

The Dynamic Relationship Between Social Support and HIV-Related Stigma in Rural Uganda

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Abstract

Background Cross-sectional studies show that human immunodeficiency virus (HIV) stigma is negatively correlated with social support.

Purpose The purpose of this study is to examine the bidirectional relationship between social support and HIV stigma.

Methods We collected quarterly data from a cohort of 422 people living with HIV in Uganda, followed for a median of 2.1 years. We used multilevel regression to model the contemporaneous and 3-month-lagged associations between social support and both enacted and internalized stigma.

Results Lagged enacted stigma was negatively correlated with emotional and instrumental social support, and lagged

instrumental social support was negatively correlated with enacted stigma. Internalized stigma and emotional social support had reciprocal lagged associations.

Conclusions Interventions to reduce enacted stigma may strengthen social support for people living with HIV. Improved social support may in turn have a protective influence against future enacted and internalized stigma.

Keywords HIV/AIDS · Stigma · Social support · Uganda

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Introduction

Human immunodeficiency virus (HIV) stigma is a well-documented barrier to the health and well-being of people living with HIV. As described by Goffman [1], stigma is a discrediting attribute that reduces a person from a whole person to a tainted or discounted person. HIV stigma has been associated with delaying or avoidance of HIV testing [2–4], poor adherence to antiretroviral therapy (ART) [5, 6], increased risk behaviors [7], and poor engagement with care [8]. In addition, people living with HIV experience numerous mental and psychological sequelae of stigma, including stress, fear, anxiety, and depression [9–12].

Recent studies have shown that people living with HIV who report experiences of HIV stigma also report lower levels of perceived social support [12–15]. Social support refers to the provision of psychological and material resources by people within one's social network [16]. The finding that people living with HIV who are more vulnerable to stigma also have less access to social resources has profound public health consequences because social support has been associated with powerful health benefits for people living with HIV. These include less depression [10], positive health behaviors such as adherence to medication [6], improved coping and

quality of life [17], and slower progression of disease to AIDS [18]. These benefits have been understood in the context of a larger body of literature examining social support and health. The mechanisms underlying the health benefits of social support have been attributed to its various functional components, which include informational, emotional (e.g., caring, empathy), and instrumental support (e.g., financial assistance or help with tasks) [16, 19, 20]. Starting with the 1979 study by Berkman and Syme [21] who showed that social isolation was a significant risk factor for mortality, research on social support and health has shown that social support fosters psychological well-being, enhances self-esteem and self-efficacy, reduces physiological arousal, and promotes functional and adaptive coping with stressors [20, 22–24]. These psychosocial benefits translate to improved health through decreased physiological stress responses, engagement in health-promoting behaviors, and avoidance of health-damaging behaviors [20, 22–24].

Conceptual Model

Based on evidence that stigma is a multidimensional construct, researchers have developed and utilized a conceptual model that separates the experience of stigma into interpersonal and intrapersonal experiences. The interpersonal experience of stigma is called enacted stigma and is defined as discriminatory behaviors directed towards people with the stigmatized condition [25]. The intrapersonal experience of stigma is called internalized stigma and is the endorsement and internalization of negative evaluations held by others [26–28]. Models of stigma describe how people internalize stigma when they perceive the negative stereotypes to be legitimate, and suffer negative cognitive, emotional and behavioral consequences, such as ambivalence about identity, low-self esteem, and low self-efficacy [26, 27, 29, 30]. While the terminology may vary, these concepts of enacted and internalized stigma are used widely in other health conditions, such as obesity [31] and mental health [32], to understand the differential effects of these two dimensions of stigma on health behaviors and outcomes.

Historically, models of stigma have predominantly focused on individuals—the stigmatized person and the stigmatizing person—and their cognitive, affective, and behavioral processes, but recent sociological and anthropological work have proposed to embed stigma in the social space [33]. These works demonstrate that stigma is a social experience in which the effects of stigma extend to the affected individual's social ties, and in which those social ties in turn shape the experience of the stigmatized individual. Qualitative studies have demonstrated that family members of people living with HIV become reluctant to disclose to others the serostatus of the affected family member for fear of discrimination and loss of social standing in their community [9, 34]. Furthermore, close

social ties can often be the source of stigmatizing attitudes and actions. People living with HIV experience avoidance, ostracism, and verbal insults from their friends and family [9], and some studies theorize that the enactment of stigma is in response to the devalued status they acquire through association with the stigmatized person [34]. While HIV stigma strains existing close relationships, it can also profoundly limit the ability of people living with HIV to seek new relationships. One proposed mechanism is the lack of disclosure. Disclosure is essential for people to receive social support; yet, fear of discrimination prevents people living with HIV from disclosing their status [35, 36], and the higher their level of internalized stigma, the more likely they are to avoid disclosure and interactions with others [11, 37]. Finally, HIV stigma has been correlated with depression [10, 12], which may further limit the capacity of people living with HIV to form and maintain social relationships. These mechanisms take on particular significance in Uganda, where HIV stigma is a prominent concern among people living with HIV with profound implications for their social experience. In one study conducted in Uganda, fear of HIV serostatus disclosure was the most common concern voiced by people living with HIV and was noted by more participants than concerns about lack of food [38], which is notable in light of the high prevalence of food insecurity among people living with HIV [39, 40].

