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Details for Manuscript Number SSM-D-07-01631R1 “HIV-Related Stigma: Adapting a Theoretical Framework for Use in India”

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Abstract

Stigma complicates the treatment of HIV worldwide. We examined whether a multi-component framework, initially consisting of enacted, felt normative, and internalized forms of individual stigma experiences, could be used to understand HIV-related stigma in Southern India. In Study 1, qualitative interviews with a convenience sample of 16 people living with HIV revealed instances of all three types of stigma. Experiences of discrimination (enacted stigma) were reported relatively infrequently. Rather, perceptions of high levels of stigma (felt normative stigma) motivated people to avoid disclosing their HIV status. These perceptions often were shaped by stories of discrimination against others HIV-infected individuals, which we adapted as an additional component of our framework (vicarious stigma). Participants also varied in their acceptance of HIV stigma as legitimate (internalized stigma). In Study 2, newly-developed measures of the stigma components were administered in a survey to 229 people living with HIV. Findings suggested that enacted and vicarious stigma influenced felt normative stigma; that enacted, felt normative, and internalized stigma were associated with higher levels of depression; and that the associations of depression with felt normative

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and internalized forms of stigma were mediated by the use of coping strategies designed to avoid disclosure of one's HIV serostatus.

Keywords

India; HIV; stigma; depression; coping

Stigma complicates the management and treatment of HIV worldwide. It reduces testing-seeking (Ma, Detels, Feng, Wu, Shen, Li et al., 2007; Obermeyer & Osborn, 2007), limits HIV-positive individuals' willingness to disclose their infection (Calin, Green, Hetherington, & Brook, 2007; Tarwireyi, 2005), and affects the attitudes of providers who deliver HIV-related care (Li, Wu, Wu, Zhaoc, Jia, & Yan, 2007; Kurien, Thomas, Ahuja, Patel, Shyla, Wig et al., 2007). As such, understanding stigma's precise nature and effects on behavior is vital in the development of interventions to facilitate health among people living with the disease (Nyblade & MacQuarrie, 2006; Weiss, Ramakrishna, & Somma, 2006).

As used here, *stigma* refers to the devalued status that society attaches to a condition or attribute. Although it can also refer to the discrediting characteristic itself, stigma is very much about the socially constructed meanings associated with that characteristic. By conveying the devalued status of some identities relative to others, stigma defines social roles within interactions (Crocker, Major, & Steele, 1998; Goffman, 1963; Herek, 2002; Jones, Farina, Hastorf, Markus, Miller & Scott, 1984; Leary & Schreindorfer, 1998). The inferior social status of stigmatized individuals means that they have less power than the non-stigmatized and less access to resources valued by society (Herek, 2008; Link & Phelan, 2001).

Based on these considerations, *HIV stigma* is socially shared knowledge about the devalued status of people living with HIV. It is manifested in prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV and the individuals, groups, and communities with which they are associated (Herek, 2002; Herek, Mitnick, Burris, Chesney, Devine, Fullilove et al., 1998; Tewksbury & McGaughey, 1997).

Because the meanings attached to the disease are created through social interactions (e.g., experiencing discrimination or learning of other people being mistreated), the experience of HIV stigma can vary across cultures. For example, whereas stigmatizing attitudes have declined in the United States (Herek, Capitanio & Widaman, 2002), they remain more overt in India (Bharat, Aggleton, & Tyrer, 2001). Prior work documented a variety of discriminatory behaviors toward people living with HIV (PLWH) in India, including denial of hospital care, eviction from homes, and termination of employment ("AIDS stigma forms an insidious barrier", 2002; Bharat, Aggleton, & Tyrer, 2001; "The Next Wave of HIV/AIDS", 2002). In rural areas, women widowed by the disease have been rejected by their deceased husbands' families and forced to return to the towns or villages in which they were born (Pallikadavath, Garda, Apte, Freedman, & Stones, 2005). In one instance, an entire village became the target of stigma after one of its bus drivers tested positive for HIV, resulting in villagers being unable to find employment, being dismissed from nearby colleges, and having difficulty arranging marriages ("India's First HIV/AIDS Village", 2001). HIV stigma has also shaped how PLWH respond to the disease. Recognizing the potentially severe consequences of being identified as having HIV, many PLWH avoid disclosing their serostatus to others (Chandra, Deepthivarma, & Manjula, 2003).

