**Examining the impact of food assistance on stigma among people living with HIV in Uganda using the HIV/AIDS stigma instrument-PLWA (HASI-P)**

## Abstract

HIV-related stigma among persons living with HIV/AIDS (PLHIV) is prevalent throughout sub-Saharan Africa. There is limited evidence, however, on whether interventions can reduce it. We used data from a prospective impact evaluation of a 12-month food assistance intervention among 904 antiretroviral therapy (ART)- naïve PLHIV in Uganda to examine the program impact on stigma. Stigma was measured using the comprehensive HASI-P scale, which demonstrated good internal consistency (Cronbach’s alpha=0.87) and was correlated with several related constructs including physical and mental health-related quality of life, disclosure, and physical health symptoms in the sample. Using quasi-experimental difference-in-difference matching methods to better infer causality, we then tested whether the intervention improved the overall stigma scale and its subscales. The food assistance intervention had a significant effect on reported internalized (but not external) stigma of approximately 0.2 SD (p<0.01). The HASI-P stigma scale is a useful tool for measuring and tracking stigma. Food assistance interventions, embedded in an HIV care program, can reduce internalized stigma.

**Introduction**

HIV is highly stigmatized throughout Sub-Saharan Africa ([1-3](#_ENREF_1)), including in Uganda ([4](#_ENREF_4)). Originally conceptualized as “an attribute that is deeply discrediting” ([5](#_ENREF_5)), various dimensions of stigma have been articulated in the literature, categorized into three broad types: 1) internalized or self ([6-8](#_ENREF_6)); 2) external, enacted, or received ([8](#_ENREF_8)); and 3) anticipated or perceived ([6](#_ENREF_6), [9-11](#_ENREF_9)). Important in and of itself for the psychosocial well-being of persons living with HIV (PLHIV) ([12](#_ENREF_12)), HIV-related stigma is also important for its potential impact on behaviors of both those with and without HIV. In particular, it can create barriers to good care ([11](#_ENREF_11)) via its influence on decisions around testing, disclosure, and treatment, and may even contribute to the spread of the disease ([9](#_ENREF_9), [13](#_ENREF_13)). Improved understanding of stigma, its progression over time, and how it, or its consequences, can be reduced, are essential in managing the epidemic.

Uganda, where prevalence of HIV was 8.3% for women and 6.1% for men aged 15-49 in 2011 ([14](#_ENREF_14)), is an important setting in which to study HIV-related stigma as it is both prevalent and persistent ([15](#_ENREF_15)). Based on a 2011 national population based-survey, 1 in 5 Ugandans felt that PLHIV should be ashamed of themselves and should be blamed for bringing the disease into the community ([4](#_ENREF_4)). Interviewing 1110 PLHIV about the previous 12 months, a separate survey from 18 (of 111) districts in Uganda in 2012/13 demonstrated the extent to which respondents experienced various types of stigma. Prevalent HIV-related internalized stigma was evidenced by the approximately one-third of respondents who felt ashamed, guilty, and blamed themselves, and the one-quarter who had low self-esteem as a result of their HIV status. External stigma was evident with 16% indicating they had faced exclusion from social gatherings. There was also evidence of anticipated stigma, as 10% indicated they had chosen not to attend a social gathering and 9% had isolated themselves from family or friends because of their HIV status ([4](#_ENREF_4)).

Understanding of stigma, its causes, and its consequences, have improved substantially in recent years, including in Uganda with much relevant research based on Uganda AIDS Rural Treatment Outcomes (UARTO) study, which enrolls PLHIV on an ongoing basis and follows them longitudinally ([15-18](#_ENREF_15)). For example, researchers have examined the relationship between stigma and food insecurity, which is also common in Uganda ([19](#_ENREF_19), [20](#_ENREF_20)) and has been demonstrated to play a detrimental role in the HIV/AIDS crisis ([21](#_ENREF_21), [22](#_ENREF_22)). Research from UARTO finds that both internalized and external stigma are positively and significantly associated with food insecurity in the cross-section, as well as over time in individual-level fixed effects models controlling for other time-varying factors, with the association with internalized stigma somewhat stronger ([19](#_ENREF_19)). Lower HIV symptom burden and better (self-reported) physical health also are associated with internalized stigma in UARTO ([18](#_ENREF_18)) as well as elsewhere ([12](#_ENREF_12)). Interventions that can influence food insecurity, symptom burden, or self-reported physical health, therefore, may have potential to influence stigma as well.

Of course, one such important intervention is antiretroviral treatment (ART). Those who initiated ART under UARTO and were followed longitudinally did in fact experience declines in internalized stigma over time, though it was not eliminated ([18](#_ENREF_18)). At the same time, later (i.e., more recent) enrollees in the study presented with higher initial or baseline internalized stigma, consistent with observed general increasing stigmatization over time. As this latter trend was occurring in an environment with increasing ART coverage at the national level, the combined evidence makes clear that improvements in ART coverage alone are not sufficient to fully reduce internalized stigma, neither for those directly on ART nor for ART-naive PLHIV ([15](#_ENREF_15)). Complementary multifaceted or livelihood interventions may be required, such as programs that target poverty ([3](#_ENREF_3), [23](#_ENREF_23)).

There is a body of evidence on some of these other possible programs with some of it exploring the relationship with stigma. Nevertheless, recent systematic reviews conclude that more work is needed both on the basic validation of stigma measures as well as on the effectiveness of such interventions to reduce it ([13](#_ENREF_13), [24](#_ENREF_24), [25](#_ENREF_25)), with the former a necessary condition for adequately assessing the latter. In particular, there are relatively few studies examining the reliability and validity of comprehensive stigma measures, i.e., ones that go beyond just internalized stigma and capture aspects of external stigma. Moreover, most of these other interventions aimed at reducing stigma focus on the general population, with only a smaller number examining how interventions targeted to PLHIV influence the stigma they experience ([24](#_ENREF_24)).

To address these gaps in the evidence base, we capitalized on an existing intervention for ART naïve PLHIV in northern Uganda, coordinated by The AIDS Support Organization (TASO)—an HIV/AIDS care and treatment organization—and the World Food Programme (WFP), to conduct a 12-month prospective impact evaluation of provision of a monthly household food basket. Principal outcomes of this intervention have been examined elsewhere ([26](#_ENREF_26), [27](#_ENREF_27)). In this paper, we use data from this impact evaluation to study the comprehensive stigma scale previously developed and validated in five other African countries—the people living with HIV/AIDS Stigma Instrument–PLWA, or HASI-P ([28](#_ENREF_28)).

