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STIGMA AND HIV CARE CONTINUUM OUTCOMES AMONG ETHIOPIAN ADULTS INITIATING ART

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Abstract

Background—Stigma harms the mental health of HIV-positive individuals and reduces adherence to antiretroviral therapy (ART), but less is known about stigma and other outcomes across the HIV care continuum.

Methods—Among 1180 Ethiopian adults initiating ART at six urban HIV clinics, we examined the relationship of internalized, anticipated, and enacted stigma to HIV care-related outcomes ascertained by interview (repeat HIV-positive testing, provider vs. self-referred testing, missed clinic visit before ART initiation, eagerness to begin ART) and by abstraction of routinely collected clinical data (late ART initiation, 3-month gap in care following ART initiation). Logistic regression was used to assess the association of each type of stigma with each outcome, adjusting for potential confounders.

Results—Scoring higher on each stigma domain was associated with 50%–90% higher odds of repeat HIV-positive testing. High internalized stigma was associated with higher odds of provider vs. self-referred test (adjusted odds ratio [aOR]_{high vs. low}: 1.7; 95% confidence interval [CI]: 1.3–2.2). Higher anticipated stigma was associated with lower eagerness to begin ART (aOR_{high vs. low}: 0.55; 0.35–0.87; aOR_{medium vs. low}: 0.45; 95% CI: 0.30–0.69). Any enacted stigma was associated

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with higher odds of a missed visit (aOR_{any vs. none} 1.8; 1.2–2.8). Stigma was not associated with late ART-initiation or with a subsequent gap in care.

Discussion and Conclusion—These findings provide further evidence of the importance of measuring and addressing stigma across the entire care continuum. Future work should test hypotheses about specific stigma domains and outcomes in prospective intervention or observational studies.

Keywords

delayed testing; delayed linkage to care; late ART initiation; retention in care

INTRODUCTION

Thirty years into the HIV/AIDS epidemic, HIV-related stigma remains an ongoing challenge and a growing priority for intervention (1, 2). People living with HIV (PLWH) who experience high perceptions of HIV-related stigma are less likely to disclose their status (3–5); they report more psychological distress (6, 7) and lower social support (8, 9) than those with lower perceptions of HIV-related stigma. Stigma also has been associated with some outcomes along the HIV care continuum. Those who hold more stigmatizing attitudes toward PLWH are less likely to undergo HIV testing themselves (10–15), and high perceived stigma among those in HIV care is associated with poorer antiretroviral therapy (ART) adherence (16). However, evidence on whether stigma influences other care continuum outcomes is limited (17–23).

As conceptualized by Earnshaw and Chaudoir (24), stigma processes and outcomes differ between PLWH, who may experience stigma around being HIV-infected, and those who are HIV-negative (or do not know their status), who may hold stigmatizing views of PLWH. Among PLWH, stigma comprises three domains – internalized, anticipated, and enacted stigma. Few studies have examined the relationship of each of these domains to care-related outcomes. Understanding how stigma processes may influence outcomes across the HIV care continuum is important for guiding interventions to achieve the UNAIDS 90-90-90 targets, especially in sub-Saharan Africa, where significant gaps have been reported (25–27).

We used data from Ethiopian adults newly initiating ART to explore associations between stigma and important care-related outcomes. We hypothesized that higher stigma would be associated with indicators of delay in HIV testing and/or care enrollment/ART initiation, and sporadic use of care once enrolled/initiated on ART.

In Ethiopia, HIV prevalence declined between 2005 to 2013 (estimated 1.2% in adults), but in 2013 there were still 590,000 adult PLWH, only 50% of whom were receiving ART(28). HIV stigma indicators in 2011 were in the mid-range of sub-Saharan countries, with 17.1% of women and 27.6% men holding stigmatizing views(29).

METHOD

Participants and Data Sources

Data were drawn from a cross-sectional and prospective study of late initiation of ART described previously (30). PLWH 18 years of age newly initiating ART between June 2012 and April 2013 at six HIV clinics in Oromia, Ethiopia were eligible for inclusion. The sites were secondary health facilities in urban areas and receiving support from ICAP at Columbia University with funding from the U.S. President's Emergency Plan for AIDS Relief.

Clinic providers referred eligible patients to study staff on the day of ART initiation. Those interested in study participation provided written informed consent and completed a 45-minute structured interview within two weeks of ART initiation; participants received 20 birr (~ 1 USD) upon interview completion. Interview data were linked to an existing database that captured routinely collected clinical data on patients from the date of their enrollment in that clinic (or the date of their HIV-positive test if done at that clinic) up to 12 months after ART initiation. Data were de-identified prior to analysis. Ethical approval was obtained from the Oromia Regional Health Bureau, Columbia University, and the City University of New York.

