model showed discriminant validity as follows: ^a $\Delta SB\chi^2(1) = 209.89, p < 0.000$; ^b $\Delta SB\chi^2(1) = 132.80, p < 0.0001$; ^c $\Delta SB\chi^2(1) = 95.43, p < 0.0001$

SB χ^2 Satorra–Bentler Chi squared statistic, *Dep* depression, *Lon* loneliness, *PWB* physical well-being, *EWB* emotional well-being, *SWB* social well-being

well-being ($\Delta SB\chi^2 [2] = 50.70, p < 0.001$) and emotional well-being ($\Delta SB\chi^2 [2] = 65.86, p < 0.001$), respectively. In contrast, the indirect association via loneliness of HIV shame with social well-being was greater than the indirect association via depression.

Post hoc analyses by gender and sexual orientation

The following exploratory analyses were conducted at $\alpha = 0.10$ to provide an indication of how associations might differ by gender and sexual orientation. The multiple-group model by the binary gender variable (i.e., men, $n = 199$; women, $n = 100$; see Table 3) fit the model adequately: $\chi^2 (752, N = 299) = 1283.09, p < 0.001$; RMSEA = 0.069 (90% CIs 0.062–0.075); TLI = 0.91; SRMR = 0.07. Analyses suggested that the indirect association of HIV shame with social well-being via loneliness, which was significant in the one-group model, was greater among men than among women ($\Delta SB\chi^2 [2] = 4.93, p = 0.085$). Although the direct associations of HIV shame with social well-being for these indirect associations did not differ ($\Delta SB\chi^2 [2] = 0.16, p = 0.692$), the significant direct association of HIV shame with social well-being for women indicated partial mediation via loneliness and the non-significant direct association for men indicated full mediation via loneliness. The multiple-group model by indicator of sexual orientation (i.e., MSM, $n = 137$; heterosexuals, $n = 162$) fit the model adequately: $\chi^2 (754, N = 299) = 1315.73, p < 0.001$; RMSEA = 0.071 (90% CIs 0.064–0.077); TLI = 0.90; SRMR = 0.07. None of these significant indirect associations differed between MSM and heterosexuals in the current sample.

Discussion

Although several studies have found shame to be a robust predictor of health and quality of life, particularly among older PLHIV (Dickerson et al., 2004a, b; Persons et al.,

2010), the present findings represent an important step in understanding how HIV-related shame, which is an individual-level, affective response to HIV-related stigma, may affect HRQoL. This study tested a model of direct and indirect associations via two separate indicators of psychosocial distress, depression and loneliness, of HIV-related shame with three, biopsychosocial dimensions of HRQoL (physical, emotional, and social well-being). Results showed that associations between HIV shame and HRQoL varied by psychosocial distress mechanism and dimension of HRQoL. Studies that examine the psychosocial experience and HRQoL of older PLHIV typically focus on HIV stigma rather than HIV shame (Sankar et al., 2011), even though HIV shame is a nuanced, robust mechanism of HIV stigma that has great impact on the HRQoL of PLHIV (Persons et al., 2010). Furthermore, it is well established that HRQoL is at least as important, if not more so, then symptom presentation in determining health outcomes for illness such as HIV (Guyatt et al., 1993). Patients with the same symptom presentation vary significantly on how their illness affects the different functional domains of their lives (i.e., physical, emotional, and emotional well-being). Thus, it is critical to understand biopsychosocial pathways to HRQoL to inform intervention and improve health outcomes.