This study has two objectives—the first of which is instrumental to the main objective of determining the impact of food assistance on different components of HIV-related stigma for PLHIV. The instrumental objective is to examine the reliability and validity of the comprehensive HASI-P scale (and subscales) for our sample in Uganda. It is necessary to have a measure with strong evidence of reliability and validity for setting a baseline against which to examine changes over time or impacts of interventions (including, for example, any assessments of the effects of ART initiation on stigma which logically require validation of instruments on an ART-naive population), enabling measurement of progress in reducing HIV-related stigma ([28](#_ENREF_28), [29](#_ENREF_29)). After providing evidence on the reliability and construct validity of the scale, our second objective is to assess whether the food assistance intervention, previously shown to have increased food security, nutritional status as measured by BMI, and self-reported physical health measures also influenced self-reported stigma as measured by the HASI-P. As the lived experience can differ across different dimensions of stigma, we examine both internalized and external stigma.

**Methods**

***Study design***

With more than 100,000 clients, the AIDS Support Organization (TASO) is the largest indigenous non-governmental organization in Uganda, providing comprehensive HIV prevention and AIDS care and support services. These include livelihood training and several forms of counseling aimed at providing psychosocial support to its clients and their families. In particular, counseling has been an integral aspect of its work since the organization was founded over two decades ago ([30](#_ENREF_30)), and there is special emphasis on disclosure to others—in practice, disclosure to someone is a condition for being a TASO client and virtually all individuals in the study had disclosed to at least one person and the vast majority to several. For individuals followed in the study, respondents indicated that TASO counseling was the main factor behind new disclosures since their baseline interview. From its beginning, the organization has sought to reduce stigma directed toward, and experienced by, PLHIV, and currently employs as a guiding principle a “philosophy of living positively with HIV.”

In some regions where it works, TASO partners with WFP to deliver food assistance in the form of monthly food baskets for specifically targeted clients. To evaluate the impacts of this food assistance, we conducted a 12-month prospective impact evaluation nested within the routine programmatic context of both TASO and WFP in two districts in northern Uganda, Gulu and Soroti ([26](#_ENREF_26)). The study districts, each with a single TASO clinic, were more than 100 kilometers apart and both were highly food insecure with histories of armed conflict and internal displacement ([31](#_ENREF_31)). The two districts differed in size—Soroti was larger in 2008 with approximately 500K residents compared to Gulu with 350K. On other broad indicators, however, they were similar with total fertility rates of approximately 7, adult literacy rates just over 60%, and 65% of households having access to water ([32](#_ENREF_32)). In 2011, HIV prevalence among women (men) 15-49 was 10.1% (6.3%) in the mid-northern region where Gulu is located, but only 5.3% (5.2%) in the north-eastern region where Soroti is located ([14](#_ENREF_14)). During the study, WFP operated in Gulu but not in Soroti; thus Soroti served as the non-randomized comparison district.

We recruited HIV-positive non-pregnant adults (aged 18 and over) during their routine visits to their respective TASO clinic who: 1) were eligible for food assistance based on WFP’s poverty assessment criteria but had not received food assistance from any source in the previous 12 months; 2) were ART naïve; and 3) had a CD4 count between 200 and 450 cells/μL. Recruitment procedures were identical across districts. We focused on those who were not yet eligible for ART (at the time of study initiation), because they were considered one of the populations most vulnerable to food insecurity. Monthly food distribution in Gulu began within 1–4 weeks of recruitment and was conditional on remaining an active TASO client, meeting with a TASO support officer at least once per month.

Multipurpose surveys were administered at baseline and again at follow-up approximately one year later. Upon recruitment, an individual questionnaire was administered to the study participant in a private room at the TASO clinic by a research interviewer unaffiliated with TASO. Among other things, the HASI-P was included in the face-to-face interview done at the clinic. Training emphasized the sensitivity of discussing the stressful topics asked about for the scale, and interviewers were instructed to put respondents at ease by, for example, making clear they could take their time and answer at the pace they felt comfortable and reminding them that all responses were confidential. Trained and standardized anthropometrists took anthropometric measurements and a TASO laboratory technician drew blood for CD4 count. Within seven days, a research interviewer visited the home of the participant to administer a household socioeconomic questionnaire. The intervention and some of its important impacts are described in more detail elsewhere ([26](#_ENREF_26), [27](#_ENREF_27)).

The ethics review boards of TASO and the International Food Policy Research Institute approved the study protocol, and the study received clearance from the Uganda National Council on Science and Technology. Interviewers read consent forms to study participants who provided signed informed consent.

***Measures***

To measure stigma, we administered the HASI-P—previously developed and validated by Holzemer et al. ([28](#_ENREF_28)) in five African countries (including Lesotho, Malawi, South Africa, Swaziland, and Tanzania, but not Uganda). Interviewers were provided with translations into the common languages of the study. A 33-item scale, the HASI-P has been categorized via factor analysis into six subscales capturing two broad types of stigma. Internalized stigma, or the “thoughts and behaviors stemming from the person’s own negative perceptions about herself or himself based on her/his HIV status” is captured by five items in a negative self-perception (NSP) subscale. External, enacted, or received stigma, reflecting “all types of stigmatizing behavior towards a person with HIV/AIDS experienced or described by people living with HIV/AIDS” is captured by 1) eight items in a verbal abuse (VA) subscale; 2) five items in a social isolation (SI) subscale; 3) six items in a fear of contagion (FC) subscale; 4) seven items in a healthcare neglect (HN) subscale; and 5) two items in a workplace stigma (WS) subscale (page 1009 ([28](#_ENREF_28))). For each of the 33 items, the survey measured whether the individual had experienced the event, coded on a 4-point Likert-type scale from 0 to 3 as follows: never=0; once or twice=1; several times=2; or most of the time=3 ([28](#_ENREF_28)). Each subscale score was calculated as the average response within that grouping and therefore lies between 0-3, with higher scores indicating greater stigma.

