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Depression is not an Inevitable Outcome of Disclosure Avoidance: HIV Stigma and Mental Health in a Cohort of HIV Infected Individuals from Southern India

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Abstract

Previous research has shown that HIV stigma in India can be characterized by a framework dividing manifestations into enacted (discrimination), vicarious (hearing stories of discrimination), felt normative (perceptions of stigma's prevalence) and internalized stigma (personal endorsement of stigma beliefs). We examined if this framework could explain associations among stigma, efforts to avoid HIV serostatus disclosure, and depression symptoms in a cohort of 198 HIV-infected individuals from southern India who were followed for one year as part of a study of antiretroviral adherence. Prior studies had suggested that disclosure avoidance was a primary outcome of stigma and that impaired well-being was a primary outcome of disclosure avoidance. Analyses from our longitudinal research revealed that the pattern of associations among stigma, disclosure avoidance, and depression symptoms remained consistent over time. Enacted and vicarious stigmas were correlated with felt normative stigma beliefs. In turn, felt normative stigma was correlated with disclosure avoidance. And enacted stigma, internalized stigma, and disclosure avoidance were all associated with depression symptoms. However, even though the overall framework held together, internalized stigma and depression symptoms dropped significantly over time while other components remained unchanged. These findings suggest that, although HIV stigma may limit disclosure, it does not invariably lead to psychological maladjustment. Amidst ongoing perceptions and experiences of stigma, HIV-positive individuals can achieve significant improvements in their acceptance of the disease and in mental wellbeing.

Stigma has profound effects on the lives of people living with HIV. It results in prejudice, discounting, discrediting, and discrimination toward individuals perceived to have the disease (Herek, Capitanio, & Widaman, 2002; Herek et al., 1998; Mahajan et al., 2008; Tewksbury & McGaughey, 1997). Our research team previously reported that a multi-component framework was appropriate for characterizing stigma-related experiences among HIV-infected individuals in India (Steward et al., 2008).

According to the framework, stigma is divided into four categories. Two categories involve *interpersonal* manifestations. *Enacted stigma* refers to overt personally-experienced

instances of hostility and discrimination (Scambler, 1989; Steward et al., 2008). *Vicarious stigma* is embodied in knowledge of stories and events that illustrate how others with HIV have been mistreated (Steward et al., 2008). The final two categories are *intrapersonal* manifestations. *Felt normative stigma* refers to people's beliefs about the prevalence of prejudicial attitudes in the local community (Scambler, 1989; Steward et al., 2008). *Internalized stigma* is the degree to which HIV-infected individuals personally endorse stigmatizing beliefs (Herek, 2008; Jones et al., 1984; Steward et al., 2008).

Our prior work showed that all forms of stigma are ultimately associated with symptoms of depression (Figure 1). The focus of these earlier cross-sectional analyses was testing the pathway by which interpersonal forms (enacted, vicarious) shape felt-normative stigma beliefs that, in turn, promote efforts to avoid disclosure of HIV status and lead to depression symptoms (Steward et al., 2008). This interest in mediation was prompted by research showing that disclosure avoidance is a principal outcome of HIV stigma (Chandra, Deepthivarma, & Manjula, 2003) and that hiding one's stigmatized status impairs overall well-being (Diaz, Ayala, Bein, Henne, & Marin, 2001; Hays et al., 1993; Herek & Capitanio, 1999; Simbayi et al., 2007).

Unfortunately, because our work was cross-sectional, we could not draw conclusive findings about temporal trends and causal relationships (Steward et al., 2008). In fact, relatively few investigators have looked at HIV stigma longitudinally, despite extensive research efforts (Franke et al., 2010; Genberg et al., 2008; Holzemer et al., 2007; Kalichman et al., 2009; Van Rie et al., 2008; Zelaya et al., 2008). The examples that do exist reveal a complicated picture. In Botswana, scientists gathered data from two population-based samples recruited several years apart. The researchers observed that HIV-related prejudicial attitudes and discriminatory experiences had decreased significantly, perhaps because of the increasing availability of treatment (Wolfe et al., 2008). Other scientists followed for one year a cohort of over 1400 people from five African countries and found that stigma declined and quality of life improved (Greef et al., 2010). And in Thailand, HIV stigma measurements were repeated with participants, but test-retest correlations were only moderate (Van Rie et al., 2008). These findings point to a potentially complicated and shifting pattern of stigma, and highlight the importance of examining attitudes and discrimination over time.