Recent findings linking social support and HIV stigma, though suggestive, have been based on cross-sectional data [12–14] or data from two time points [15], limiting our ability to illuminate the dynamic relationship between social support and HIV stigma. Furthermore, these studies have not examined how the interpersonal and intrapersonal dimensions of HIV stigma could differentially affect the social experience of people living with HIV. To address these gaps in our current understanding of HIV stigma and social support, we examined the dynamic relationship between two dimensions of social support and two dimensions of HIV stigma using longitudinal data collected from people living with HIV receiving ART at a public hospital in rural southwestern Uganda. The primary aim of our analysis was to use time-lagged models to understand how the interpersonal and intrapersonal experiences of HIV stigma shape the social support networks of people living with HIV in rural Uganda, and to understand how these relationships in turn shape their experience of HIV stigma.

Methods

Setting and Participants

We used data from an ongoing, prospective cohort of people living with HIV initiating ART in rural Uganda. Eligibility criteria included having no prior history of treatment with ART,

being over 18 years of age, and living within 20 km of the Immune Suppression Syndrome (ISS) Clinic at the Mbarara Regional Referral Hospital. The ISS Clinic is located in Mbarara District, 275 km southwest of Kampala, and provides free ART for people living with HIV in southwestern Uganda, Rwanda, and the Democratic Republic of Congo [41]. Most participants live in outlying villages surrounding the town of Mbarara, spending an hour on average to travel to the clinic by paid motorbike and on foot [42]; live in multigenerational households with other relatives living close by; engage in subsistence agriculture; and frequently interact with other members of the community through religious services, agricultural work, and community gatherings. The predominant ethnic group is Ankole, and the local language is Runyankole.

Our analyses are based on data from participants who were enrolled into the cohort from 2007 through 2010. Survey questions were translated into Runyankole, back-translated into English, further modified through focus groups with key informants, and pilot-tested to ensure clarity and relevance. Trained research assistants who spoke Runyankole interviewed participants every 3 months in a private room at a research office near the ISS Clinic. Each survey took approximately 1 h to complete. Informed consent was obtained from all study participants. Ethics approval for all study procedures was obtained by the Committee on Human Research, University of California at San Francisco; the Partners Human Research Committee at Massachusetts General Hospital; and the Institutional Ethical Review Committee, Mbarara University of Science and Technology. Consistent with national guidelines, we received clearance for the study from the Uganda National Council for Science and Technology and from the Research Secretariat in the Office of the President.

Measures

The four variables of interest were emotional social support, instrumental social support, internalized stigma, and enacted stigma. We measured social support using the Social Support Scale [43], which contains six items on emotional support and four items on instrumental social support. This scale was adapted from the Duke/University of North Carolina Functional Social Support Questionnaire, which was designed to measure multiple dimensions of social support among patients in a primary care setting [44]. Higher scores reflect higher levels of social support.

We measured internalized HIV stigma using the Internalized AIDS-Related Stigma Scale, which contains six items corresponding to the guilt, shame, and worthlessness described in Goffman's conceptualization of stigma [45, 46]. The internalized stigma scale has demonstrated good internal reliability, a coherent internal structure, and good construct validity among people living with HIV in rural Uganda [47]. To measure enacted stigma, we asked participants about

whether they had experienced ten different discriminatory events in the past 3 months as a result of their HIV status, such as abandonment, housing, property loss, or physical violence (see [Electronic Supplementary Material](#)). These questions were adapted from a previous publication by Nyblade et al. [48]. We created an enacted stigma index by constructing a total count of the different types of discriminatory events experienced, with higher index scores indicating greater intensity of enacted stigma. Of note, we did not have any a priori expectation that the variables would be internally consistent because these different events are diverse in both severity as well as potential drivers. Nonetheless, for the sake of comparison with our other variables of interest, we calculated the reliability of the index at baseline.

Statistical Analysis

In our regression models, we adjusted for baseline and quarterly health status using the Medical Outcome Study-HIV (MOS-HIV) Physical Health Summary (PHS) [49, 50] and CD4+ T-lymphocyte cell count. A higher PHS score reflects a better health status. Because prior studies have shown that both HIV stigma and low social support are associated with depression [10, 12], we also adjusted for depression symptom severity. We measured depression symptom severity using a version of the 15-item Hopkins Symptom Checklist for Depression [51] that was adapted to the local context with the addition of a 16th item, “feeling like I don't care about my health” [10, 52]. We restricted our calculation of the score to the 12 affective items in light of prior research suggesting that the somatic items overlap with symptoms of HIV infection and may inflate the prevalence of depression among people living with HIV [53, 54]. Participants were classified as having probable depression based on the conventional threshold score of 1.75 [55].