Through prior research on HIV stigma, we developed a preliminary framework for understanding the stigmatizing experiences of PLWH in the developed countries of the West, particularly the United States (Herek, 1990, 2002; Herek & Capitanio, 1999; Herek, Capitanio,

& Widaman, 2002; Herek & Glunt, 1988; Herek et al., 1998). To examine the cross-cultural applicability of the framework, we undertook new research examining HIV stigma in India.

A Preliminary Conceptual Framework for Understanding the Experience of HIV Stigma

—We began with a conceptual framework that builds on Scambler's (1989) hidden distress model. It emphasizes three ways in which individuals experience stigma and considers the importance of stigma management in the social interactions of PLWH (Figure 1). The first component captures *interpersonal* actions and is labeled *enacted stigma*. It refers to overt acts of discrimination and hostility directed at a person because of his or her perceived stigmatized status.

By contrast, the second and third components are designed to capture *intrapersonal* experiences of stigma. The second component of our framework, *felt normative stigma*, refers to the subjective awareness of stigma. Here we operationalized a belief about the prevalence of stigmatizing attitudes among people in the local community, or the degree to which stigma is perceived as normative. These perceptions, in turn, may provide a basis for individual behavior. Felt normative stigma is expected to motivate individuals with a stigmatized condition to take actions to protect against enacted stigma. Such actions can include attempting to pass as a member of the non-stigmatized majority. Successful passing may reduce people's likelihood of experiencing enacted stigma but significantly disrupts their lives and often increases psychological distress (Scambler, 1989).

The extent to which an individual accepts stigma as valid is referred to here as *internalized stigma*. It constitutes the third component of our framework. When stigma is internalized by members of the non-stigmatized majority, the result is prejudice toward the stigmatized. When it is internalized by stigmatized individuals themselves, the result is self-stigma. In the latter case, people's self-concept is congruent with the stigmatizing responses of others; they accept their discredited status as valid (Herek, 2008; Jones et al., 1984).

Based on research with other stigmatized groups and in other settings, we hypothesized that experiencing each of these components of stigma has important consequences for a stigmatized person's overall well-being. As shown in Figure 1, experiencing enacted stigma is likely to increase PLWH's risk for psychological distress, such as depression (Diaz, Ayala, Bein, Henne, & Marin, 2001; Herek, Gillis, & Cogan, 1999). It also is likely to affect beliefs about the prevalence of stigma (felt normative stigma). Felt normative stigma, in turn, is expected to lead PLWH to monitor and modify their behavior, usually with a goal of trying to avoid future enactments of stigma (Burris, 1997). Based on prior research in India, we specifically expected that the primary behavioral modification would be avoiding disclosure of HIV serostatus (Chandra, Deepthivarma & Manjula, 2003). However, these decisions not to disclose come with consequences. By isolating and depriving themselves of needed resources, PLWH are likely to experience psychological distress (Hays, McKusick, Pollack, Hilliard, Hoff & Coates, 1993). Finally, internalized stigma is hypothesized to be associated with psychological distress both directly and indirectly (because it prevents PLWH from seeking social support and other needed resources) (Simbayi, Kalichman, Strebel, Cloete, Hende & Mqeketo 2007).

We began our research in India by conducting qualitative interviews with a small sample of PLWH, focusing on their perceptions of and experiences with HIV stigma. In Study 2, we used our findings from the interviews to create instruments to measure the different components of our stigma framework, and examined the associations of the stigma components with disclosure-avoidance and psychological distress.

STUDY 1

Method

A convenience sample was recruited in the general medicine department in a large, urban, private hospital in Southern India. Eligible persons were referred by their doctors. Interviewers explained the interview's purpose and procedures, and obtained informed consent. Participants were recruited if they were at least 18 years old; capable of communicating verbally in English or a South Indian language (Kannada, Tamil, Telugu, Malayalam); and had known about their HIV diagnosis for at least six months.

Procedures and Analysis—A one-hour interview was conducted by trained Indian interviewers in a private space in the hospital. Participants were asked to discuss their attitudes about HIV and their awareness of HIV-related discrimination against other people, to identify people to whom they had disclosed their serostatus, and to describe personal experiences of HIV-related discrimination. Interviews were audio-recorded and subsequently translated and transcribed in English. During transcription, personally identifying information was deleted.