We previously demonstrated that our proposed framework for stigma (Figure 1) was valid at one assessment. For maximum utility, the observed relationships would need to remain valid over time. As such, in this paper, we report on the perceptions and experiences of stigma among a cohort of HIV-infected individuals in southern India followed for one year.

Method

Participants were recruited as part of a study of adherence to antiretroviral therapy (ARV) (Ekstrand, Chandy, Heylen, Steward, & Singh, 2010). All enrolled individuals were 18 years of age or older, HIV-seropositive, and had taken ARV medications for at least one month prior to recruitment. Most respondents were referred via the outpatient general medicine department of an urban, private hospital. A screener in the medical records department flagged the charts of potentially eligible individuals, who were then invited by a nurse to meet with a project interviewer while waiting for their appointment. The remaining patients were informed of the study by providers at local non-governmental agencies (NGO) and referred to study personnel for participation. All participants met privately with a study interviewer, who described the research's purpose and obtained informed consent.

Procedures

Participants completed interviewer-administered surveys at enrollment and during follow-up visits held every three months. Stigma assessments were completed at the baseline, six-month follow-up, and 12-month follow-up visits. As such, data from only those three observations are presented here. The survey lasted one hour and assessed demographics, HIV stigma, disclosure avoidance, and psychological well-being. It was completed in Kannada, Telugu, Tamil, or English. Instruments were developed in English, translated into the Indian languages, and independently back-translated into English to ensure semantic equivalence (Marín & Marín, 1991). Interviewers were instructed to administer the surveys by reading the questions exactly as they were printed on the page. To meet ethical responsibilities, interviewers were permitted after the survey was completed to correct misinformation and clarify basic questions about HIV (e.g., methods of transmission). Participants with queries about treatment were referred to physicians.

Stigma Assessments—The complete assessments were published previously (Steward et al., 2008). Brief descriptions are provided here.

Enacted Stigma: Ten items measured whether participants had experienced discriminatory acts because of HIV (example: *Has someone threatened to hurt you physically because you have HIV?*). Response options were 0 (*no*) or 1 (*yes*) (Steward et al., 2008). There was little reason to believe that responses would be driven by a single underlying construct. (Hence, calculations of inter-item reliability are not appropriate.) Instead, we treated the measure as an index of past experience and scored it by summing item responses.

Vicarious Stigma: Ten items captured the frequency with which participants had heard about people being mistreated because of HIV (example: *How often have you heard stories about people being forced by family members to leave their home because they had HIV?*) (Steward et al., 2008). Responses ranged from 0 (*never*) to 3 (*frequently*). Answers were averaged for scoring (Cronbach's $\alpha = .88$).

Felt Normative Stigma: Ten items assessed participants' perceptions of the prevalence of HIV stigmatizing attitudes (Steward et al., 2008). (Example: *In your community, how many people avoid visiting the homes of people with HIV?*) Responses were provided on a 4-point scale ranging from 0 (*no one*) to 3 (*most people*). Answers were averaged for scoring ($\alpha = .93$).

Internalized Stigma: Ten items captured whether participants believed that they should be treated in a discriminatory manner or be a target of stigmatizing beliefs (Steward et al., 2008). Using a 4-point scale running 0 (*not at all*) to 3 (*a great deal*), participants responded to questions such as, *How much do you feel that you should avoid visiting people because of your HIV?* Items were averaged for scoring ($\alpha = .81$).

Other Assessments

Disclosure Avoidance: We developed a 14-item measure that assessed the use of strategies to avoid revealing one's HIV infection (Steward et al., 2008). Examples included describing one's illness as tuberculosis and seeking care outside the local community. Participants used a 4-point scale ranging from 0 (*never*) to 3 (*often*) to indicate the frequency with which they employed each disclosure-avoidance technique. Scores were derived by averaging responses ($\alpha = .81$).