The instrument was administered for two distinct reference periods and importantly refers to actual, rather than hypothetical, experience over the previous 3-months (“how often did the following event/feeling happen in the past 3 months because of your HIV status”) in both the baseline and the follow-up surveys and ever since HIV diagnosis (“how often did the following event/feeling happen because of your HIV status EVER since you tested HIV positive”) in the follow-up. In this paper, we present evidence for the reliability and validity of the scale using the 3-month reference period at baseline; results for parallel analyses examining the 3-month reference period measured at follow up and for the ever since HIV diagnosis reference period were similar (not shown). Notably, the well-defined reference period used in the HASI-P is distinct from scales such as the Internalized AIDS-Related Stigma Scale ([11](#_ENREF_11), [16](#_ENREF_16)), which frames questions more generally in the present, with phrasing like “I feel guilty that I am HIV-positive.”

A variety of indicators, including several other constructs shown in the literature to have been related to stigma, also were captured in the surveys (**Table 1**). We measured individual-level characteristics, including gender, age, education, civil status, nutritional status (body mass index and mid-upper arm circumference [MUAC]), disease severity (CD4 count), hemoglobin, and time since diagnosis. We also measured household-level characteristics such as household size, monthly per capita household food and total consumption (the sum of cash expenditures and respondent imputed value of consumption from own-production ([33](#_ENREF_33))), and the value of household assets to assess economic well-being. Distance to the nearest market (in kilometers) was included as it is associated with food prices and access to food, as well as the degree to which households are connected to more urban areas.

A separate relevant construct was health-related quality of life (HRQoL), a comprehensive measure of how well a person functions and his or her perceptions, based on experiences, beliefs, and expectations of their physical, mental, and social well-being ([34](#_ENREF_34)). HRQoL was measured using the MOS-HIV Health Survey ([34-36](#_ENREF_34)) which was first adapted for use in rural Africa in Uganda and has been implemented widely in sub-Saharan Africa including elsewhere in Uganda ([37](#_ENREF_37), [38](#_ENREF_38)), and has been shown to strong evidence of reliability and validity among PLHIV ([35](#_ENREF_35), [39](#_ENREF_39)). We operationalized HRQoL using two summary scores, physical health summary (PHS) and mental health summary (MHS), as derived from factor analyses conducted by Revicki et al. ([40](#_ENREF_40)). These measures are described in more detail elsewhere ([27](#_ENREF_27)).

Given the emphasis of TASO on the importance of disclosure, as well as its close connection to stigma ([2](#_ENREF_2)) (for example, ([4](#_ENREF_4)) indicates that 73% of their Ugandan sample of PLHIV reported that fear of stigma, discrimination, and related phenomena were hindrances to disclosing their HIV status), the questionnaire also solicited detailed information on disclosure to various types of family members and relatives as well as unrelated community members. For the current analyses, we measured the extent of disclosure as the percentage of applicable types of person the individual had disclosed their HIV status to from 16 possible types, including 8 types of family members (partner if had, mother if alive, father if alive, etc.) and 8 types of unrelated community members (friends, religious leader, community leader, etc.).

We also measured the total number of HIV-related physical conditions and, separately, symptoms ([27](#_ENREF_27), [41](#_ENREF_41), [42](#_ENREF_42)). We counted the number of distinct healthcare provider-reported physical conditions from a pre-defined list of 17 items (including, e.g., opportunistic infections, other illnesses, and medical conditions associated with HIV) indicated in the individual’s current TASO clinical records, updated just prior to each research interview. Separately, we counted self-reported physical symptoms (in the previous 30 days) associated with HIV from a pre-defined list of 16 items.

And last, given the focus of the evaluation on the food assistance intervention, we captured food security by measuring diet quality at the individual level using a validated individual diet diversity score (IDDS), the total number of items consumed on the previous day of nine different food groups ([43](#_ENREF_43)), and food access at the household level based on a validated household food insecurity access scale (HFIAS) ranging from 0-27 (and used in UARTO), with higher scores reflecting greater food insecurity ([26](#_ENREF_26), [44](#_ENREF_44)).

***Statistical analysis part (1): Reliability and validity of the HASI-P***

The reliability and construct validity analyses for the HASI-P (and its subscales) use the baseline 3-month recall data for stigma and closely parallel the original development of the scale by Holzemer et al. ([28](#_ENREF_28)) as well as recent similar exercises for different stigma indices for PLHIV ([11](#_ENREF_11), [16](#_ENREF_16), [45](#_ENREF_45), [46](#_ENREF_46)) and for healthcare providers ([47](#_ENREF_47)).

We examined the reliability of the HASI-P in our data as follows. First, to explore whether the original subscales were appropriate for the Ugandan sample, we carried out confirmatory factor analysis with orthogonal varimax rotation ([48](#_ENREF_48)) on all items simultaneously. We examined the eigenvalues to assess the number of important factors present and their congruence with the original pre-determined subscales developed ([28](#_ENREF_28)), including whether the factor loadings on individual items were of sizeable magnitude. This exercise was then repeated for each of the subscales separately. Second, to assess internal consistency of the item responses overall and for each subscale, we calculated Cronbach’s alpha (α), computing the standard errors and resulting confidence intervals via bootstrapping with 10,000 repetitions. As an additional check, we recalculated the Cronbach’s alpha (αd) removing one item at a time from each subscale.

We next examined the validity of the overall scale and each of the subscales. As with other validation assessments for HIV-related stigma measures, there was no gold standard in our data against which to assess stigma for criterion-related validity, nor is it clear what such a standard would be ([16](#_ENREF_16)), so we considered several different assessments of construct validity suggested by the literature and for which we had data. When examining the relationship between stigma and a construct represented by a binary variable, we calculated the point-biserial correlation between the means of the stigma scale and the binary indicator. For all other variables, we calculated the Pearson correlation coefficients between each of the stigma subscales and the constructs hypothesized to be related to one or more types of stigma, computing the standard errors and resulting confidence intervals for all correlations via bootstrapping with 10,000 repetitions.

We examined the correlation (or point-biserial correlation coefficient in the binary case ([49](#_ENREF_49))) between the subscale and overall stigma scale scores at baseline with each of the constructs described above in *Measures*. These constructs have been shown to be associated with stigma in the literature ([10](#_ENREF_10), [12](#_ENREF_12), [50](#_ENREF_50)) and also have been used in other validation studies ([11](#_ENREF_11), [16](#_ENREF_16), [28](#_ENREF_28), [45](#_ENREF_45), [46](#_ENREF_46)). Constructs examined were: quality of life, including health related quality of life and self-reported health ([2](#_ENREF_2), [28](#_ENREF_28), [51](#_ENREF_51), [52](#_ENREF_52)); disclosure ([2](#_ENREF_2)); health indicators (CD4, nutritional status, and conditions); and a binary indicator of time since diagnosis greater than 12 months ([53](#_ENREF_53)).