All transcribed interviews were read by at least two research team members. One individual coded interviews for themes pertaining to the question of interest (Ryan & Bernard, 2003), namely the kinds of stigma experiences and concerns that participants described in relation to their own or someone else's HIV diagnosis. The coded interviews were entered into *ATLAS.ti*, a software program to manage narrative data. The second team member verified the identified themes. Disagreements among coders were resolved by consensus.

Results

One respondent who was not responsive to interviewer questions was excluded from the analyses, leaving a sample of 16 (11 men, 5 women). Eleven were married, three separated or divorced, and two widowed. Their ages ranged from 26 to 42.

The interviews provided multiple examples of enacted, felt normative, and internalized stigma. Most participants had experienced some type of enacted stigma when others knew about their HIV infection. Seven individuals reported having their HIV status disclosed without permission. Five received inequitable medical treatment, including denial of care and having hospital staff refuse to touch them for fear of infection. Two were rejected completely by family members, two experienced rejection from friends, one from the community, and one by work colleagues.

Consistent with prior stigma theorizing (Scambler, 1989), respondents in our study made efforts to keep their HIV status secret in the belief that it would help minimize future experiences of enacted stigma. Twelve individuals described specific strategies, included stating or implying that they were being treated for a different disease; refusing to discuss their HIV infection unless asked directly about it; lying outright about their HIV status; seeking treatment far away from home; and not explaining written medical documents to illiterate family members. Ten individuals stated explicitly that they feared negative reactions if they told others that they had HIV. Examples of such sentiments included, “*Everybody will poke me; they will look down upon me*” and “*My wife knows that I had gone to the hospital and taken treatment. I told her not to tell anyone as it [is] a humiliation for us.*” This sense of vulnerability resulted in part from stories about stigma against other people with HIV. The events in these stories ranged from relatively undeveloped accounts of social ostracism (a man was refused treatment in a hospital when a physician learned that he had HIV) to very vivid and specific stories. For example, one participant said he had heard about a man who stopped his upcoming wedding upon learning that he was infected. When townspeople discovered the

reason for the cancellation, they ridiculed the HIV-infected man until he finally committed suicide.

Although respondents perceived high levels of stigma in their communities (felt normative stigma), they varied in their levels of internalized stigma. When asked specifically to describe their opinions, the majority of individuals said that discrimination against PLWH was inappropriate. However, their explanations suggested that these attitudes were complex. For example, one woman said, *“What wrong have I committed? Why has god given me this disease? It is okay if I have committed anything wrong; I [would then] deserve this punishment.”* For a male participant, the appropriateness of discrimination was dependent on its form. He felt that isolating PLWH was wrong (*“[People in the community] should encourage us to have self-confidence and make us feel like ordinary people”*), but that restrictions on marriage were at least partially appropriate (*“Let [PLWH] get married. But let them choose their life partner from the infected ones”*).

Discussion

The findings from the interviews suggest that the constructs of enacted, felt normative, and internalized stigma are applicable to the experiences of PLWH in India. Although limited in number, participants reported personal experiences of enacted stigma, which were similar to experiences reported in other investigations (Bharat, Aggleton, & Tyrer, 2001). Notably, participants had strong expectations about the prevalence of normative stigma (felt normative stigma), which led them to limit disclosure of their infection. However, their personal views about HIV stigma were more nuanced, often reflecting general disapproval of stigmatizing beliefs but leaving open the possibility that discrimination was sometimes appropriate (internalized stigma).

In addition, the interview responses highlighted how hearing about enactments of stigma represents an important source of perceived norms of stigma. Consistent with social learning theory, which argues that people learn from observing the experiences of others (Bandura, 1979), stories communicated information about the likely consequences of being publicly identified as having HIV and thereby contributed to respondents' perceived need to manage access to information about their health status. Hearing the stories made the possibility of enacted stigma highly salient, even if participants had not personally experienced discrimination. We refer to this channel for transmitting information about enacted stigma as *vicarious stigma*, and adopted it as a component of our model (Figure 1).

STUDY 2

Based on our findings, we next created instruments to measure the four components of stigma (enacted, vicarious, felt normative, and internalized) in order to test hypothesized associations in our theoretical model (Nyblade & MacQuarrie, 2006). We anticipated that psychological distress (e.g. depression) would be associated with higher levels of enacted, felt normative, and internalized stigma. However, we predicted that the associations between depression and intrapersonal forms of stigma (felt normative, internalized) would be mediated by the use of disclosure-avoidance strategies that limit individuals' access to social support (Hays et al., 1993; Simbayi et al., 2007). Finally, we anticipated that both enacted stigma and the newest framework component, vicarious stigma, would influence perceptions about the prevalence of stigmatizing attitudes in the community (felt normative stigma).