We adjusted for a range of other baseline (time-invariant) demographic and socioeconomic covariates with potential for influencing the relationships among stigma, social support, and health. We measured household wealth using a household asset index [56], which was entered into the models as a continuous variable, with higher values of the asset index indicating greater household wealth relative to other households in the sample. We also adjusted for baseline age, sex, educational attainment, and marital status. Time on treatment was measured in years since starting ART.

Data analysis was conducted using SAS statistical software (version 9.2, SAS Institute Inc., Cary, NC, USA). We employed multilevel modeling to address the lack of independence among residuals in the hierarchically structured data. Since our data consisted of measures that are nested within individuals, measures from the same individual may share common, unobserved characteristics that may affect the outcomes of interest. Our modeling technique allowed us to separate the

composite residual into two parts: a measure-level residual unique to the particular time at which the survey was conducted, and an individual-level residual unique to a particular individual (but not to a particular time). We used multilevel models for change, in which the models are specified by simultaneously postulating a pair of subsidiary models: a level-1 submodel that describes how each individual changes over time, and a level-2 submodel that describes how these changes differ across individuals [57]. Our level-1 submodel stipulated that the trajectories of stigma and social support are linear with time.

To examine the effects of each of the two social support dimensions on each of the two stigma dimensions and, reciprocally, the effects of each of the stigma dimensions on each of the social support dimensions, we specified eight contemporaneous regression models. First, in two regression models, internalized stigma was specified as the outcome, with instrumental and emotional social support alternately included as the main predictors (while adjusting for covariates). Second, enacted stigma was specified as the outcome, with instrumental and emotional social support alternately included as the main predictors. Third, emotional social support was specified as the outcome in two regression models, with internalized and enacted stigma alternately included as the main predictors. Finally, instrumental social support was specified as the outcome, with internalized and enacted stigma alternately included as the main predictors. We also fitted lagged-covariate models, in which each of the predictors of interest were lagged by 3 months, adjusting for covariates and the lagged outcome variable. In total, we fitted 16 regression models: 8 models in which the explanatory variables of interest were measured contemporaneously with the outcomes and 8 models in which the explanatory variables were measured with a 3-month lag.

Results

Table 1 presents the baseline demographic characteristics of the 422 participants. The average age of participants at baseline was 35 years, and they were enrolled in the study for a mean of 2.3 years (median of 2.1 years). The majority of participants [298 (71 %)] were female. Approximately half were married and half were widowed or divorced. Most [357 (85 %)] had completed primary school or more. The mean internalized stigma score at baseline was 1.3 points (median, 1.0; SD, 1.5) with a range of 0–6, the mean enacted stigma score was 0.4 points (median, 0; SD, 0.8) with a range of 0–7, the mean emotional social support score was 3.8 points (median, 4; SD, 0.4), and the mean instrumental social support score was 3.6 (median, 4; SD, 0.6). The mean CD4 count at baseline was 230 cells/mL (median, 204; SD, 149). Sixteen percent of participants screened positive for probable depression at baseline.

Table 1 Participant baseline characteristics ($N=422$)

Characteristic	N (%) or mean (median)
Gender	
Female	298 (71 %)
Male	124 (29 %)
Age (years)	35 (34)
Time in study (years)	2.3 (2.1)
Marital status	
Not married	238 (56 %)
Married	184 (44 %)
Education	
None	65 (15 %)
Primary or more	357 (85 %)
Internalized stigma	1.3 (1)
Enacted stigma	0.4 (0)
Emotional social support	3.8 (4)
Instrumental social support	3.6 (4)
CD4 count (cells/mL)	230 (204)
MOS-HIV Physical Health Summary	46 (49)
Probable depression	67 (16 %)

Throughout the study period, the most frequently endorsed item on the internalized stigma scale was “difficult to tell other people about my HIV status,” (852 responses, 29 % of all responses), followed by “I hide my HIV status from others,” [832 (28 %)]. Similarly, the most frequently endorsed form of enacted stigma was “being gossiped about,” [768 (25 %)] followed by “being teased or insulted” [201 (7 %)].

At baseline, the Cronbach's alpha of the internalized stigma scale was 0.73. Both social support subscales showed good internal reliability at baseline (instrumental social support Cronbach's alpha=0.87, emotional social support Cronbach's alpha=0.89), as did the social support scale as a whole (Cronbach's alpha=0.91). The Cronbach's alpha for the enacted stigma index was 0.56.

Preliminary analyses supported the use of multilevel models for change and lagged models. Briefly, empirical growth plots showed substantive changes within individuals over time in enacted stigma, internalized stigma, emotional social support, and instrumental social support. Furthermore, intraclass correlation coefficients indicated large variability within individuals over time. The intraclass correlation for emotional social support was 0.53, indicating that an estimated 53 % of the total variation in social support was attributable to differences between individuals while 47 % was attributable to variability over time within individuals. Overall, over the entire study period, 198 (47 %) participants had a negative slope over time for internalized stigma (i.e., indicating that internalized stigma decreased over time) while 69 (16 %) had a slope of zero and 155 (37 %) had a positive slope. Averaged across all participants, internalized stigma decreased at a rate

of 0.13 points per year. Similarly, the intraclass correlations for enacted stigma, emotional social support, and instrumental social support were 0.74, 0.83, and 0.72, respectively.