Measures

Exposures

Internalized stigma: Internalized stigma was assessed with the 5-item negative self-perception subscale of the HIV/AIDS Stigma Instrument, PLWHA (HASI-P)(31), developed in sub-Saharan Africa. Items inquired how often over the previous three months participants, for example, *felt that you did not deserve to live, that you were no longer a person*, with response options ranging from *Never* (4) to *Most of the time* (1). An additional item not from this scale (*You thought someone had cursed you*) also was included (Cronbach's alpha=0.95). Scores were recoded so that higher scores represented higher internalized stigma. Because summary responses were skewed (mean = 1.55, median = 1.33), we categorized them into tertiles.

Anticipated stigma: Anticipated stigma was assessed with 12 items following the concept described by Earnshaw and Chaudoir (24), using the stem, *Do you think the following could happen if others know or suspect you are HIV-positive* (e.g., *your partner might get violent; your children might be abused or discriminated against; family members might treat you differently*), with *yes/no* response options (Cronbach's alpha=0.76). A total anticipated stigma score was constructed as the proportion of endorsed items from among all questions the participant was eligible to answer (i.e., participants without children or without a partner were not eligible to answer those items), and the score was categorized into tertiles.

Enacted Stigma: Enacted stigma was measured with nine items selected from HASI-P (31) subscales (verbal abuse, fear of contagion, and social isolation); items inquired how often in the prior three months the participant had experienced rejection because of his/her HIV status (e.g., *You were told that you have no future, You were told that God is punishing you*,

Someone stopped being your friend), with response options ranging from *Never* (4) to *Most of the time* (1) (Cronbach's $\alpha = 0.99$). Because the reported occurrence of all items was low, the summary measure was re-coded as *any* vs. *none*.

HIV care continuum outcomes—Outcomes included six care-related indicators that were ascertained in the study and thought potentially to be influenced by stigma: (1) a repeat HIV+ test prior to enrolling in care, a possible indicator of delayed enrollment; (2) provider- vs. self-initiated testing, a possible indicator of delayed diagnosis; (3) a missed clinic visit prior to ART initiation; (4) eagerness vs. reluctance to initiate ART; (5) late ART initiation (initiating ART with advanced disease); and (6) 3-month gap in care after ART initiation.

By interview, participants were asked the date of their most recent HIV-positive test, and if they had previously tested HIV-positive; those who did were characterized as having a repeat HIV-positive test. For this variable, we excluded 349 participants for whom it was not possible to determine which test occurred first or if they reported a test date after their HIV clinic enrollment date. To determine who initiated testing, participants were asked if they sought the test on their own, or it was offered by a provider including as part of PMTCT services. They were additionally asked if they had missed a clinic visit before initiating ART (*ever/never*), and about their eagerness to start ART (5 response options dichotomized into [*somewhat/very eager*] vs. [*somewhat/very reluctant or neither reluctant nor eager*]). Outcomes ascertained from electronic medical record data were late ART initiation, defined as CD4+ count <150 cells/ μ l or WHO stage IV at ART initiation (30), and a gap in HIV care of 3 months or more in the year after ART initiation. Participants (N=146) who had no opportunity to experience a 3-month gap in care because they were lost to follow-up, transferred out, or had died before three months on ART were excluded from this variable.

Potential confounders—Time from diagnosis in months was ascertained from the earliest self-reported date of HIV-positive test or the diagnosis date noted in the medical record to date of interview. Other measures examined as potential confounders were age, gender, education, religion, relationship status, widowhood, residence location (rural/urban), employment status, and food insecurity.

Statistical Analyses

Pairwise correlations between stigma domain measures were assessed with Spearman correlation coefficients. Bivariate associations between stigma and potential confounders were evaluated using chi-squared statistics for categorical variables, and Mann-Whitney U and Kruskal Wallis tests for skewed continuous data. Logistic regression was used to model change in the log odds of each care continuum outcome associated with high and medium versus low stigma in each domain (or any vs. no enacted stigma). Time from diagnosis was included *a priori* as a confounder because it could be associated with lower stigma and poorer care continuum outcomes. Other potential confounders that were significantly associated with stigma and altered the crude estimate of association were retained in the adjusted models.

RESULTS

Description of the population

Of 1180 study participants, clinical data for up to one year following ART initiation was available for 1179. As described above, 831 were available for analysis of repeat HIV-positive testing and 1033 participants were available for analysis of a 3-month gap in care following ART initiation. Among the 1180, mean age was 34 years, interquartile range (IQR) 28–40; the median length of time since diagnosis was 8.3 months (IQR: 1.1 months–3.4 years). Median time since enrollment in care was 2.9 months (IQR: 15 days–2.6 years). Other sample characteristics are shown in Table 1.