***Statistical analysis part (2): Impact of food assistance on HASI-P***

After providing evidence on the reliability and construct validity of the HASI-P in the Ugandan context as our first (instrumental) objective, we next modelled the overall scale, as well as the subscales, in univariate and multivariate ordinary least squares regression frameworks exploring the individual-, household-, and community-level correlates of stigma at baseline. This analysis was done in order to assess whether in our sample, and after controlling for a set of background characteristics, stigma was associated with various factors previously shown to be related to stigma ([53-55](#_ENREF_53)) *and* shown in this context to have been influenced directly by the food assistance intervention. In particular, these included food insecurity, nutritional status, and self-reported physical health. Such baseline associations support the hypothesis that the food assistance intervention we examine had potential to influence stigma, though they do not demonstrate themselves such influence. Standard errors were estimated using a heteroskedasticity robust estimator.

Last, with evidence in hand on the potential mechanisms through which food assistance might alleviate it, we estimated the impact of food assistance on stigma. To do this, we combined difference-in-difference techniques with the bias-adjusted nearest-neighbor matching estimator proposed by Abadie et al. ([56-58](#_ENREF_56)), with matching based on the estimated propensity scores. The nearest-neighbor matching methodology performs well when there is dense common support for the two distributions, i.e., when there are many nearby neighbors (or possible matches) for treatment observations, as found in the current study. Thus, we incorporated the follow-up data and compared the change over time in stigma outcomes for all individuals in the intervention group with the change over time in stigma outcomes for weighted matched individuals from the comparison group, an approach increasingly used in evaluations without randomization to construct a comparable statistical counterfactual group ([59](#_ENREF_59)) and used in other studies to evaluate the current intervention ([26](#_ENREF_26), [27](#_ENREF_27)). Below we describe the matching procedure we undertook in more detail.

Although individual-level eligibility criteria were identical across districts (limiting potential selection problems related to differential recruitment across study arms), with only two sites (and without randomization), initial differences between treatment and comparison were possible. Therefore, we identified a set of observable individual-, household-, and community-level characteristics associated with the outcomes (**Table A1**), including variables from the multivariate regression models. We also included the actual baseline values of the primary outcome, stigma, to help ensure that there were minimal initial differences between matched groups; such differences could lead to bias if the magnitude of change in the outcome depended on the initial baseline level ([56](#_ENREF_56), [59](#_ENREF_59)). Using these variables, we constructed a propensity score for each individual, estimating the predicted probability of being in the intervention group (i.e., living in the intervention district), as a function of all of the baseline characteristics listed in **Table A1** with logit regression models. We transformed some variables used in the logit as indicated in the table (e.g., using logarithmic transformations) until there were no statistically significant differences in the mean of each variable across intervention and comparison groups for each 20-percent quantile of the propensity score. (Statistical significance of the difference between intervention and comparison groups for each variable, in each quantile, was assessed via a simple regression of the variable on an indicator for the intervention group for all observations in that quantile, using heteroskedasticity-robust standard errors.) Referred to as balancing, this procedure helps ensure that propensity-score based matches have similar values of the underlying balance variables ([60](#_ENREF_60), [61](#_ENREF_61)).

We then used the predicted propensity score from this final model specification, as well as three other key characteristics (initial baseline level of NSP and VA, and the time in months between baseline and follow-up interviews), to match each individual in the intervention group to the most similar individual, or “nearest neighbor,” of the same gender in the comparison group ([56](#_ENREF_56)). The estimated average treatment effect on the treated (ATT), then, is the difference-in-difference in mean outcomes over 12 months for the intervention group compared to the matched comparison group, with more weight given to closer matches as per the bias-adjusted estimator ([56](#_ENREF_56)). We implemented a heteroskedasticity-robust variance estimator developed for this matching technique ([56](#_ENREF_56)).

As with any matching estimator, the validity of this approach relies on the unverifiable assumption that conditional on a set of observable characteristics, treatment assignment is independent of the potential outcomes. The use of a number of baseline variables to construct the propensity score, as well as several key variables in addition to the propensity score for matching ([56](#_ENREF_56)) served to strengthen the validity of the comparison. The specific maintained assumption required for validity differs with alternative sets of matching variables or different matching procedures. Therefore, we can indirectly assess the validity of the approach by examining various alternatives; large differences in results across small modifications in the matching variables, for example, would suggest that the assumption required for validity may not hold. We carried out sensitivity analyses to explore this possibility, including: 1) examining results for nearest 3 and nearest 5 matches (instead of only the single nearest neighbor as in the primary results); 2) examining results for single nearest neighbor match limiting the common support to propensity scores lying between 0.1 and 0.9 only; and 3) an alternative set of matching variables—using all of the balancing variables directly in the matching procedure, while continuing to match exactly on gender.

All analyses were carried out using Stata version 13 (College Station, TX) and we set statistical significance at a two-tailed P<0.05.

## Results

***Results part (1): Reliability and validity of the HASI-P***

Between August 2008 and October 2009, we recruited 904 subjects at the intervention (Gulu) and comparison (Soroti) district TASO clinics (but who resided in more than 100 different villages and urban neighborhoods in their respective districts), and between August 2009 and October 2010 followed up with 639 individuals with complete information on stigma. We did not re-interview individuals who: 1) lived in the comparison district and had been provided food assistance from another program after recruitment; 2) had begun ART; 3) could not be located; or 4) had died. Loss to follow-up was the same across districts (29%) and driven largely by ART initiation, a pre-specified exclusion criterion in the study ([27](#_ENREF_27)).