Internalized Stigma

In the contemporaneous models specifying internalized stigma as the outcome, we found no relationship between internalized stigma and either emotional or instrumental social support (Table 2). In the lagged-covariate models, we found an inverse relationship between internalized stigma and lagged emotional social support. A 1-point increase in emotional social support was associated with a 0.13-point decrease in subsequent internalized stigma (95 % CI, -0.25 to -0.005), a 10 % relative difference compared to the baseline value. There was no statistically significant association between internalized stigma and lagged instrumental social support. In all four models, higher levels of self-reported physical health and lower levels of depression were correlated with lower levels of internalized stigma.

Enacted Stigma

In the contemporaneous models with enacted stigma as the outcome, we found that individuals with higher levels of emotional social support or instrumental social support reported lower levels of enacted stigma (Table 3). A 1-point increase in emotional social support was correlated with a 0.30-point decrease in enacted stigma (95 % CI, -0.37 to -0.24), and a 1-point increase in instrumental social support was correlated with a 0.16-point decrease in enacted stigma (95 % CI, -0.21 to -0.12). In the lagged-covariate models, we found that lagged instrumental social support was negatively correlated with subsequent enacted stigma ($b = -0.07$, 95 % CI -0.11 , -0.03), but we found no statistically significant relationship between lagged emotional social support and subsequent enacted stigma. A 1-point increase in lagged instrumental social support was correlated with a 0.07-point decrease in subsequent enacted stigma. In all four models, higher levels of education, wealth, and physical health status were consistently associated with lower levels of enacted stigma.

Table 2 The contemporaneous and lagged effects of emotional social support and instrumental social support on internalized stigma

	Effect of emotional social support on internalized stigma		Effect of instrumental social support on internalized stigma	
	Contemporaneous	Lagged	Contemporaneous	Lagged
Variables	<i>b</i> (95 % confidence interval [CI])	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)
Intercept	1.02 (0.41, 1.62)**	1.08 (0.49, 1.67)***	0.95 (0.46, 1.44)***	0.57 (0.12, 1.03)*
Emotional social support	-0.082 (-0.20, 0.04)	-	-	-
Instrumental social support	-	-	-0.070 (-0.15, 0.01)	-
Lagged emotional social support	-	-0.13 (-0.25, -0.005)*	-	-
Lagged instrumental social support	-	-	-	0.0083 (-0.067, 0.084)
Lagged internalized stigma	-	0.11 (0.077, 0.15)***	-	0.113 (0.078, 0.15)***
Time	-0.08 (-0.12, 0)	-0.058 (-0.13, 0.014)	-0.088 (-0.17, -0.007)*	-0.063 (-0.14, 0.009)
Gender				
Male	Ref	Ref	Ref	Ref
Female	0.11 (-0.13, 0.35)	0.08 (-0.14, 0.30)	0.10 (-0.14, 0.35)	0.087 (-0.14, 0.31)
Age	-0.013 (-0.026, 0)	-0.012 (-0.023, 0)	-0.013 (-0.026, 0.001)	-0.012 (-0.024, 0.00)
Marital status				
Not married	Ref	Ref	Ref	Ref
Married	0.032 (-0.13, 0.19)	0.005 (-0.15, 0.16)	0.030 (-0.13, 0.19)	0.0054 (-0.15, 0.16)
Education				
No school	Ref	Ref	Ref	Ref
Primary school or more	0.057 (-0.23, 0.35)	0.11 (-0.16, 0.37)	0.063 (-0.23, 0.35)	0.10 (-0.16, 0.36)
Household asset wealth	0.075 (0, 0.15)	0.065 (-0.004, 0.13)	0.079 (0.003, 0.15)*	0.062 (-0.01, 0.13)
MOS-HIV Physical Health Summary	-0.019 (-0.02, -0.01)***	-0.018 (-0.024, -0.012)***	-0.019 (-0.025, -0.013)***	-0.018 (-0.024, -0.012)***
CD4 count (per 100 cells/mL)	0.009 (-0.03, 0.45)	0.004 (-0.033, 0.040)	0.007 (-0.030, 0.044)	0.005 (-0.031, 0.042)
Probable depression	0.46 (0.26, 0.67)***	0.049 (0.28, 0.71)***	0.46 (0.26, 0.67)***	0.49 (0.28, 0.70)***

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$

Table 3 The contemporaneous and lagged effects of emotional social support and instrumental social support on enacted stigma