Method

Participants were recruited as part of a larger study of adherence to antiretroviral therapy (ART). All participants were 18 years of age or older, HIV-seropositive, and had taken ART

medications for at least one month. Most respondents were referred via the outpatient general medicine department of a large, urban, private hospital in southern India. We intentionally sought to over-represent women (who comprised only 10% of HIV patients at the hospital) to enhance our likelihood of detecting gender differences. A screener in the medical records department flagged the charts of potentially eligible individuals, who were then invited by the clinic charge nurse to meet with a project interviewer while waiting for their appointment. The remaining patients were informed of the study by their physician or by a service provider at local non-governmental agencies (NGO) that served HIV-infected individuals. All referred individuals met privately with a study interviewer, who described the research purpose and obtained informed consent.

Procedures—Participants completed an interviewer-administered, baseline survey on the day of their enrollment into the study. It lasted one hour and assessed a variety of topics, including demographics and health history, HIV stigma, and psychological well-being. Surveys were completed in Kannada, Telugu, Tamil, and English. The instruments were developed in English and then translated into the three Indian languages. All translations were independently back-translated into English to ensure semantic equivalence.

Stigma Assessments: An initial pool of items for the HIV stigma instruments was drawn from anecdotes provided by participants in Study 1, findings from prior work in India (Bharat, Aggleton, & Tyrer, 2001), and, when appropriate, existing measures (e.g., Berger, Ferrans, & Lashley, 2001; Herek, 2006). In order to reduce respondent fatigue and interview time in future research, we intended to use an initial pool of items to identify a smaller set of items to be used in the final version of each scale. The complete sets of items used in all stigma instruments can be found in the appendices (available from the authors on request).

Enacted Stigma: An initial pool of 21 items was assembled to assess if participants had experienced specific discriminatory acts because of their HIV infection. Responses were *no* (0) or *yes* (1). Because we expected the incidence of enacted stigma to be fairly low and did not predict that different experiences of enacted stigma would necessarily be correlated, we did not conceptualize our measure of enacted stigma as a scale per se. Rather, it was meant to be an index, capturing the kinds of discriminatory events that people experienced. As such, we initially inspected the outcomes on this measure by looking at the distribution. The 21 enacted stigma items differed widely in terms of the frequency with which they were endorsed, ranging from 0.4% to 26.2% of the sample. We selected 10 items that included both severe and mild enactments and that varied in terms of the frequency of endorsement.

Total scores on the brief and longer versions of the instrument were highly correlated, $r(229) = .92, p < .01$. Furthermore, the results of all analyses were identical, regardless of which version was used. These findings suggest that the shorter version is representative of the enacted stigma experiences measured by the longer version. The items for this brief version are displayed in Table 2. The appendices display the original pool of items and the frequency with which each item was endorsed by both male and female participants.

Vicarious Stigma: An initial pool of 20 items captured the frequency with which participants had heard stories about people being mistreated because of HIV infection. For each item, the participant responded on a 4-point scale that ranged from 0 (*never*) to 3 (*frequently*).

Felt Normative Stigma: An initial pool of 15 items assessed participants' perceptions of the prevalence of HIV stigmatizing attitudes. They reported their expectations of how many people in their community would engage in a discriminatory behavior or would endorse a stigmatizing belief. Responses were given on a 4-point scale ranging from 0 (*no one*) to 3 (*most people*).

Internalized Stigma: Using parallel versions of the 15 felt normative stigma items, participants reported the extent to which they believed that, as HIV-infected people, they should be treated in a discriminatory manner or be a target of stigmatizing beliefs. Responses were given on a 4-point scale running from 0 (*not at all*) to 3 (*a great deal*).