**Table 1** reports summary statistics by district and overall. At baseline, the overall sample comprised 647 (71.6% of 904) women and individuals were on average 39.1 years old with 4.5 completed grades of schooling; only 20% had completed primary school (seven years). Nearly 90% were either the head of their household or spouse of the head. Nearly half (48.3%) were married or in a union and another 32.5% were widowed. Average CD4 count was 338.2 cells/μL and 40% of the sample were anemic. Subjects had been diagnosed, on average, for just over 2 years (2.2, SD=1.8). Average household size was 6.3 members and based on per capita consumption, fully one-quarter of households were below the national poverty line. Other constructs potentially associated with stigma are reported in **Table 1**. In particular, we see that individuals have on average disclosed to about 80% of types of family members and slightly less, 70%, of other types of unrelated community members. Categorizing the HFIAS scores as in Coates et al. ([44](#_ENREF_44)), two-thirds of households were severely food insecure at baseline, and nearly all the rest were moderately insecure. Respondents were on average similar in Gulu and Soroti and, after matching, the matched samples were even more similar (not shown).

**Table 2** reports the response data for each item in the HASI-P, as well as the results from the confirmatory factor analyses. One subscale, workplace stigma (WS) had minimal variation, with less than 2% reporting anything but “never,” possibly because only 7% of the sample indicated working for pay outside the home. In what follows, we did not analyze WS further, removing its two items from the analysis. Factor analysis on all remaining 31 items in the overall scale yielded five eigenvalues greater than one, identical to the number of subscales from the original validation of the instrument for these items ([28](#_ENREF_28)). Moreover, extracting these five factors, the items from each subscale map onto the different factors with positive factor loadings generally above 0.4 in a pattern similar to the original formulation (shown in bold in columns 5-9) ([28](#_ENREF_28)). After this overall confirmatory factor analysis, we next carried out separate factor analyses on each of the five individual subscales. For each, the first eigenvalue (shown in bold in column 10) was 2.1 or larger and the second (not shown) 0.25 or smaller, suggesting that each subscale captures well a single factor. Examining the factor loadings across the five subscales, 29 of 31 were above 0.40 and 23 of 31 above 0.50 (column 10).

Estimates for Cronbach’s alpha (α) on all 31 items in the overall scale was 0.873 (95% CI 0.856-0.891) and for the five subscales between 0.740 (CI 0.682-0.798) and 0.848 (0.808-0.887), suggesting a high degree of correlation among the underlying dimensions and internal consistency (**Table 3**). Removal of individual items from the calculations did not alter appreciably the Cronbach’s alphas (αd) (not shown).

**Table 3**, which combines the individual items from **Table 2** into the different subscales, makes clear that the most commonly reported stigma-related items were those associated with negative self-perception (NSP), which was approximately 50% higher than the second most common, verbal abuse (VA). The other elements, however, were all generally uncommon with 90% or more reporting none of the items in the 3 months prior to their interview.

While all of the Pearson correlations among the subscales indicate significant and non-trivial correlation, only three of ten were above 0.4, consistent with the possibility that the different subscales capture different components of stigma. NSP and healthcare neglect (HCN) were the two subscales most weakly correlated with the others. Taking all 31 items together, 15% of respondents reported having never experienced any form of stigma in the past 3 months as opposed to 28% who had not experienced NSP (not shown).

Evidence in support of construct validity is shown in **Table 4** which presents a number of statistically significant correlations with factors previously shown in the literature to be associated with stigma. All stigma indicators are negatively correlated with physical and mental summary scores of HRQoL, with correlations for overall stigma the strongest and correlations with mental summary scores generally larger than with physical summary scores. Correlations with NSP are stronger than with the other stigma components. While the association with overall stigma and the two types of disclosure (to family members and to unrelated community members) is positive, this is not uniform across stigma components and HCN stigma is negatively correlated with disclosure, and significant in the case of disclosure to relatives. NSP stigma is not significantly correlated with disclosure but VA, social isolation (SI), and fear of contagion (FC) are generally positively and significantly associated. Among objective measures of disease progression and health (BMI, CD4 count, and healthcare provider-reported symptoms), correlations are small and few are significant, though with one modest significant positive correlation between HCN stigma and provider-reported symptoms. Self-reported physical symptoms are strongly related to stigma, in a pattern similar to HRQoL physical summary scores. Those more recently diagnosed (within 12 months) have experienced less VA stigma but slightly more HCN stigma in the past 3 months.

***Results part (2): Impact of food assistance on HASI-P***

Results from bivariate and multivariate regressions exploring the association of the set of characteristics with the two most commonly reported types of stigma in the sample, NSP (which reflects internalized stigma) and VA (which reflects external), as well as overall stigma, are shown in **Table 5** for the baseline sample from Gulu. Our analyses focus on these two subscales since while each is highly related to overall stigma (as shown in **Table 3**), they are less strongly related to one another and therefore may capture different elements of stigma or be influenced by different factors. Overall there are relatively few significant associations with the stigma measures, possibly reflecting the smaller sample size limited only to Gulu. Examining those factors previously demonstrated to have been influenced by the food assistance intervention in the multivariate context (columns 2, 4, and 6), BMI is not associated with any of the stigma measures, HFIAS is negatively associated with NSP and the overall measure, PHS is negatively associated with NSP, and self-reported physical symptoms are positively associated with all three stigma measures.

Last, the ATT bias-adjusted difference-in-difference matching estimates are presented in **Table 6**. We present impact estimates for each subscale of the HASI-P, as well as for the overall scale, based on matching the sample of 318 intervention observations. Food assistance significantly decreased reported stigma for all but the VA component (P=0.31). The overall scale showed a reduction of 0.066 relative to the matched comparison group (which also declined slightly over time, by approximately half that amount). With a baseline mean of 0.258 (SD 0.27) (**Table 3**), this and other estimated effects represented approximately 0.2 SD for each measure. Sensitivity analyses (not shown) demonstrated very similar results.

## Discussion

In this paper, we examined the validity of the comprehensive HASI-P stigma scale proposed by Holzemer et al. ([28](#_ENREF_28)) for a population of highly vulnerable ART naïve PLHIV in a new setting. With evidence of reliability and validity for the scale, we then examined prospectively the impacts of a food assistance intervention on stigma. Using quasi-experimental matching methods to better infer causality, we tested whether the intervention improved the overall stigma scale and its subscales reflecting both internalized and external stigma.

Overall, our findings provided strong evidence of reliability and construct validity for the HASI-P in the baseline sample. Factor analyses confirmed the general pattern of factor loadings and demonstrated the replicability in Uganda of the 5-factor structure for the 31 items of the HASI-P we examined. There was a high degree of internal reliability for the overall stigma scale as well as for its various subscales. Moreover, the overall scale and subscales were strongly associated with several constructs found in the literature to be related to stigma, supporting its validity.