	Effect of emotional social support on enacted stigma		Effect of instrumental social support on enacted stigma	
	Contemporaneous	Lagged	Contemporaneous	Lagged
Variables	<i>b</i> (95 % confidence interval [CI])	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)
Intercept	1.74 (1.43, 2.05)***	0.72 (0.41, 1.04)***	1.16 (0.94, 1.39)***	0.79 (0.57, 1.00)***
Emotional social support	−0.30 (−0.37, −0.24)***	–	–	–
Instrumental social support	–	–	−0.16 (−0.21, −0.12)***	–
Lagged emotional social support	–	−0.045 (−0.12, 0.03)	–	–
Lagged instrumental social support	–	–	–	−0.070 (−0.11, −0.03)**
Lagged enacted stigma	–	0.046 (0.009, 0.083)*	–	0.044 (0.007, 0.081)*
Time	0.004 (−0.04, 0.04)	0.006 (−0.033, 0.045)	−0.0009 (−0.049, 0.032)	0.006 (−0.033, 0.044)
Gender				
Male	Ref	Ref	Ref	Ref
Female	0.096 (0.003, 0.189)*	0.099 (0.006, 0.19)*	0.077 (−0.017, 0.17)	0.091 (−0.002, 0.18)
Age	0.001 (−0.004, 0.006)	0.001 (−0.004, 0.006)	0.002 (−0.004, 0.007)	0.001 (−0.004, 0.006)
Marital status				
Not married	Ref	Ref	Ref	Ref
Married	−0.031 (−0.11, 0.043)	−0.037 (−0.11, 0.038)	−0.034 (−0.11, 0.04)	−0.038 (−0.11, 0.037)
Education				
No school	Ref	Ref	Ref	Ref
Primary school or more	−0.15 (−0.26, −0.04)**	−0.014 (−0.25, −0.03)*	−0.14 (−0.25, −0.03)*	−0.13 (−0.24, −0.02)*
Household asset wealth	−0.045 (−0.074, −0.016)**	−0.049 (−0.078, −0.020)***	−0.039 (−0.068, −0.01)**	−0.046 (−0.074, −0.017)**
MOS-HIV Physical Health Summary	−0.009 (−0.012, −0.005)***	−0.010 (−0.013, −0.006)***	−0.009 (−0.012, −0.005)***	−0.009 (−0.013, −0.006)***
CD4 count (per 100 cells/mL)	0.004 (−0.015, 0.022)	0.006 (−0.013, 0.025)	0.0003 (−0.019, 0.019)	0.006 (−0.013, 0.025)
Probable depression	0.075 (−0.041, 0.19)	0.086 (−0.031, 0.020)	0.083 (−0.033, 0.20)	0.085 (−0.032, 0.20)

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$

Emotional Social Support

In the contemporaneous models with emotional social support as the outcome, we found that individuals with higher levels of internalized stigma or enacted stigma reported lower levels of emotional social support (Table 4). Each 1-point increase in the internalized stigma scale was associated with a 0.014-point decrease in the emotional social support scale (95 % CI, −0.024 to −0.003). Each one-point increase in enacted stigma was correlated with a 0.095-point decrease in emotional social support (95 % CI, −0.11 to −0.075). In the lagged-covariate models, lagged internalized stigma was negatively correlated with subsequent emotional social support ($b = -0.016$; 95 % CI, −0.026 to −0.005), and lagged enacted stigma was negatively correlated with subsequent emotional support ($b = -0.032$; 95 % CI, −0.062 to −0.01). In all four models, higher levels of wealth and physical health status were correlated with higher levels of emotional social support.

Instrumental Social Support

In the contemporaneous models with instrumental social support as outcome, we found that individuals who reported higher levels of enacted stigma reported lower levels of instrumental social support, but we found no statistically significant relationship between internalized stigma and instrumental social support (Table 5). A 1-point increase in enacted stigma was associated with a 0.11-point decrease in instrumental social support (95 % CI, −0.14 to −0.08). In the lagged-covariate models, lagged enacted stigma was negatively correlated with subsequent instrumental social support ($b = -0.032$; 95 % CI, −0.062 to −0.001), but lagged internalized stigma did not have a statistically significant relationship with subsequent instrumental social support. In all four models, higher levels of education, wealth, and physical health status were correlated with higher levels of instrumental social support, while higher CD4 counts were associated with lower levels of instrumental social support.

Table 4 The contemporaneous and lagged effects internalized stigma and enacted stigma on emotional social support