Depression, but not loneliness, accounted for how HIV-related shame might affect the physical well-being of older PLHIV. Given that depression is itself associated with somatic symptoms (e.g., lack of energy, physiological symptoms of anxiety; Greden, 2003; Henningsen et al., 2003), depression may be a critical mechanism by which HIV-related shame influences physical aspects of quality of life in older PLHIV. Depressed persons also tend to have a more negative view of themselves, their situations, and their health (Beck, 1963; Swann et al., 1992). Thus, HIV shame may contribute to poor physical well-being to the extent that the patient is also depressed. Furthermore, prior research has shown that, when physiological measures are

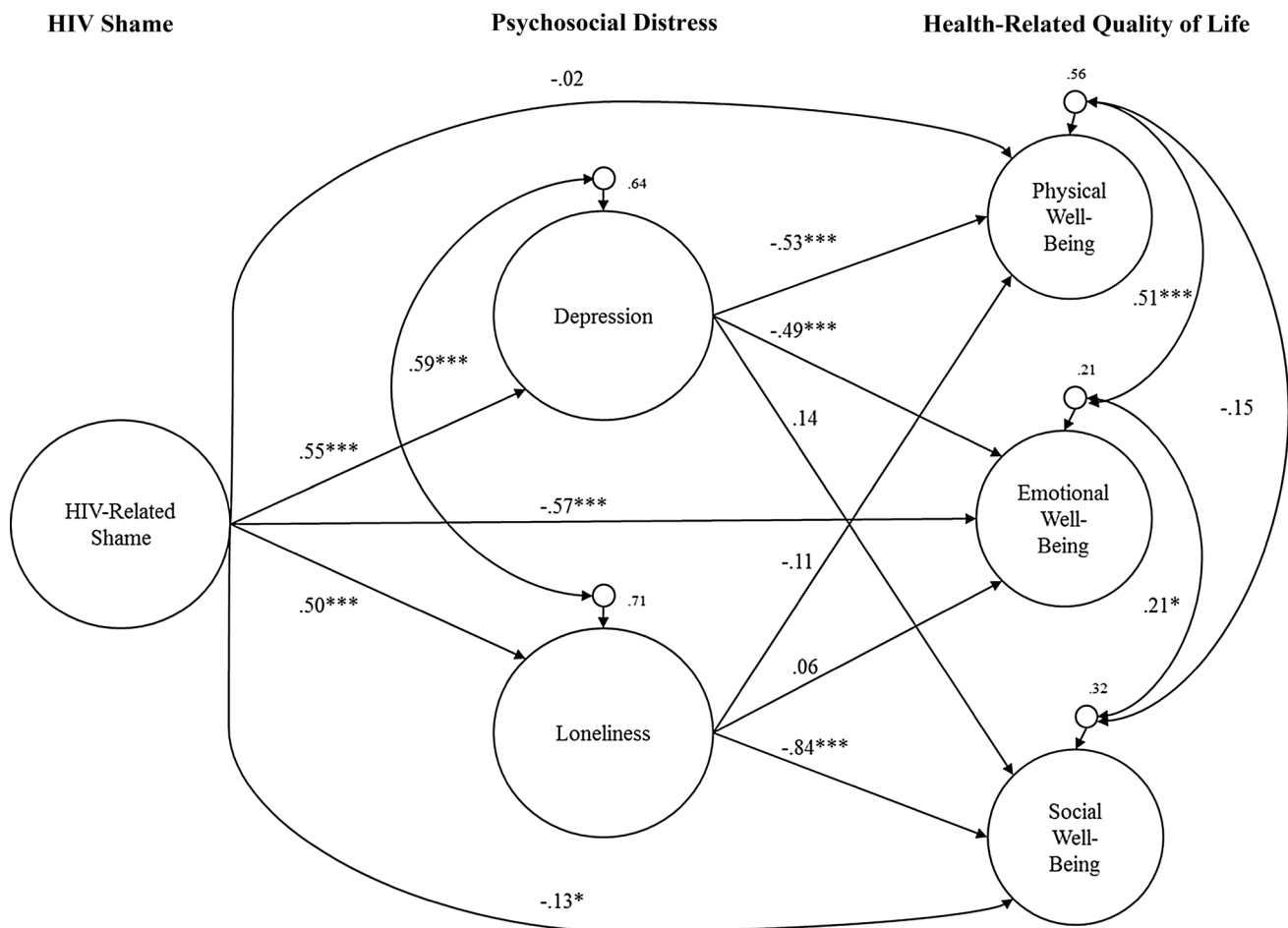


Fig. 1 Variables in the figure represent latent variables with standardized coefficients. Given that each factor was unidimensional, indicator variables were randomly assigned to parcels for each latent variable to reduce model complexity. The intermediary and outcome variables were regressed on the following covariates: age, gender