Psychometric reduction of Stigma measures: For vicarious, felt normative, and internalized stigma, we entered items from each scale into an exploratory principal axis factor analysis with an oblique (promax) rotation. Initially, we permitted an analysis to return all factors with eigenvalues above 1.0. We then inspected the scree plot and factor loadings to determine if the full solution was interpretable or if it was advisable to limit the number of factors. As appropriate, we ran subsequent analyses specifying the number of factors to be extracted; 2-factor solutions emerged, with the first factor accounting for most of the explained variance. However, for all three sets of items, the two factors were highly correlated (vicarious: $r = .63$; felt normative: $r = .78$; internalized: $r = .43$), suggesting that, in each case, they were facets of the same stigma construct and could be appropriately combined into a single unidimensional scale. Therefore, for each scale, we selected five of the highest loading items from each of the original factors to create 10-item measures. To ensure equivalence between felt normative and internalized stigma, we selected parallel items. The final 10-item versions of the scales all demonstrated acceptable reliability (Vicarious Stigma Scale: $\alpha = .88$; Felt Normative Stigma Scale: $\alpha = .94$; Internalized Stigma Scale: $\alpha = .83$). Table 2 provides the final set of items in each scale. The appendices display the original multi-factor solutions and the final single factor solutions.

Other Assessments: Disclosure Avoidance: Study 1 findings confirmed our expectation that felt normative stigma motivates many PLWH to limit their disclosure of HIV. Thus, we developed a 14-item measure assessing the use of strategies to avoid revealing that one has HIV. Examples included hiding medications, describing one's illness as tuberculosis, and seeking care away from one's local village. For each item, participants indicated the frequency with which they employed a disclosure-avoidance technique using a 4-point scale ranging from 0 (*never*) to 3 (*often*). Scores were derived by averaging responses to the questions (Cronbach's $\alpha = .82$). The scale's items are provided in the appendices.

Beck Depression Inventory: To assess psychological distress, which we predicted would result from stigma and use of disclosure-avoidance techniques, we included a variant of the Beck Depression Inventory (Version I) (BDI) that had been validated previously in Southern India (Chandra, Gandhi, Satishchandra, Kamat, Desai, Ravi et al., 2006). The scale was available in Kannada. We translated it into Tamil and Telugu, and then translated all Indian language versions into English to ensure semantic equivalence. The Indian version of the BDI uses the same items as found in the United States. However, some wording is modified to reflect local cultural norms or to make statements understandable in Indian languages. The scale had acceptable reliability in our sample (Cronbach's $\alpha = .90$).

Visibility of HIV Status: We opted to include an additional measure that captured the degree to which a person's HIV status is known to others. This concept is not represented formally in our model (Figure 1) because disclosure avoidance is thought to be potentially harmful regardless of its success at helping a person pass as a member of the nonstigmatized majority (e.g., Scambler, 1989). Nonetheless, in spite of disclosure avoidance, a substantial number of participants in Study 1 reported that their HIV status had been disclosed to others without permission.

In our measure, participants were asked to identify (by name or pseudonym) the people to whom they turned for emotional support and assistance, and to indicate how many of these people knew of their serostatus, regardless of the source. We computed the ratio of the number

of people who knew of the person's HIV status to the total number of people she or he listed as sources of support. Scores could range from 0 (none of support network knows of infection) to 1 (100% of support network knows of infection).

Participant demographic and health history characteristics: Individuals were asked to describe their gender, age, marital status, household composition, employment status, monthly income, years of education, religion, and length of time since HIV diagnosis.

Data Analyses—Composite scores for all stigma measures were correlated with psychological and behavioral outcomes. To examine the potential for mediation among our measures, we regressed a presumed mediator onto the respective predictor variable, and the outcome variable onto a predictor variable both when the mediator was included in and excluded from the model (Baron & Kenny, 1986). Analyses were conducted using *SPSS 13.0*.

Results

The sample consisted of 229 respondents. A majority were male, married, and Hindu (Table 1). Most had obtained 10 or fewer years of education and reported earnings of 3000 or fewer rupees per month, indicative of low socioeconomic status. Participants reported living with a variety of relatives, including spouses ($n = 160$; 70%), children ($n = 161$; 70%), parents ($n = 81$, 35%), siblings ($n = 54$; 23%), and other extended family ($n = 45$; 20%). A majority could read Kannada ($n = 161$; 70%), whereas smaller percentages could read English ($n = 110$; 48%), Hindi ($n = 56$; 25%), Telegu ($n = 52$; 23%), and Tamil ($n = 28$; 12%). Participants had been diagnosed with HIV for an average of 3.85 years (range: 0.13-17.22 years). Although we do not have information on individuals who refused participation, the age and religious profile of our sample was similar to the profile of all patients in the HIV clinic at the hospital where the study was conducted. The sample's representation of women was higher (31% female vs. 10% female among all HIV patients at the hospital), a reflection of our intentional efforts to oversample females.