	Effect of internalized stigma on emotional social support		Effect of enacted stigma on emotional social support	
	Contemporaneous	Lagged	Contemporaneous	Lagged
Variables	<i>b</i> (95 % confidence interval [CI])	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)
Intercept	3.81 (3.73, 3.89)***	3.69 (3.52, 3.85)***	3.85 (3.78, 3.93)***	3.70 (3.44, 3.96)***
Internalized stigma	−0.014 (−0.024, −0.003)*	–	–	–
Enacted stigma	–	–	−0.095 (−0.114, −0.075)***	–
Lagged internalized stigma	–	−0.016 (−0.026, −0.005)**	–	–
Lagged emotional social support	–	0.035 (−0.003, 0.074)	–	0.019 (−0.04, 0.077)
Lagged enacted stigma	–	–	–	−0.032 (−0.062, −0.001)*
Time	−0.011 (−0.032, 0.010)	−0.013 (−0.034, 0.008)	−0.008 (−0.028, 0.012)	−0.003 (−0.051, 0.046)
Gender				
Male	Ref	Ref	Ref	Ref
Female	−0.034 (−0.079, 0.012)	−0.032 (−0.077, 0.013)	−0.025 (−0.068, 0.017)	−0.052, (−0.12, 0.020)
Age	−0.0002 (−0.003, 0.002)	0.0001 (−0.002, 0.003)	0.0001 (−0.002, 0.002)	0.0003 (−0.003, 0.004)
Marital status				
Not married	Ref	Ref	Ref	Ref
Married	−0.004 (−0.042, 0.033)	−0.007 (−0.044, 0.031)	−0.009 (−0.044, 0.027)	−0.039 (−0.101, 0.023)
Education				
No school	Ref	Ref	Ref	Ref
Primary school or more	0.021 (−0.033, 0.074)	0.010 (−0.043, 0.063)	0.002 (−0.048, 0.053)	0.034 (−0.048, 0.116)
Household asset wealth	0.025 (0.011, 0.039)***	0.025 (0.011, 0.039)***	0.020 (0.007, 0.033)**	0.002 (0.000, 0.045)*
MOS-HIV Physical Health Summary	0.002 (0.001, 0.004)**	0.003 (0.001, 0.004)**	0.002 (0.00, 0.004)*	0.003 (0.0004, 0.006)*
CD4 (per 100 cells/mL)	−0.009 (−0.019, 0.001)	−0.009 (−0.019, 0.014)	−0.008 (−0.017, 0.002)	−0.002 (−0.018, 0.014)
Depression	−0.048 (−0.111, 0.016)	−0.067 (−0.13, 0.002)*	−0.047 (−0.11, 0.015)	−0.067 (−0.17, 0.03)

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$

We further examined this apparently paradoxical relationship between instrumental social support and CD4 count. We estimated the effect of the two dimensions of stigma and two dimensions of social support on CD4 count using four multilevel modeling controlling for covariates, and found no statistically significant relationship between internalized stigma, enacted stigma, or emotional social support with CD4 count (data not shown). However, we found that individuals who reported higher levels of instrumental social support had lower CD4 counts and that a 1-point increase in instrumental social support was correlated with a 14.7 decrease in CD4 count (95 % CI, −22.6 to −6.9). We conducted exploratory subgroup analyses to further explore this finding and estimated the effects of interactions between sociodemographic variables and instrumental social support. We found that the joint interaction between gender and instrumental social support did not have a statistically significant relationship with CD4 count, but that the joint interaction of education and instrumental social support ($b = -21.7$; 95 % CI, −42.3 to −1.1) as well as the joint interaction of marital status and instrumental social support ($b = -18.6$; 95 % CI, −34.2 to −3.0) were statistically

significant predictors of CD4 count. We also estimated separate multilevel models with CD4 count as the outcome and instrumental social support as the main predictor for men and women, married and unmarried participants, and participants with and without education. We found that instrumental social support was a statistically significant predictor of CD4 count for men ($b = -22.0$; 95 % CI, −38.4 to −5.6), women ($b = -12.0$; 95 % CI, −21.0 to −3.1), married participants ($b = -26.0$; 95 % CI, −38.2 to −13.8), and educated participants ($b = -0.19$; 95 % CI, −27.1 to −10.0), but not among unmarried participants or participants without a formal education.

Figure 1 summarizes the lagged relationships between the two dimensions of stigma and two dimensions of social support. In summary, low levels of instrumental social support are associated with high subsequent levels of enacted stigma, which in turn are associated with lower subsequent instrumental social support. High levels of enacted stigma are associated with low subsequent levels of emotional support. Low levels of emotional social support are associated with high subsequent levels of internalized stigma, which in turn are associated with even lower subsequent levels of emotional support.

Table 5 The contemporaneous and lagged effects of internalized stigma and enacted stigma on instrumental social support