Separate consideration of multiple dimensions of stigma was warranted since reported levels of, and correlations among, the various components differed. In the HASI-P, NSP captures aspects of internalized stigma while the other subscales reflect external stigma ([10](#_ENREF_10), [28](#_ENREF_28)). Internalized NSP was the most commonly reported component of stigma, followed by VA, and then the other forms of external stigma. This relative ranking, including a large percentage gap between those reporting NSP and VA, closely parallels evidence reported for the five Sub-Saharan African countries first examined by Holzemer et al. ([28](#_ENREF_28)), as well as from a different sample also measured in 2009 from Gulu district, comprising a mixture of TASO and non-TASO clients ([53](#_ENREF_53)). Overall stigma in our sample, however, was lower than the average levels reported in those other settings and in an additional study using the same HASI-P for four other African countries and the U.S. in 2006 ([2](#_ENREF_2)). All subjects in our sample were TASO clients and thus receiving HIV care, treatment, and counselling from an organization that has focused on HIV/AIDS for decades, and this may explain in part the lower levels of reported stigma.

Also consistent with the original validation study ([28](#_ENREF_28)), there was weaker correlation between NSP and the other subscales capturing aspects of external stigma, further underscoring the value of considering different dimensions of stigma. For example, approximately 15% of respondents reported having experienced one or more forms of external stigma but not internalized NSP so that in the absence of measures for external stigma they would be treated as individuals experiencing no HIV-related stigmatization.

The bivariate assessment of construct validity demonstrated that all components of stigma were significantly associated with self-reported physical and mental health, with stronger associations for the latter as found in other contexts ([16](#_ENREF_16), [50](#_ENREF_50)). Indicators of external stigma except for HCN were positively associated with disclosure; as TASO actively encourages disclosure it is plausible that real or perceived healthcare attention by its staff is better for those who have disclosed more fully. Associations between NSP and disclosure, while positive, were not significant unlike related findings for internalized stigma in Uganda ([62](#_ENREF_62)). Among the more objective health indicators (BMI, CD4 count, and healthcare provider-reported conditions), BMI was the only construct with a significant correlation and was negatively associated with NSP. Individuals who were diagnosed more recently (within the previous 12 months) reported lower VA but higher HCN, possibly reflecting less time having appeared ill and relatively more interactions with healthcare providers external to TASO. These correlations supported the validity of the stigma scales measured.

With the evidence in hand supporting the reliability and validity of the stigma scale in this context, we next examined the correlates of stigma in a multivariate context in the baseline cross-section for the intervention group to explore the potential mechanisms via which a food assistance intervention might influence stigma. When examining these models we put the spotlight on factors that themselves had been influenced by the intervention, and examined whether they were significantly associated with stigma in our specific context. After controlling for a wide range of background characteristics, HFIAS and PHS were negatively associated with NSP and self-reported physical symptoms was positively associated with it. For VA, however, only self-reported physical symptoms had a significant and positive association.

Based on these baseline associations, and previous literature, we hypothesized that the food assistance intervention, previously shown to have decreased food insecurity and self-reported symptoms, and increased PHS ([26](#_ENREF_26), [27](#_ENREF_27)), would decrease stigma. Additionally, the strength of the baseline associations suggested that there would be more scope for improving NSP relative to VA. Non-experimental matching results supported our hypothesis for overall stigma and all components of stigma other than VA. Effect sizes, however, were moderate—approximately 0.2 SD. Sensitivity analyses described in the statistical methods section, including the use of alternative matching variables and approaches, yielded similar results, supporting the internal validity of these findings.

In designing the intervention, there was concern that provision of food aid to households might actually *increase* stigmatization, if receipt of food was interpreted by others as an indication that the individual, or someone in the household, was HIV positive, in a fashion similar to inadvertent disclosure related to initiating ART ([15](#_ENREF_15)). For this reason, food was not provided at the clinic itself, but rather at a neutral distribution point unaffiliated with TASO. In addition, a number of questions about this possible phenomenon were asked in the baseline and follow-up to assess prior expectations, or anticipated stigma at baseline, and actual experiences later on. At baseline, 71% of subjects in Gulu indicated they were concerned that some people would learn of their HIV status because they were receiving food assistance and more than half indicated this might lead to insults and jealousy. At follow-up after having received food assistance, however, less than 5% indicated that this had actually happened. So while the vast majority had prior concern about food aid and inadvertent disclosure and resulting stigmatization, very few reported having experienced it. Nevertheless, the smaller and statistically insignificant impacts on VA also may be related to linkages between food receipt and stigma.

There are limitations to our study. First, with respect to our instrumental objective, we had no gold standard against which to evaluate the stigma components, although we did have a number of constructs shown in the literature to be associated with stigma and commonly used in other validation studies. Second, the sample was from only two district TASO clinics. While directly relevant for the assessment of the impact of the intervention, the sample was not necessarily representative of PLHIV in those districts. Moreover, an important component of the TASO model incorporates substantial psychosocial counseling around issues like disclosure and stigma, which may have led to lower reported stigma for this group, consistent with their lower levels relative to findings in the multi-country samples of the original validation study ([28](#_ENREF_28)) and another study in Gulu district in Uganda ([53](#_ENREF_53)). Perhaps even more importantly, the nature of the intervention (which may have led to inadvertent disclosure for some) or the nature of TASO counselling services provided in equal measure to intervention and comparison groups alike, may have muted the potential impacts of food assistance on stigma and as a consequence, the estimates reported here may be conservative.

Third, because the comparisons were not randomized and were drawn from a different district, it is possible that unobserved geographical, sociocultural, or other factors explain part of the observed differences in stigma over time between groups. Gulu district, for example, suffered more intensively from conflict during the civil war with higher likelihood of internal displacement ([31](#_ENREF_31)), though even before matching, the differences across districts in initial PHS and MHS, for example, were small (**Table 1**). Several features of the study help to minimize possible bias from these differences. These include that we 1) recruited subjects into intervention and comparison groups using identical criteria to mitigate potential program selection bias; 2) differenced the outcomes over time (thereby controlling for all district-level, as well as individual- and household-level, time invariant factors that enter the model additively); and 3) included a number of matching variables, many of which capture potentially important differences between the two geographic areas. Further reducing concern about bias introduced by geographic-specific confounders was the fact that sample individuals were not concentrated in small geographic areas within the two districts, living in more than 100 different villages or urban neighborhoods with about half residing more than 10 km away from the TASO clinic.