The mean internalized stigma score was 1.55 (SD: 0.57); the median was 1.33 (IQR: 1–2) (possible range: 1–4) (Table 1). The mean anticipated stigma score was 26.9 (SD: 22.60); the median was 22.22 (IQR: 9.09–44.44) (possible range: 1–100), indicating that on average individuals endorsed approximately one-quarter of possible anticipated stigma concerns. The most frequently-cited concerns were *people might start gossiping about you* (62.0%) and *your children might become upset or fearful* (52.2%) (data not shown). Experiencing any enacted stigma in the past three months was reported by 16.3% of participants. Internalized stigma was correlated with both anticipated ($\rho = 0.422$, $p < 0.0001$) and enacted stigma ($\rho = 0.196$; $p < 0.0001$), but anticipated and enacted stigma were not significantly correlated ($\rho = 0.040$, $p = 0.1651$) (data not shown).

Stigma and care continuum outcomes

Internalized stigma—High vs. low internalized stigma was significantly associated with higher odds of having had more than one HIV-positive test (vs. one HIV-positive test) (adjusted odds ratio [aOR]: 1.8; 95% CI: 1.1–3.1); higher odds of provider-(vs. self-) initiated testing (aOR: 1.7; 95% CI: 1.3–2.2); and lower odds of a missed visit (vs. none) (aOR: 0.63; 95% CI: 0.40–0.98) (Table 2). Internalized stigma was not associated with late ART initiation, eagerness to begin ART, or a 3-month gap in care.

Anticipated stigma—Higher levels of anticipated stigma were significantly associated with higher odds of a repeat HIV-positive test (vs. one HIV-positive test) (aOR_{medium vs. low}: 1.9; 95% CI: 1.1–3.2); and lower odds of being eager (vs. reluctant) to begin ART (aOR_{high vs. low}: 0.55; 95% CI: 0.35–0.87; aOR_{medium vs. low}: 0.45; 95% CI: 0.30–0.69). Anticipated stigma was not associated with provider- vs. self-initiated test, a missed visit prior to ART initiation, late ART initiation, or a 3-month gap in care following ART initiation.

Enacted stigma—Experiencing any vs. no enacted stigma was significantly associated with higher odds of a repeat HIV-positive test (vs. one HIV-positive test) (aOR: 1.9; 95% CI: 1.1–3.2), and higher odds of a missed visit prior to ART initiation (aOR: 1.8; 95% CI: 1.2, 2.8). Enacted stigma was not associated with any of the other outcomes.

DISCUSSION

In a large population of PLWH initiating ART in Ethiopia, measures of internalized, anticipated, and enacted stigma were associated with several outcomes across the HIV care continuum: high internalized stigma with a provider- vs. a self-initiated HIV-test, possibly indicating delayed testing; higher internalized and anticipated stigma with repeat testing after an HIV-positive result, possibly indicating delayed enrollment in care; higher anticipated stigma with reluctance to initiate ART; and enacted stigma with missing a clinic visit prior to ART initiation.

These findings support emerging evidence that beyond reducing ART adherence, stigma influences other care continuum outcomes. Although data were collected prior to the most recent expansion of ART access, the study encompassed a period of expanding access (30). A limitation is that temporality cannot be established for the associations of stigma with repeat testing and provider- vs. self-initiated testing, as these outcomes were ascertained concurrently with stigma but they occurred earlier. Additionally, repeat testing and provider-initiated testing are only potential indicators of delayed testing and delayed enrollment in care. It is notable, however, that higher anticipated stigma, assessed close in time to ART initiation, was associated with greater reluctance to initiate. We are unsure why no stigma measure was associated with late ART initiation, but this outcome has multiple causes (30). Finally, the population in this study was restricted to those initiating ART, thereby excluding those lost at earlier stages of the care continuum. Overall, scores on stigma measures were low, especially enacted stigma, for which only 16% of participants reported an event. Although internalized and enacted stigma were assessed with reliable scales developed in sub-Saharan Africa (31), they may lack sensitivity for some outcomes. Further, anticipated stigma was newly-developed and had acceptable but lower internal consistency reliability ($\alpha = 0.76$) than the other stigma measures.

Despite these limitations, our study had several strengths: the large sample size, the distinct domains of stigma assessed, and the range of outcomes examined. The findings provide further support for the importance of investigating and addressing stigma across the entire HIV care continuum, especially given the need for effective stigma reduction interventions (32, 33). Future research should examine care continuum outcomes prior to ART initiation, refine the anticipated stigma measure, and assess specific hypotheses about the association of each measure with important HIV care continuum outcomes prospectively or in the context of an intervention.