Mean Levels of Stigma—Reports of enacted stigma on the 10 item scale were low ($M = 0.73$, $SD = 1.41$). Seventy-one percent of participants ($n = 163$) did not report any instance of discrimination as a result of their HIV status. Vicarious, felt normative, and internalized stigma scores were computed by summing the responses and dividing by the number of items. Scores could range between 0 and 3, with higher scores indicating greater levels of stigma. Participants reported more felt normative stigma ($M = 1.19$, $SD = 1.00$) than internalized stigma ($M = 0.60$, $SD = 0.64$; $Z = 7.63$, $p < .001$) or vicarious stigma ($M = 0.82$, $SD = 0.72$; $Z = 5.75$, $p < .001$).

There were a limited number of significant correlations between the stigma instruments and demographic characteristics. Women had experienced more vicarious stigma than men: Women: $M = 0.99$, $SD = 0.84$; Men: $M = 0.75$, $SD = 0.65$; $F(1, 227) = 5.33$, $p < .05$, $\eta^2 = .02$. However men had higher scores than women on internalized stigma: Men: $M = 0.65$, $SD = 0.65$; Women: $M = 0.47$, $SD = 0.57$; $F(1, 227) = 4.30$, $p < .05$, $\eta^2 = .02$. There were no gender differences for enacted or felt normative stigma. Having been diagnosed with HIV for longer periods of time was correlated with higher scores for vicarious stigma, $r(229) = .25$, $p < .01$, but lower scores for internalized stigma, $r(229) = -.13$, $p < .05$. And increasing age was negatively associated with vicarious stigma, $r(229) = -.20$, $p < .01$.

Association of HIV Stigma with Disclosure, Disclosure Avoidance, and Depression—Table 3 displays correlations among the constructs in our model (Figure 1), i.e., the four stigma instruments and the measures of avoidant coping ($M = 0.82$, $SD = 0.59$) and depression ($M = 12.69$, $SD = 11.42$). Greater levels of depression were associated with felt

normative, internalized, and enacted stigma, but not with vicarious stigma. Furthermore, the use of disclosure avoidance techniques was associated positively with all forms of stigma, as well as with depression. This pattern of associations did not differ by gender, nor were there gender differences in the overall reported levels of disclosure-avoidance and depression.

Mediation Among Stigma, Disclosure Avoidance, and Depression—The conceptual model depicted in Figure 1 predicted that several of the observed correlations (specifically, the associations between vicarious stigma and disclosure avoidance, enacted stigma and disclosure avoidance, felt normative stigma and depression, and internalized stigma and depression) would be partially or fully mediated by associations with other variables. To test for the possibility of mediation, we looked to see if the size of the beta-weight for a predictor variable was reduced significantly by including a mediator in a regression model (Baron & Kenny, 1986). Figure 2 diagrams four successful tests of mediation. In each depiction, the beta weights represented along the bottom (horizontal) arrow are critical. The first number is the beta weight of the predictor without the mediator in the model. The second number (in parentheses) is the reduced weight for the predictor with the mediator included in the model. The Sobel test identifies if this reduction in the beta weight size is significant.

For the correlation between vicarious stigma and disclosure avoidance, we predicted that the association would be mediated by felt normative stigma. As seen in Figure 2, Cell A, this mediated model was fully supported. The association between vicarious stigma and disclosure avoidance was reduced to near 0 when felt normative stigma was included in the regression. Similarly, as seen in Figure 2, Cell B, felt normative stigma fully mediated the association between enacted stigma and disclosure avoidance, consistent with our predictions in Figure 1. We next examined whether disclosure avoidance mediated the associations between felt normative stigma and depression (Figure 2, Cell C) and between internalized stigma and depression (Figure 2, Cell D). The regression weight for felt normative stigma dropped to non-significant levels when disclosure avoidance was included in the model, suggestive of full mediation as predicted by Figure 1. Similarly, the correlation between internalized stigma and depression was reduced significantly with the inclusion of disclosure avoidance in a regression model. However, internalized stigma still remained a significant unique predictor of depression. This pattern of results suggests that disclosure avoidance only partially mediates the association between internalized stigma and depression, which is consistent with Figure 1.