Last, a relatively large proportion of individuals (29%) were lost to follow-up, including 21% because they received ART during the study period, an exclusion criterion in the study. We examined baseline characteristics of individuals lost to follow-up, and found no significant differences across intervention and comparison groups so that attrition across the two groups was not evidently different on observable characteristics. Unsurprisingly, ART-related loss to follow-up was associated with lower initial CD4 counts—individuals with baseline CD4>350 were only half as likely to be lost to follow-up. In addition to inclusion of baseline CD4 in the propensity score prediction in the analyses, we also examined estimated effects on stigma for those with baseline CD4>350 (N=167) and found even larger point estimates. We interpret this as evidence that selective attrition is not driving our main results which may even be conservative, since loss to follow-up in this subsample was under 15%.

**Conclusions**

Using a sample of ART naive PLHIV, we provided evidence of the reliability and construct validity of the HASI-P stigma scale in the Ugandan context, complementing earlier validation work done for the scale elsewhere. This first result is important because monitoring stigma among PLHIV, and assessing interventions to reduce it, requires valid and comprehensive measures that go beyond measured internalized stigma. It is also relevant given the recent attention on the role ART plays in HIV-related stigma—any such assessments require stigma measures that are valid on an ART naive population, i.e., prior to initiation, to assess changes accurately.

We further demonstrated that a food assistance program, in combination with the comprehensive psychosocial counseling services offered by TASO, can reduce stigma (and, in particular, internalized stigma) in a highly food insecure population. This is important first because despite increased incorporation of food assistance components into HIV/AIDS programs, few studies have investigated the many potential benefits for PLHIV, including those on stigma, of continued relevance to the crisis. It is even more important, however, given the recent evidence that even with substantial progress in ART provision, stigma remains persistent—interventions with a greater focus on livelihoods or poverty may be necessary and we demonstrated that at least one such intervention had modest effects. It is plausible, but remains to be seen, that the combination of ART and food assistance or other anti-poverty interventions ([3](#_ENREF_3)) could lead to even greater reductions in stigma.

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| --- | --- | --- | --- |
| **Table 1. Selected Background Characteristics** |  |  |  |
|  | **Gulu** | **Soroti** | **Total** |
| *Individual* | (N=448) | (N=456) | (N=904) |
| Female, N (%)  | 338 (75.5%) | 309 (67.8%) | 647 (71.6%) |
| Marital or other partner, N (%) | 195 (43.5%) | 242 (53.1%) | 437 (48.3%) |
| Household head, N (%) | 292 (65.2%) | 324 (71.1%) | 616 (68.1%) |
| Spouse of household head, N (%) | 98 (21.9%) | 86 (18.9%) | 184 (20.4%) |
| Widow/er, N (%) | 164 (37%) | 130 (28.5%) | 294 (32.5%) |
| Age in years, mean (SD) | 37.9 (9.4) | 40.3 (9.7) | 39.1 (9.7) |
| Highest grade attained, mean (SD) | 4.7 (4.3) | 4.3 (4.4)  | 4.5 (4.3) |
| BMI (kg/m2), mean (SD) (N=900) | 20.9 (2.7) | 20.2 (2.8) | 20.5 (2.7) |
| Mid-upper arm circumference (mm), mean (SD) (N=902) | 269.2 (32.7) | 264.9 (27.4) | 267.0 (30.2) |
| CD4 count (cells/μL ), mean (SD) (N=903) | 339.8 (64.0) | 336.6 (62.4) | 338.2 (63.2) |
| Anemia, N (%) (N=742) | 154 (42.0%) | 143 (38.1%) | 297 (40.0%) |
| Time since HIV diagnosis (years), mean (SD) (N=903) | 2.1 (1.9) | 2.3 (1.7) | 2.2 (1.8) |
|  |  |  |  |
| *Household*, mean (SD) |  |  |  |
| Household size | 6.4 (2.5) | 6.3 (3.0) | 6.3 (2.8) |
| Per capita monthly food consumption (Ugandan Shillings) | 24461 (21179) | 32368 (20926) | 28445 (21409) |
| Per capita monthly consumption (Ugandan Shillings) | 40609 (31264) | 55738 (33405) | 48232 (33217) |
| Food share of household monthly consumption (fraction) | 0.6 (0.1) | 0.6 (0.1) | .6 (.1) |
| Distance to TASO clinic (km) | 8.1 (9.9) | 10.4 (8.5) | 9.1 (9.3) |
| Distance to nearest market (km) | 1.2 (1.6) | 2.2 (1.9) | 1.6 (1.8) |
|  |  |  |  |
| *Constructs potentially associated with stigma*, mean (SD) |  |  |
| Physical health summary score (PHS) | 45.9 (8.5) | 46.5 (7.4) | 46.2 (8.0) |
| Mental health summary score (MHS) | 45.4 (7.5) | 47.0 (7.1) | 46.2 (7.3) |
| Disclosure to family members (fraction) | 0.76 (0.27) | 0.82 (0.24) | 0.79 (0.26) |
| Disclosure to unrelated community members (fraction) | 0.65 (0.27) | 0.71 (0.25) | 0.68 (0.26) |
| Number of healthcare provider-reported physical conditions (0-17)a | 2.0 (1.7) | 1.9 (1.6) | 1.9 (1.7) |
| Number of self-reported physical symptoms (0-16)b | 7.6 (3.0) | 7.5 (3.1) | 7.5 (3.0) |
| Individual Dietary Diversity Scale (IDDS) | 3.7 (1.2) | 4.5 (1.2) | 4.1 (1.3) |
| Household Food Insecurity Access Scale (HFIAS) | 16.1 (4.4) | 14.3 (5.3) | 15.2 (5.0) |
| Notes: N=904 unless otherwise noted |  |  |  |
| a. Clinic-reported physical conditions: Includes tuberculosis, malaria, diarrhea, respiratory infections/difficulty breathing, syphilis, oral thrush/oral lesions, oral candidiasis, high fever, skin rash, cough, depression, fatigue, herpes zoster, genital herpes, vaginal candidiasis, weight loss, and vision problems. |
| b. Self-reported physical symptoms: Includes skin rash, body pains, dizzy/headaches, weakness/fatigue, insomnia, numbness (lack of sensation), reduced or loss of vision, fever, stomach upset, vomit, diarrhea, stomach ache, losing hair, loss of appetite, losing weight, and sunken cheeks. |