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Table 1

Characteristics of the population and associations with internalized, anticipated, and enacted stigma among 1180 Ethiopian adults at ART initiation, 2012–2013

		Internalized stigma			Anticipated stigma			Enacted stigma		
		N (%)	Mean (SD)	p-value	Overall concern score, mean (SD) (0–100%)	p-value	% Yes	p-value		
Overall			1.55 (0.57)	.	26.9 (22.6)	.	16.3	.		
Gender	Male	458 (38.8 %)	1.57	0.169	27.5	0.498	17.4	0.451		
	Female	722 (61.2)	1.53		26.5		15.7			
Age	18–29	374 (31.7)	1.49	0.253	25.4	0.111	15.3	0.610		
	30–49	720 (61.0)	1.58		28.1		17.2			
	>=50	86 (7.3)	1.58		23.7		14.0			
Current religion	Ethiopian Orthodox	824 (70.4)	1.53	0.878	27.7	0.036	15.5	0.556		
	Protestant	239 (20.4)	1.58		24.1		17.7			
	Moslem	108 (9.2)	1.59		28.5		18.5			
Highest level of school completed	None	374 (31.8)	1.56	0.549	26.8	0.646	14.4	0.037		
	Any primary	473 (40.2)	1.57		27.0		20.3			
	Any secondary	237 (20.0)	1.52		28.3		13.7			
	Any tertiary	82 (7.0)	1.50		24.3		9.9			
	Vocational or other	11 (0.01)	1.50		19.4		18.2			
Currently in a relationship	Yes	673 (57.0)	1.52	0.133	24.7	<0.001	15.2	0.233		
	No	507 (43.0)	1.59		29.8		17.8			
Ever widowed	Yes	293 (25.9)	1.53	0.472	26.7	0.888	17.1	0.488		
	No	839 (74.1)	1.56		26.5		15.4			
Working for cash/other payment	Cash	780 (66.2)	1.57	0.088	29.5	<0.001	16.5	0.648		
	Cash & in-kind	97 (8.2)	1.51		12.4		19.6			
	In-kind	27 (2.3)	1.70		22.4		18.5			
	Not working for cash or in-kind	274 (23.3)	1.50		25.0		14.3			

	Internalized stigma			Anticipated stigma			Enacted stigma	
	N (%)	Mean (SD)	p-value	Overall concern score, mean (SD) (0–100%)	p-value	% Yes	p-value	
Residence								
Rural	259 (22.0)	1.61	0.118	26.0	0.358	17.1	0.707	
Urban	920 (78.0)	1.53		27.1		16.1		
How often did HH have trouble satisfying food needs in last year								
Never	422 (35.9)	1.43	<0.001	18.7	<0.001	13.3	0.002	
Seldom	157 (13.4)	1.57		23.5		18.5		
Sometimes	345 (29.3)	1.57		34.1		13.5		
Often	240 (20.4)	1.71		33.0		23.3		
Always	12 (1.0)	1.93		27.0		33.3		
Time since diagnosis								
< 3 months	473 (40.1)	1.61	0.002	26.9	0.181	11.9	0.002	
3–12 months	165 (14.0)	1.58		29.6		21.8		
> 12 months	542 (45.9)	1.49		26.0		18.5		

* statistically significant (p<0.05) tests in bold (Mann-Whitney U, Kruskal Wallis tests for internalized and anticipated stigma; chi-squared tests for enacted stigma)

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	Eagerness to begin ART			Late initiation of ART			3-month gap in care in 1st year on ART					
	Some- what or very eager	Very/some- what reluctant/ neither way	OR	aOR	Yes	No	OR	aOR	Yes	No	OR	aOR
Bottom tertile (least stigma)	89.8	10.2	ref	ref	30.2	69.7	ref	ref	9.8	90.2	ref	ref
Middle tertile	79.0	21.0	0.43 (0.28–0.64)	0.45 (0.30–0.69)	30.0	70.0	1.0 (0.73–1.4)	0.98 (0.71–1.3)	10.1	89.9	1.1 (0.75–1.5)	1.1 (0.76–1.6)
Top tertile (most stigma)	81.2	18.8	0.49 (0.32–0.76)	0.55 (0.35–0.87)	33.0	67.0	1.1 (0.83–1.6)	1.0 (0.74–1.5)	7.4	92.6	0.97 (0.66–1.4)	1.0 (0.68–1.5)
Enacted stigma												
None	83.4	16.6	ref	ref	30.8	69.2	ref	ref	13.8	86.2	ref	ref
Any	80.2	19.8	0.81 (0.54–1.2)	0.80 (0.53–1.2)	32.8	67.2	1.1 (0.79–1.5)	1.2 (0.85–1.7)	8.4	91.6	0.92 (0.61–1.4)	0.94 (0.62–1.4)

In logistic regression (OR, aOR estimates), the modeled outcome category is underlined in the top row

Models adjusted for time since diagnosis, relationship status, and food security. Each stigma-specific model is separate (i.e. other types of stigma were not adjusted for)