Beck Depression Inventory: To assess depression symptoms, we included a variant of the Beck Depression Inventory, Version I (BDI) ($\alpha = .91$) that had been validated previously in

Southern India (Chandra et al., 2006). The Indian BDI uses the same items as found in the United States, but with minor wording modifications to reflect local cultural norms or to make statements more understandable in local languages.

Participant demographic characteristics: Individuals were asked to describe their gender, age, marital status, employment status, monthly income, years of education, and religion.

Analyses—We initially used descriptive statistics to examine temporal patterns on each measure. Differences in mean scores across assessments were tested with repeated-measures t-tests, and longitudinal (test-retest) reliabilities were calculated with Pearson product-moment correlations.

We then used two approaches to examine the longitudinal validity of our framework (Figure 1). First, we explored if it represented a causal model by examining whether cross-wave associations corresponded with the framework's hypothesized order of events. Specifically, we used Pearson product-moment correlations to determine if stigma at earlier assessments was associated with disclosure avoidance at later assessments, and if disclosure avoidance at earlier time points was correlated with subsequent reports of depression symptoms.

Second, we treated the associations in Figure 1 as cross-sectional and looked to see if they remained consistent over time. For these analyses, we used generalized estimating equations (GEE) (Stata SE, 2007) and included data from all time points. To account for changes over time, assessment wave was included as a model predictor. GEE enabled us to adjust standard errors for clustering due to repeated observations of each participant.

Results

Two hundred twenty-nine individuals were enrolled in the study. Of these, 198 (86%) completed the baseline (T1), six-month follow-up (T2), and twelve-month follow-up visits (T3). Participants who completed all three waves were more likely than others to have spoken Kannada (81.3% vs. 64.5%, $\chi^2(1) = 5.81, p < .02$). This difference was likely due to Kannada being the dominant language among individuals living in cities and towns nearer the hospital. Most participants were male (68.2%), married (76.3%), employed (72.2%), Hindu (87.4%), and had 10 or fewer years of education (60.6%). They had a mean age of 37.5 years (range: 23–74) and a mean income of 4,600 rupees per month (range: 0–22,000). Participants had been on ARVs for 1 month to 10 years, with 73% having initiated treatment within the previous two years. Individuals who had been on treatment for longer were older ($r(198) = .28, p < .01$) and more likely to have had at least 11 years of education ($r_{pb}(198) = .17, p < .05$). Compared to individuals recruited at the hospital, those recruited from NGOs were on average younger (35.7 vs. 38.9 years of age, $F(1,196) = 5.79, p < .02$), had less income (3132 vs. 5600 rupees per month, $F(1,156) = 12.84, p < .001$), and more likely to be female (42% vs. 25%, $\chi^2(1) = 6.00, p < .02$). Because recruitment site was related to participant characteristics, it was included as a predictor in analytic models.

Temporal Trends

Figure 2 displays mean scores on the stigma, disclosure avoidance, and BDI measures across time points. There were two distinct temporal patterns. Four measures—enacted stigma, vicarious stigma, felt-normative stigma, and disclosure avoidance—displayed relatively flat patterns. Mean scores had no significant change from T1 to T2. For three of these measures, scores then increased significantly from T2 to T3 (vicarious stigma: $t(197) = 3.29, p < .01$; felt stigma: $t(197) = 3.05, p < .01$; disclosure avoidance $t(197) = 3.05, p < .01$). However, only vicarious stigma showed a statistically significant change from the baseline to final assessment ($t(197) = 2.35, p < .05$). By contrast, internalized stigma and the BDI had clear

downward trends over time, with scores progressively and significantly decreasing across the three assessments (internalized stigma change from T1 to T3: $t(197) = -6.59, p < .001$; BDI change from T1 to T3: $t(197) = -9.15, p < .001$).

As indicated by Table 1, there were only moderately-sized test-retest correlations. These findings indicate that *individual participants'* responses were varying to some degree from one assessment to the next, even though *average* levels across participants remained relatively constant on most of the measures.