	Effect of internalized stigma on instrumental social support		Effect of enacted stigma on instrumental social support	
	Contemporaneous	Lagged	Contemporaneous	Lagged
Variables	<i>b</i> (95 % confidence interval [CI])	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)	<i>b</i> (95 % CI)
Intercept	3.53 (3.38, 3.67)***	3.25 (3.06, 3.43)***	3.58 (3.43, 3.72)***	3.25 (3.07, 3.44)***
Internalized stigma	-0.017 (-0.034, 0.000)	-	-	-
Enacted stigma	-	-	-0.11 (-0.14, -0.08)***	-
Lagged internalized stigma	-	-0.013 (-0.029, 0.004)	-	-
Lagged enacted stigma	-	-	-	-0.032 (-0.062, -0.001)*
Lagged instrumental social support	-	0.083 (0.046, 0.119)***	-	0.084 (0.047, 0.120)***
Time	-0.12 (-0.15, -0.08)***	-0.11 (-0.15, -0.08)***	-0.11 (-0.15, -0.07)***	-0.11 (-0.15, -0.077)***
Gender				
Male	Ref	Ref	Ref	Ref
Female	-0.16 (-0.25, -0.076)***	-0.15 (-0.24, -0.07)***	-0.15 (-0.24, -0.07)***	-0.15 (-0.23, -0.07)***
Age	0.001 (-0.004, 0.005)	0.0004 (-0.0004, 0.0047)	0.001 (-0.004, 0.005)	0.0006 (-0.004, 0.005)
Marital status				
Not married	Ref	Ref	Ref	Ref
Married	-0.028 (-0.094, 0.039)	-0.032 (-0.096, 0.033)	-0.03 (-0.096, -0.034)	-0.026 (-0.090, 0.038)
Education				
No school	Ref	Ref	Ref	Ref
Primary school or more	0.12 (0.02, 0.22)*	0.10 (0.008, 0.20)*	0.10 (0.004, 0.20)*	0.098 (0.0044, 0.19)*
Household asset wealth	0.082 (0.056, 0.11)***	0.079 (0.053, 0.010)***	0.075 (0.049, 0.10)***	0.077 (0.052, 0.101)***
MOS-HIV Physical Health Summary	0.004 (0.001, 0.007)**	0.004 (0.002, 0.007)**	0.003 (0.001, 0.006)*	0.004 (0.001, 0.007)**
CD4 (per 100 cells/mL)	-0.032 (-0.048, -0.015)***	-0.030 (-0.046, -0.014)***	-0.032 (-0.048, -0.016)***	-0.032 (-0.048, -0.016)***
Probable depression	-0.024 (-0.12, 0.074)	-0.053 (-0.15, 0.047)	-0.026 (-0.12, 0.071)	-0.040 (-0.14, 0.058)

P*<0.05; *P*<0.01; ****P*<0.001

Discussion

In this longitudinal analysis of data from people living with HIV initiating ART in rural Uganda, we found evidence that enacted stigma may compromise the ability to access both emotional and instrumental support from friends and family. We also found that internalized stigma may compromise the ability to access emotional support. At the same time, we found that instrumental social support was protective against future experiences of enacted stigma but not against internalized stigma. Finally, emotional social support was protective against future internalization of stigma, but not future experiences of enacted stigma. The estimated associations were strong, large in magnitude, and robust to lagged specifications that ensured a temporal ordering between the exposures and outcomes.

One of our primary findings was that the relationship between enacted stigma and social support was bi-directional. Lagged enacted stigma had an inverse association with both emotional and instrumental social support, indicating that people living with HIV who experienced

discrimination lost social support. Lagged instrumental social support had an inverse association with subsequent enacted stigma, indicating that people living with HIV who had

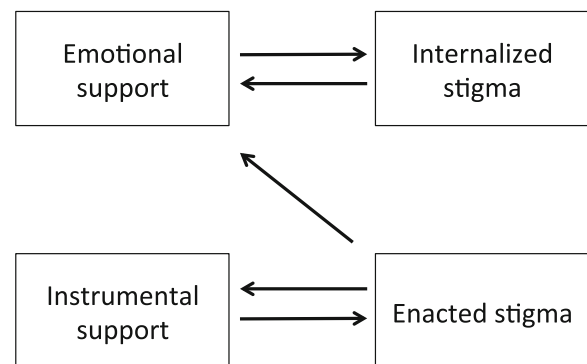


Fig. 1 This figure represents the relationships between emotional support, instrumental support, enacted stigma, and internalized stigma. The arrows indicate statistically significant lagged, inverse associations, where the arrow points toward the construct that follows in temporal sequence

less access to instrumental social support experienced more subsequent discrimination. These findings suggest that enacted stigma may trigger a vicious cycle, in which friends and family of people living with HIV abandon the HIV-affected person, and themselves become perpetrators of discrimination toward people living with HIV. One explanation may be that friends and family members become targets of discrimination by association. Goffman [1] describes this stigma by association, called courtesy stigma, as the process in which people who are “related through the social structure to a stigmatized individual...are all obliged to share some of the discredit of the stigmatized person” (p. 30). Goffman [1] further added that courtesy stigma “provides a reason why such relations tend either to be avoided or to be terminated” (p. 30). Bogart and colleagues [9] similarly reported that people living with HIV experience avoidance and ostracism by family members and friends, as well as overt acts of discrimination or hurtful remarks from those who remained in contact. Yang and colleagues [34], using the example of mental illness in Hong Kong, proposed that stigma threatens the moral standing of the family and friends, and the family members' fear of social contamination and loss of face motivated them to abandon and discriminate against their ill family member.

A second primary finding of our study was that there was an inverse and bidirectional relationship between emotional social support and internalized stigma. The inverse association between emotional support and reduced subsequent internalized stigma is consistent with previously published findings from cross-sectional studies [12, 13, 15, 32]. The social cognitive behavioral model of internalized stigma holds that stigmatized people are more likely to endorse demeaning beliefs when they blame themselves (instead of broader social processes) for negative evaluations or when they do not have positive self-perceptions [26]. Having emotionally supportive family and friends may help decrease the perceived legitimacy of negative evaluations and help people living with HIV develop a more positive sense of self, leading to less internalization of stigma.