(male as reference group), location (New York as reference group, Ohio as non-reference group), race/ethnicity (Blacks as reference group), highest level of education achieved (less than high school diploma as reference group), and income (\$0–10,000 as reference group). * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

assessed, the affective experience of shame is directly linked to immunological functioning and health indicators, including that of PLHIV (Dickerson et al., 2004a, b). Additional research is needed to further clarify the effect of shame on the health outcome of physical well-being versus physiological indicators of health.

Depression partially accounted for the association between HIV-related shame and emotional well-being. It appears that the emotional sequelae of HIV-related shame may be quite robust, as evident in the significant, direct association of shame with emotional well-being when accounting for the mediating role of depression. This is consistent with a prior study that controlled for psychological distress, broadly defined, and found a significant association of HIV-related shame with emotional well-being (Persons et al., 2010).

The current findings suggest that feelings of shame may be important to address in older PLHIV when considering

their feelings of loneliness and sense of isolation. Loneliness appears to be a particularly critical mechanism in the link between shame and social aspects of quality of life. Loneliness represents a major correlate of mental health challenges to which older adults are particularly vulnerable (McInnis & White, 2001; Pinguart, 2003). An important factor that may be involved in the indirect link of HIV shame with social well-being via loneliness is disclosure of HIV status. For example, older PLHIV (i.e., ages 50 and above) are less likely than younger PLHIV to disclose their HIV status (Arnold et al., 2008; Emlet, 2006), which may be contributing to a sense of isolation. Qualitative research has shown that feeling “other” (i.e., different, alien, or inferior to others) and fear of rejection and other consequences of disclosure of HIV status are salient, shame-related themes for older adults living with HIV (Emlet, 2007). Indeed, a meta-analysis found that increased stigma, of which shame is an indicator, was linked to lower disclosure and social

Table 3 Direct and indirect effects of HIV-related shame on three dimensions of health-related quality of life (N = 299)