Framework Associations

As noted earlier, we employed two approaches to examine the longitudinal validity of the framework. First, we considered whether the hypothesized associations formed a causal model. For this to be the case, earlier assessments of constructs “upstream” in the framework would need to be associated with later assessments of constructs “downstream” in the framework. However, the basic pattern of associations did not support this interpretation, and obviated the need for more advanced modeling. As seen in Table 2, there were inconsistent correlations between stigma constructs assessed at earlier time points, and disclosure avoidance and depression symptoms assessed at later time points. Similarly, there were inconsistencies in the associations between disclosure avoidance and BDI scores. Depression symptoms at the six-month follow-up were associated with disclosure avoidance efforts at baseline ($r(198) = .30, p < .001$). But depression symptoms at the 12-month follow-up were not significantly related to disclosure avoidance at baseline ($r(198) = .10, p = .19$) or six-month follow-up ($r(198) = .12, p = .10$).

Our second approach used GEE to test whether the associations in Figure 1 were cross-sectional and held together consistently over time. Table 3 presents the outcomes of three analyses. Model A demonstrates that enacted and vicarious stigmas remained significant predictors of felt-normative stigma across observations. Model B shows that felt normative and internalized stigmas continued to be significant predictors of disclosure avoidance. And Model C indicates that enacted stigma, internalized stigma, and disclosure avoidance remained significant predictors of depression symptoms, even after accounting for temporal changes in BDI scores. As shown in Table 4, an additional model revealed that felt normative stigma was significantly associated with depression (Model D). However, when disclosure avoidance was added to the analysis (Model E), the association between felt normative stigma and depression dropped to nonsignificant levels, indicative of mediation. These findings are fully consistent with our framework.

Discussion

The findings demonstrate that our framework remains a valid model for understanding HIV stigma in India even amidst changes in internalized stigma and depression symptoms. HIV-infected people on treatment who experience discrimination (enacted stigma) and who believe stigma against them is just (internalized stigma) are more likely to report symptoms of depression. In addition, experiences of discrimination (enacted stigma) and hearing stories about others being mistreated because of HIV (vicarious stigmas) correlate with the perception that stigma is more prevalent in the local community (felt normative stigma). These perceptions are in turn associated with efforts to avoid disclosure of one's HIV status and with reports of depressive symptoms.

The strong and consistent association between internalized stigma and depression symptoms highlights the important role that this form of stigma may play in mental health. Depression is hallmarked by a pattern of thinking in which negative events are seen as resulting from personal failings (e.g., “a bad thing happened because of me”), whereas positive events are

considered a byproduct of outside forces (e.g., “something good happened because of luck”) (Peterson, 1988; Peterson, Seligman, & Vaillant, 1988). Internalized stigma, which by definition consists of beliefs justifying why one deserves to be a target of prejudice, fits perfectly within this attributional typology and would serve to reinforce depressive feelings.

What remains less clear is the directionality of the associations. The predictions outlined in Figure 1 did not form a unidirectional causal model. Earlier observations of upstream constructs (e.g. baseline reports of stigma) were not consistently associated with later observations of downstream constructs (e.g., follow-up reports of disclosure avoidance and depression symptoms). These findings may be a limitation of the measurement tools. Our instruments do not impose time-limited recall periods (e.g., “in the last six months”), which reduces their precision. Furthermore, it is possible that the six month spacing between assessments was simply too large to detect clear temporal relationships.

Although the findings did not establish a causal pathway across time, the data successfully demonstrated that the cross-sectional associations depicted in Figure 1 were reliably observed from assessment to assessment. The stability of the data pattern suggests that the constructs mutually influence and reinforce one another (i.e., the arrows in Figure 1 are best thought of as bidirectional). It may strike some as odd to think of vicarious and enacted stigmas as part of a mutually reinforcing system, given that these measures relate to prior experience. But human memory is known to be influenced by mood and cognitive associations (Higgins, 1996; Parrott & Spackman, 2000). A person who hears stories about people experiencing discrimination or who believes there is substantial prejudice in the local community may be more likely to remember events as stigmatizing or to attribute experiences to discrimination.