Conversely, lagged internalized stigma was inversely associated with emotional social support, indicating that people living with HIV who internalize stigma are less able to have supportive relationships with friends and family. This is consistent with reports that people with high internalized stigma are less likely to disclose their HIV status to their friends and family or to solicit support from them [12, 37]. Internalized stigma has also been associated with depression [10, 12], which could also compromise the affected persons' effectiveness in maintaining supportive relationships. Furthermore, caring for people living with HIV exerts substantive physical and psychological burdens on their caregivers, particularly in the setting of depression [58]. This could result in a negative “feedback loop” of social support [23], in which the strain of supporting a

person with a serious illness results in caregivers withdrawing and severing the relationship in order to cope with the strain.

How can we understand why individuals living with HIV who report high levels of perceived instrumental social support subsequently report low levels of enacted stigma, but not internalized stigma, while those who report high levels of emotional social support subsequently report low levels of internalized stigma, but not enacted stigma? We hypothesize that having friends and family who provide tangible help with tasks and finances can protect the person from becoming targets of external, visible acts of discrimination and insults. However, such transactional relationships may not be as helpful as emotionally supportive relationships in protecting people living with HIV from endorsing negative views about themselves and losing self-esteem. While internalized stigma has been implicated in loss of self-efficacy such as that required for the disclosure of HIV serostatus to partners [27], the null association between lagged internalized stigma and instrumental social support may reflect that this loss of self-efficacy is most relevant to intimate, emotional relationships. Our results confirm the conceptual difference [11] between enacted stigma and internalized stigma by showing that internalized and enacted stigma each originate from different interpersonal processes.

These findings suggest that people living with HIV who are most affected by HIV stigma may suffer the additional burden of losing social support. The emotional and material resources provided by social support are critical for people living with HIV in resource-poor settings like Uganda, who must address day-to-day economic challenges while adhering to ART, maintaining positive health behaviors, and coping with the burden of illness and stigma. In one qualitative study of 252 individuals living with HIV in three sub-Saharan African countries, social relationships were critical for maintaining ART adherence, not only because individuals living with HIV relied on them for transport to clinic, encouragement, and regular reminders but also because of the social expectations that created obligations for people living with HIV to adhere [59].

We acknowledge several limitations of this study. First, our measures are self-reported and therefore suffer challenges generic to all analyses based on self-reported data. Second, it is difficult to disentangle the extent to which the estimated associations may simply reflect an unmeasured common factor. However, in the lagged models, we examine determinants of stigma or social support after adjusting for lagged values of the variables. Third, the perception of social support may not correlate perfectly with the actual degree of social support received. However, prior studies have demonstrated that

perceived social support is more predictive of health outcomes than actual social support for people living with HIV/AIDS [60]. Fourth, our study sample consisted of individuals living with HIV who were initiating ART. Given that stigma is known to compromise the ability of people living with HIV to access and adhere to ART [6, 61], and given that access to ART has been shown to lower stigma [62–64], it is likely that overall levels of internalized stigma were lower in our sample compared to untreated individuals living with HIV. Because social support is also known to be positively associated with treatment access [59], this could have biased our estimates away from the null. Fifth, the enacted stigma index had a relatively low reliability, which was expected given the diversity of behaviors included in the index. The lack of internal consistency simply increases the amount of random noise so that regression models in which enacted stigma was specified as the dependent variable would have yielded estimates that were biased towards the null. The mean of the internalized stigma and enacted stigma scores were low, but comparable to those found in the literature [45]. Finally, the cut-off for the Hopkins Symptom Checklist used to determine probable depression is based on studies conducted in Western populations, and we acknowledge that this specific cutoff has not been validated in the Ugandan context.

Of note, we found that internalized stigma, enacted stigma, and emotional social support did not have statistically significant associations with CD4 count and that instrumental social support had an *inverse* association with CD4 count. This finding is paradoxical in that social support is generally thought of as being linked with better ART adherence [6] and other positive health behaviors. However, there are likely multiple pathways leading from social support to improved health, so extrapolating a direct association from the data may not be warranted. In addition, instrumental social support may not have uniformly beneficial effects on health, especially in settings where the nature of the support does not meet the recipient's needs. For example, instrumental social support has been found to increase dependency and disability among older adults [65] or worsen glycemic control among people with diabetes mellitus [66]. Further research is indicated to clarify these associations among people living with HIV.

In summary, we found that enacted stigma may compromise the ability of people living with HIV to access support from close social ties, and that instrumental social support may be protective against future experiences of discrimination. We also found that emotional social support may be protective against future internalization of stigma. Taken together, our findings provide unique longitudinal evidence on the bidirectional relationships between stigma and social support. They also suggest the potentially powerful impacts that antistigma interventions may have on the lives of people living with HIV by interrupting the vicious feedback loop between stigma and social isolation.

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