	β	<i>b</i>	<i>SE</i>	<i>p</i>	CI ₉₅ for <i>b</i>
Direct associations					
HIV shame → physical well-being (PWB)	−0.015	−0.010	0.047	0.829	−0.087, 0.067
HIV shame → emotional well-being (EWB)	−0.568	−0.450	0.053	<0.001	−0.537, −0.363
HIV shame → social well-being (SWB)	−0.127	−0.112	0.053	0.035	−0.200, −0.024
Indirect associations					
HIV shame → depression → PWB	−0.290	−0.193 _a	0.042	<0.001	−0.268, −0.131
HIV shame → depression → EWB	−0.268	−0.212 _a	0.042	<0.001	−0.286, −0.149
HIV shame → depression → SWB	0.076	0.068 _a	0.044	0.128	−0.002, 0.143
HIV shame → loneliness → PWB	−0.054	−0.036 _b	0.031	0.242	−0.087, 0.013
HIV shame → loneliness → EWB	0.031	0.024 _b	0.029	0.398	−0.022, 0.071
HIV shame → loneliness → SWB	−0.420	−0.372 _b	0.058	<0.001	−0.471, −0.281
Gender					
	<i>Men/women</i>				
Direct associations					
HIV shame → PWB	−0.021/−0.015	−0.013/−0.011	0.056/0.106	0.810/0.920	−0.101, 0.080; −0.216, 0.136
HIV shame → EWB	−0.629/−0.460	−0.494/−0.375	0.064/0.099	<0.001/< 0.001	−0.602, −0.390; −0.545, −0.222
HIV shame → SWB	−0.114/−0.178	−0.103/−0.153	0.066/0.120	0.118/< 0.001	−0.211, 0.006; −0.369, 0.015
Indirect associations					
HIV shame → depression → PWB	−0.311/−0.234	−0.202/−0.171	0.051/0.093	<0.001/0.065	−0.289, −0.124; −0.330, −0.042
HIV shame → depression → EWB	−0.249/−0.267	−0.196/−0.217	0.049/0.095	<0.001/0.022	−0.281, −0.122; −0.386, −0.083
HIV shame → depression → SWB	0.087/0.135	0.079/0.166	0.055/0.140	0.148/0.405	−0.002, 0.174; −0.043, 0.369
HIV shame → loneliness → PWB	−0.044/−0.075	−0.028/−0.055	0.044/0.058	0.516/0.348 ^a	−0.103, 0.041; −0.168, 0.024
HIV shame → loneliness → EWB	0.046/−0.011	0.036/−0.009	0.044/0.048	0.404/0.854 ^a	−0.033, 0.109; −0.091, 0.063
HIV shame → loneliness → SWB	−0.512/−0.287	−0.463/−0.246	0.079/0.123	<0.001/0.045 ^a	−0.595, −0.343; −0.470, −0.099
Sexual orientation					
	<i>MSM/heterosexual men and women</i>				
Direct associations					
HIV shame → PWB	0.109/−0.093	0.075/−0.062	0.065/0.072	0.255/0.389 ^a	−0.026, 0.191; −0.185, 0.048
HIV shame → EWB	−0.528/−0.591	−0.406/−0.475	0.073/0.075	<0.001/< 0.001	−0.529, −0.290; −0.598, −0.350
HIV shame → SWB	−0.142/−0.118	−0.131/−0.101	0.081/0.081	0.104/0.159	−0.264, −0.003; −0.224, 0.012
Indirect associations					
HIV shame → depression → PWB	−0.318/−0.261	−0.219/−0.173	0.072/0.054	0.002/0.001	−0.340, −0.108; −0.272, −0.095
HIV shame → depression → EWB	−0.320/−0.194	−0.246/−0.156	0.066/0.054	<0.001/0.004	−0.360, −0.145; −0.253, −0.079
HIV shame → depression → SWB	0.052/0.088	0.049/0.075	0.072/0.063	0.499/0.231	−0.054, 0.177; −0.011, 0.188
HIV shame → loneliness → PWB	−0.103/−0.026	−0.071/−0.017	0.059/0.036	0.233.636	−0.181, 0.017; −0.080, 0.037
HIV shame → loneliness → EWB	0.048/−0.006	0.037/−0.005	0.057/0.032	0.514/0.883	−0.051, 0.133; −0.062, 0.043
HIV shame → loneliness → SWB	−0.477/−0.347	−0.443/−0.296	0.101/0.076	<0.000/< 0.001	−0.616, −0.297; −0.429, −0.183

Unstandardized coefficients (*b*) with different subscripts among pairs of indirect effects are significantly different from each other. Bias-corrected bootstrapping was used to yield estimates, standard errors, and 95% confidence intervals

MSM = men who have sex with men

^a Significant difference between groups at $\alpha = 0.10$ but not at $\alpha = 0.05$

support (Smith et al., 2008). Although stigma, not shame, was assessed in the Smith et al. study, other research has shown that self-disclosure, which is an important means by which to receive social support and improve social well-being (Emlet, 2006), may be impeded by shame and stigma (Landau & York, 2004). Although not specifically examined in the present analyses, future research may benefit

from examining an indirect link via disclosure in the associations between shame, loneliness, and social well-being.