HIV Serostatus Visibility—Although not formally diagrammed in our model, we included a measure of HIV serostatus visibility ($M = 0.44$, $SD = 0.40$; median number of individuals who had knowledge of a participant's serostatus = 4) in order to examine the degree to which disclosure avoidance strategies were successful. Interestingly, there were notable gender differences in the average levels of HIV status visibility (men: $M = 0.38$, $SD = .39$; women: $M = 0.59$, $SD = 0.38$; $F(1, 223) = 13.65$, $p < .001$, $\eta^2 = .06$) and in how visibility correlated with disclosure avoidance and with stigma. For men, higher serostatus visibility was significantly associated with lower levels of disclosure avoidance, $r(158) = -.22$, $p < .01$, but was uncorrelated with reports of enacted, $r(158) = .07$, $p = .33$; vicarious $r(158) = .05$, $p = .50$; or felt normative stigma, $r(158) = .05$, $p = .46$. For women, however, the pattern of results was almost exactly opposite. Greater serostatus visibility was unrelated to disclosure avoidance, $r(67) = -.01$, $p = .95$, but was significantly correlated with enacted, $r(67) = .24$, $p = .05$ and vicarious stigma, $r(67) = .35$, $p < .01$. Furthermore, although the association between serostatus visibility and felt normative stigma was not significant among women, ($r(67) = .16$, $p = .19$), the size of correlation was substantially greater than that observed among men and would likely be significant with a larger sample of women. This pattern of results suggests that nondisclosure efforts may be more successful for men than women in hiding HIV infection.

General Discussion

We developed four new instruments to assess different facets of HIV stigma—enacted, vicarious, felt normative, and internalized. All demonstrated good psychometric properties and proved useful in understanding experiences and beliefs in the Indian context. Participants reported very few enactments of stigma. Rather, they were more likely to perceive high levels of HIV stigma in the community (felt normative stigma), and to personally hold mixed views about the validity of this stigma (internalized stigma). Because stigma enactments were low, felt normative stigma was driven most strongly by stories that participant had heard of other PLWH experiencing discrimination. The addition of vicarious stigma to our framework was critical. It helped explain the observed pattern of results by documenting a channel for the communication of HIV information. Participants did not need to encounter actual enactments of stigma to fear its social consequences. Stories communicated norms about HIV and shaped behavior.

Although striking, the low levels of enacted stigma and the relatively higher levels of felt normative stigma are consistent with prior research. Early stigma theories classified scorned conditions into those that create *discredited* and *discreditable* identities (Goffman, 1963). The distinction focuses on a condition's visibility. Those that cannot be hidden create discredited identities, in which a person's inferior status is known in all social situations and the individual must develop strategies for coping with the resulting prejudice and discrimination. By contrast, conditions that can be hidden create discreditable identities. In this case, the fundamental challenge becomes the management of stigma information. A person with a discreditable condition tries to control who does and does not know about a scorned condition to minimize the likelihood of being assigned a discredited status.

Our data clearly align with the latter category. Participants experienced low levels of enacted stigma, which is to be expected given that HIV is often not readily apparent (unless a person develops symptoms stereotypically associated with the disease). By contrast, participants were more acutely aware of the potential for stigma and employed strategies such as disclosure avoidance, that they thought would help protect against being discredited (i.e., stigmatized). Unfortunately, these strategies come with a cost. In our second study, greater efforts to limit disclosure of HIV status were associated with higher levels of depression. In addition, disclosure-avoidance techniques did not always accomplish their intended goal. For women specifically, disclosure avoidance had no relationship to the proportion of people in their social networks who knew of their infections. This observation may reflect how gender influences HIV care. Prior research has shown that the consequences of HIV stigma are particularly harsh for women, including rejection from husbands' families and fewer financial resources for managing the disease (Pallikadavath et al., 2005). These consequences may place women at the mercy of extended relatives or public assistance programs, making it more challenging to maintain medical privacy.