Although mean scores for internalized stigma and depression symptoms decreased over time, their pattern of associations with other framework components remained unchanged. This suggests that the reductions in the two constructs over the year were due to other unmeasured factors. The data that we collected do not allow us to determine conclusively what those other factors might be. But one possibility is that the study, itself, served as a type of intervention. Reporting regularly on experiences may have altered participants’ personal attitudes and feelings.

Regardless of what led to the decline of internalized stigma and depression symptoms, the work has important implications. Previous research had suggested that disclosure avoidance was an outcome of stigma (Chandra et al., 2003) and that psychological distress was a primary outcome of disclosure avoidance (Diaz et al., 2001; Hays et al., 1993; Herek & Capitanio, 1999; Simbayi et al., 2007). Our findings points to a more nuanced picture. They suggest that it isn’t necessary for stigma among local community members to change before a patient on treatment can experience improvements in mental health. This conclusion is of much practical value given the nature of the epidemic. In high prevalence settings, such as sub-Saharan Africa, ARV rollouts are leading to changes in stigma at a community-wide level (Wolfe et al., 2008). But in India, where prevalence is low (WHO & UNAIDS, 2008), the experience of having HIV is hallmarked by isolation and feeling different from others (Steward et al., 2008). It is less clear if the rollout of ARV treatment can alter such dynamics. It is thus vital to find ways to enhance the wellbeing of infected individuals, even in the absence of stigma reduction among community members. The strong association between internalized stigma and depression offers one promising direction for intervention. By challenging HIV-positive individuals’ own hostile attitudes toward the disease, it may be possible to improve their overall psychological health.

Stigma continues to influence strongly the lives of people with HIV. However, its tendency to silence and isolate infected individuals does not inevitably lead to psychological maladjustment. Even amidst continuing perceptions and experiences of stigma, HIV-positive individuals on treatment can achieve significant improvements in their acceptance of the disease and in their mental wellbeing.

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Figure 1. Framework describing relationships among component of stigma, disclosure avoidance, and depression
 From Steward et al., 2008

Figure 2. Mean scores on stigma, disclosure avoidance, and depression symptom measures across three waves of data collection

Notes: T1 = baseline assessment; T2 = 6 month follow-up assessment; T3 = 12 month follow-up assessment To present all measures on a common metric, BDI scores were divided by 10. For example, a BDI score of 10 would be graphed as 1.0 in the figure above.

Table 1

Test-retest reliabilities of stigma components, disclosure avoidance, and depression symptoms

Measure	Between T1 & T2	Between T2 & T3	Between T1 & T3
<i>Enacted Stigma</i>	0.51	0.65	0.45
<i>Vicarious Stigma</i>	0.57	0.54	0.43
<i>Felt-Normative Stigma</i>	0.26	0.38	0.35
<i>Internalized Stigma</i>	0.35	0.41	0.34
<i>Disclosure Avoidance</i>	0.30	0.49	0.31
<i>Depression Symptoms (BDI)</i>	0.38	0.47	0.32

Note: All correlations significant at $p < .01$

Table 2

Correlations Between Stigma at Earlier Time Points, and Disclosure Avoidance and Depression Symptoms at Later Time Points

Stigma Measures at Baseline	<i>6-MONTH FOLLOW-UP</i>		<i>12-MONTH FOLLOW-UP</i>	
	Disclosure Avoidance	Depression Symptoms	Disclosure Avoidance	Depression Symptoms
Enacted Stigma	0.102	0.148*	0.175*	0.104
Vicarious Stigma	0.002	0.097	0.002	0.064
Felt Stigma	0.054	0.243*	0.133	0.224*
Internalized Stigma	0.154*	0.257*	0.180*	0.124

Stigma Measures at 6-month Follow-up	<i>12-MONTH FOLLOW-UP</i>	
	Disclosure Avoidance	Depression Symptoms
Enacted Stigma	0.054	0.122
Vicarious Stigma	−0.114	0.036
Felt Stigma	0.061	0.087
Internalized Stigma	0.196*	0.183*

Note. The numbers in the table are Pearson product-moment correlations. We also examined all associations using logistic regression models that controlled for participant recruitment site (hospital vs. NGO). Doing so did not substantively alter the observed pattern of results or change our conclusion that the pattern of data did not support an interpretation of the framework (Figure 1) as a causal model.