|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Table 4: HASI-P Stigma scale and subscales: Correlation with related constructs** |   |  |  |  |
|   | HRQOL |   | Disclosure |   | Health reports |  |   |   | Time HIV |
|   | Physical health summary score | Mental health summary score | Family members | Unrelated community members | BMI  | CD4  | Healthcare provider-reported conditions | Self-reported symptoms | Diagnosed within previous 12 months1 |
|  |  |  |  |  |  |  |  |  |  |
| Negative Self-Perception (NSP) | **-0.244** | **-0.305** | 0.032 | 0.062 | **-0.100** | -0.035 | 0.053 | **0.278** | 0.034 |
| p-value | <0.001 | <0.001 | 0.334 | 0.063 | 0.003 | 0.296 | 0.114 | <0.001 | 0.028 |
|  |  |  |  |  |  |  |  |  |  |
| Verbal Abuse (VA) | **-0.184** | **-0.264** | **0.155** | **0.187** | -0.047 | 0.006 | 0.050 | **0.287** | **-0.073** |
| p-value | <0.001 | <0.001 | <0.001 | <0.001 | 0.160 | 0.864 | 0.134 | <0.001 | 0.032 |
|  |  |  |  |  |  |  |  |  |  |
| Social Isolation (SI) | **-0.187** | **-0.249** | 0.062 | **0.111** | -0.042 | 0.022 | 0.076 | **0.255** | 0.001 |
| p-value | <0.001 | <0.001 | 0.064 | 0.001 | 0.212 | 0.517 | 0.023 | <0.001 | 0.021 |
|  |  |  |  |  |  |  |  |  |  |
| Fear of Contagion (FC) | **-0.166** | **-0.210** | **0.067** | **0.076** | 0.018 | -0.037 | 0.056 | **0.220** | 0.001 |
| p-value | <0.001 | <0.001 | 0.045 | 0.024 | 0.591 | 0.265 | 0.095 | <0.001 | 0.020 |
|  |  |  |  |  |  |  |  |  |  |
| Healthcare Neglect (HCN) | **-0.206** | **-0.182** | **-0.067** | -0.028 | 0.004 | -0.052 | **0.084** | **0.173** | **0.088** |
| p-value | <0.001 | <0.001 | 0.044 | 0.395 | 0.914 | 0.118 | 0.012 | <0.001 | 0.035 |
|  |  |  |  |  |  |  |  |  |  |
| Overall | **-0.283** | **-0.362** | **0.101** | **0.146** | **-0.067** | -0.021 | 0.083 | **0.364** | 0.008 |
| p-value | <0.001 | <0.001 | 0.002 | <0.001 | 0.044 | 0.535 | 0.013 | <0.001 | 0.021 |
|  |  |  |  |  |  |  |  |  |  |
| Notes: Numbers in bold indicate significant p<0.05 |  |  |  |  |  |  |  |
| 1.Point-biserial correlation coefficient and associated standard error calculated via bootstrapping with 10,000 repetitions |  |



**Table 6. Difference-in-Difference Average Treatment Effect on the Treated (ATT): Nearest Neighbor Matching Results for HASI-P stigma measures**

|  |  |  |
| --- | --- | --- |
|  | Effect (standard error) | 95% confidence interval |
|  |  |  |
| Negative Self-Perception (NSP) | **-0.135** | (0.057) | [-0.25, | -0.02] |
| Verbal Abuse (VA) | -0.056 | (0.054) | [-0.16, | 0.05] |
| Social Isolation (SI) | **-0.082** | (0.027) | [-0.13, | -0.03] |
| Fear of Contagion (FC) | **-0.045** | (0.020) | [-0.08, | -0.01] |
| Healthcare Neglect (HN) | **-0.037** | (0.012) | [-0.06, | -0.01] |
|  |  |  |  |  |
| Overall | **-0.066** | (0.017) | [-0.10, | -0.03] |
|  |  |  |  |  |

Notes: Intervention N=318, Comparison N=321. Standard error in parentheses, 95% confidence interval in square brackets. Numbers indicated in bold indicate significant p<0.05. All models match exactly on gender and match on the predicted propensity score, baseline measures of NSP and VA, and months between surveys.

|  |
| --- |
| **Table A1. Baseline survey variables used in constructing propensity score for matching** |
|   |  |
| *Individual background (Source: individual survey at clinic)* |
|   | Male (=1) |
|   | Had marital or other partner for at least two years (=1) |
|   | Widow/er (=1) |
|   | Age (logarithm of number of years) |
|   | Highest grade attained (number of grades) |
| *Individual measured health status (Source: individual survey at clinic)* |
|   | BMI (kg/m2) |
|   | Mid-upper arm circumference or MUAC (mm) |
|   | CD4 count (cells/μL) |
| *Individual self-reported health status, diet, and stigma (Source: individual survey at clinic)* |
|   | Little or no pain in previous month (=1) |
|   | Too ill to work in previous month (=1) |
|   | Individual dietary diversity score (IDDS) |
|   | Negative Self-Perception subscale score (HASI-P)1 |
|  | Verbal Abuse subscale score (HASI-P)1 |
| *Household background (Source: household survey at residence)* |
|   | Household Food Insecurity Access Scale (HFIAS score) |
|   | Logarithm of household size (number of members) |
|  | Dependency ratio (members aged 0-14 plus members aged 65 and over divided by members aged 15-64) |
|   | Per capita monthly consumption (logarithm of value in Ugandan Shillings [USh]) |
|   | Per capita monthly food consumption (logarithm of value in USh) |
|   | Food share of household monthly consumption (fraction) |
|   | Value of assets (logarithm of value in USh) |
|   | Other social program beneficiary in previous 12 months (=1) |
| *Distance from household to (Source: individual survey at clinic):* |
|   | TASO clinic (logarithm of km) |
|   | Nearest market (logarithm of km) |
| *Survey interview characteristics* |
|   | Time between baseline and follow-up survey interview (months and months squared)1 |
|   | Calendar quarter of follow-up survey interview (quarters 1 to 4) |

Notes: Units and transformation for balancing shown in parentheses.