Two-group analyses based on gender (i.e., men and women) and sexual orientation (i.e., MSM and heterosexual men and women) showed that, for the present sample, significant direct and indirect associations in the model

generally did not differ between men and women and between MSM and heterosexuals. Correspondingly, although men and women did not differ significantly in the direct association of HIV shame with social well-being, the direct association of HIV shame with social well-being was significant among women, but not men. These results suggest that loneliness was a critical factor in whether HIV shame was linked to poor social well-being for men but not for women. Again, disclosure may play a role. For example, women are more likely than men to disclose their HIV status to others (Arnold et al., 2008), thus, loneliness may play less of a role in social well-being for women than for men in the link between HIV shame and social well-being.

Limitations

Several limitations should be noted. First, the cross-sectional nature of the study precludes definitive inferences regarding causal or temporal relations among the variables and interpretations around mediated effects should be made with cautions. Other research methodologies, including longitudinal studies, may help to confirm results of the present study. The sample was a non-probabilistic sample of older adults. However, this limitation may be mitigated by the fact that the participants represented two different geographic regions of the United States and the disparate impact of HIV and AIDS on racial minorities, particularly Blacks, was reflected in the demographic composition of the sample. Furthermore, participants were recruited to participate in an intervention study and eligibility requirements included a minimum level of depressive symptoms (BDI-II score of 10). Though this is well below the clinical cutoff for depression (i.e., 22; scores from 0 to 13 indicate minimal depression), there may have been a higher prevalence of depression in this sample than the general HIV-positive population. Also, in the present study, it is not possible to determine associations among the variables among older PLHIV who report no psychological distress in the form of depressive symptoms. It is also possible that older people who struggle with a particularly high level of HIV-related shame may have chosen not to participate. Additionally, it must be noted that MSM is not a sexual orientation; nonetheless, at least 70% of men who are identified by researchers as MSM are gay (Halkitis, 2010). Furthermore, although loneliness was assessed, loneliness in the present study represented participants' subjective experience of the social support. However, this may be more useful than other measures of social support (e.g., quantity of social support, such as number of friends), as loneliness assesses whether participants feel that their social and intimacy needs are actually met.

Implications

The affective sequela of HIV-related stigma that is HIV-related shame (Persons et al., 2010) plays a key but often understudied role in multiple dimensions of HRQoL, including physical, emotional, and social well-being, among PLHIV. Mental and behavioral health researchers and practitioners should assess and focus on HIV shame as a critical individual-level mechanism by which experiences of HIV stigma might exercise its health-related effects on PLHIV. Given that HIV shame may be strongly linked to depression and loneliness and directly and indirectly linked to multiple aspects of HRQoL, practitioners should clearly incorporate HIV shame into their assessments and treatments. For example, emerging interventions that expressly address HIV shame are using well-established techniques of cognitive-behavior therapy (CBT) in addition to acceptance and commitment therapy and compassion-focused therapy (e.g., Skinta et al., 2015). Such approaches help patients to recognize feelings of shame, raise patients' awareness of how shame affects their mental and physical health outcomes and social support-seeking, challenge shame-based feelings and thoughts, and increase their levels of self-acceptance and compassion. For resource-limited settings, CBT can be adapted for delivery by paraprofessionals (e.g., HIV or STD counselors) who, although not licensed clinicians, can be trained in specific techniques of CBT (Dilley et al., 2007, 2011; Eaton et al., 2012).

Conclusion

As the population of adults with HIV/AIDS ages, there are growing opportunities to improve their health and enhance their quality of life. To this end, HIV shame presents an important area for which increased research and intervention may be useful. Additionally, loneliness may be a uniquely salient issue among older PLHIV, particularly for men. It is critical that mental-health interventions and social supports continue to be developed for older PLHIV.

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Compliance with ethical standards

Conflict of interest Wilson Vincent, Xindi Fang, Sarah K. Calabrese, Timothy G. Heckman, Kathleen J. Sikkema, and Nathan B. Hansen declares that they have no conflict of interest.

Human and animal rights and Informed consent All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national

research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors. Informed consent was obtained from all individual participants included in the study.

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