Table 3

GEE Models Examining Whether Key Associations in Framework Remained Consistent Across Observations

GEE MODEL A: Predicting Felt Normative Stigma¹

Explanatory Variable	Coefficient	Semi-Robust Standard Error [*]	z	95% CI ^{**}
Recruited at Hospital (vs. NGO)	-0.149	0.086	-1.730	(-0.317, 0.020)
Data Collection Wave	0.034	0.043	0.800	(-0.050, 0.118)
Enacted Stigma	0.116	0.050	2.310	(0.018, 0.214)
Vicarious Stigma	0.525	0.052	10.020	(0.422, 0.628)
Enacted Stigma*Wave	-0.037	0.019	-1.950	(-0.074, 0.000)

GEE MODEL B: Predicting Disclosure Avoidance²

Explanatory Variable	Coefficient	Semi-Robust Standard Error [*]	z	95% CI ^{**}
Recruited at Hospital (vs. NGO)	0.178	0.061	2.910	(0.058, 0.297)
Data Collection Wave	0.055	0.026	2.100	(0.004, 0.107)
Felt Normative Stigma	0.164	0.028	5.840	(0.109, 0.220)
Internalized Stigma	0.233	0.056	4.170	(0.123, 0.342)

GEE MODEL C: Predicting Depression Symptoms³

Explanatory Variable	Coefficient	Semi-Robust Standard Error [*]	z	95% CI ^{**}
Recruited at Hospital (vs. NGO)	-1.090	0.854	-1.280	(-2.766, 0.582)
Data Collection Wave	-1.665	0.422	-3.950	(-2.492, -0.838)
Enacted Stigma	1.033	0.292	3.540	(0.461, 1.606)
Disclosure Avoidance	1.619	0.655	2.470	(0.336, 2.903)
Internalized Stigma	10.985	1.933	5.680	(7.197, 14.774)
Intern. Stigma * Wave	-3.163	0.915	-3.450	(-4.957, -1.369)

* Standard errors are adjusted for repeated observations of individual participants

** 95% CI = 95% Confidence Interval (Note: because the 95% CI refers to coefficient estimates, and not to odds ratios, significant associations are evidenced by intervals that do not encompass 0.)

¹ Model A only includes main effects and the interaction term for Enacted Stigma*Wave. Interaction terms involving recruitment site, as well as the interaction term for Vicarious Stigma*Wave, were nonsignificant and dropped from the model.

² Model B only includes main effects. All interaction terms were nonsignificant and dropped from the model.

³ Model C only includes main effects and the interaction term for Internalized Stigma*Wave. All other interaction terms were nonsignificant and dropped from the model.

Table 4

GEE Models Examining Whether the Relationship Among Felt Normative Stigma, Disclosure Avoidance, and Disclosure Symptoms Remained Consistent Across Observations

**GEE MODEL D: Predicting Depression Symptoms
WITHOUT Disclosure Avoidance in the Model**

Explanatory Variable	Coefficient	Semi-Robust Standard Error [*]	z	95% CI ^{**}
Recruited at Hospital (vs. NGO)	-0.921	0.972	-0.950	(-2.826, 0.984)
Data Collection Wave	-3.827	0.417	-9.180	(-4.644, -3.009)
Felt Normative Stigma	0.937	0.368	2.540	(0.215, 1.659)

**GEE MODEL E: Predicting Depression Symptoms
WITH Disclosure Avoidance in the Model**

Explanatory Variable	Coefficient	Semi-Robust Standard Error [*]	z	95% CI ^{**}
Recruited at Hospital (vs. NGO)	-1.511	0.923	-1.640	(-3.320, 0.297)
Data Collection Wave	-3.885	0.419	-9.280	(-4.705, -3.064)
Felt Normative Stigma	0.455	0.371	1.230	(-0.271, 1.181)
Disclosure Avoidance	2.776	0.730	3.800	(1.345, 4.208)

* Standard errors are adjusted for repeated observations of individual participants

** 95% CI = 95% Confidence Interval Note: because the 95% CI refers to coefficient estimates, and not to odds ratios, significant associations are evidenced by intervals that do not encompass 0.)