By design, our felt normative and internalized stigma instruments paralleled each other. Although responses on these measures were correlated, it was clear that personal endorsements of stigmatizing beliefs were driven only partially by perceptions of stigma in the local community. The finding reinforces the importance of keeping perceptions of stigma levels (felt normative) and endorsement of stigma (internalized) conceptually distinct (Herek, 2008). Furthermore, the consequences of felt normative and internalized stigma are somewhat different. Perception of high levels of stigma was linked to depression exclusively through its influence on disclosure-avoidance behaviors. By contrast, internalized stigma directly correlated with depression, even while also influencing disclosure-avoidance behaviors. Our data do not allow us to understand *why* some people believe HIV stigma is valid whereas others do not. But, given the strong link with depression, it is clear that a major need for people with high internalized stigma is helping them challenge their negative beliefs about the disease. It

also points to the importance of reducing negative stereotyping in popular media, which could reinforce internalized stigmatizing beliefs.

Our findings offer several potential avenues for developing stigma interventions in India. First, the critical mediating role of disclosure-avoidance indicates that programs are needed to help participants disclose their infection. Interestingly, the link between disclosure-avoidance and depression held true for men and women, even though there were gender differences in the effectiveness of the strategies at limiting knowledge of a participant's serostatus. This suggests that it may be the act itself (and not the success of its intended outcome) that makes disclosure avoidance psychologically damaging. Indeed, prior research has shown that disclosure of one's HIV status sometime has direct health benefits (Cole, Kemeny, Fahey, Zack, & Naliboff, 2003; Cole, Kemeny, Taylor, Visscher, & Fahey, 1996; Smyth & Pennebaker, 2001; Strachan, Bennett, Russo, & Roy-Byrne, 2007). Thus, a critical first step may be providing opportunities for disclosure, even if it is to people who do not provide critical forms of social support in daily life.

Establishing opportunities for disclosure and social support—even ones as straightforward as hospital-based social groups or peer counselors—holds significant challenges. First, hospitals that provide HIV care attract patients from large geographical areas. PLWH from rural areas often travel long distances to receive treatment. As such, their access to support services may be limited, particularly if they rely on family for transportation and housing when seeking care. Second, PLWH may not always be able to communicate with one another. In southern India alone, there are four major languages (in addition to English). If people are unwilling to seek services locally, one must implement programs in urban centers where PLWH do not all speak a common language. Fortunately, many Indian NGOs already are tackling these and similar challenges as they develop services for PLWH.

A second area for intervention development is challenging PLWH's own stigmatizing beliefs about the disease. How this is best accomplished remains an area in need of urgent study. Prior research has suggested that accurate knowledge about the disease is a major determinant of attitudes (Ambati, Ambati, & Rao, 1997), highlighting a potential role for education. But there may also be culturally-specific beliefs that complicate education-based strategies. For example, traditional Hindu theology places importance on accepting one's fate. Endorsement of this tenet may make people hesitant to challenge beliefs about the disease.

Third, it is critical to consider how interventions can create structural change. As suggested earlier, many women may not have—by circumstances, family, or finances—the ability to exert agency over how they respond to their own infection. Social support groups and educational programs will have little influence if a person's attitudes, beliefs, and behaviors are driven primarily by environmental constraints. Finally, future study is needed to understand how interventions should address related forms of stigma, such as prejudices against sex workers, migrant laborers, injection drug users, and men who have sex with men. Our current study doesn't allow us to determine to what degree these stigma drive beliefs about HIV, nor how they might modify the kind of interventions needed for PLWH. But it is notable that many of the better-performing items in our felt normative and internalized scales related to morality and shame. This suggests that attitudes about the disease are still driven by judgments about how it is acquired.

Our findings are limited by several aspects of the study design. First, the scales were examined in a cross-sectional assessment, precluding definitive conclusions about causality. We currently are collecting longitudinal data to determine how stigma, disclosure avoidance, and psychological reactions relate over time. Second, our sample consisted of PLWH on antiretroviral treatment. As such, it over-represents individuals in later stages of the disease

when immune system impairments may produce more visible symptoms. (That said, it should be noted that the primary symptom of HIV in India is tuberculosis, a condition that also occurs commonly among people uninfected with HIV. Characterizing one's HIV illnesses as being due solely to tuberculosis was one of the more common disclosure-avoidance strategies employed by our participants.) Finally, the findings may be affected by selection bias. It is possible that individuals who experienced very high levels of stigma were unwilling to participate in an HIV-specific study.

Stigma is an important consideration in the response to HIV in India. Interventions and policies are needed to ensure the PLWH have the safety and security to disclose their serostatus and to promote more positive opinions about the disease to ensure psychological well-being among people living with the disease.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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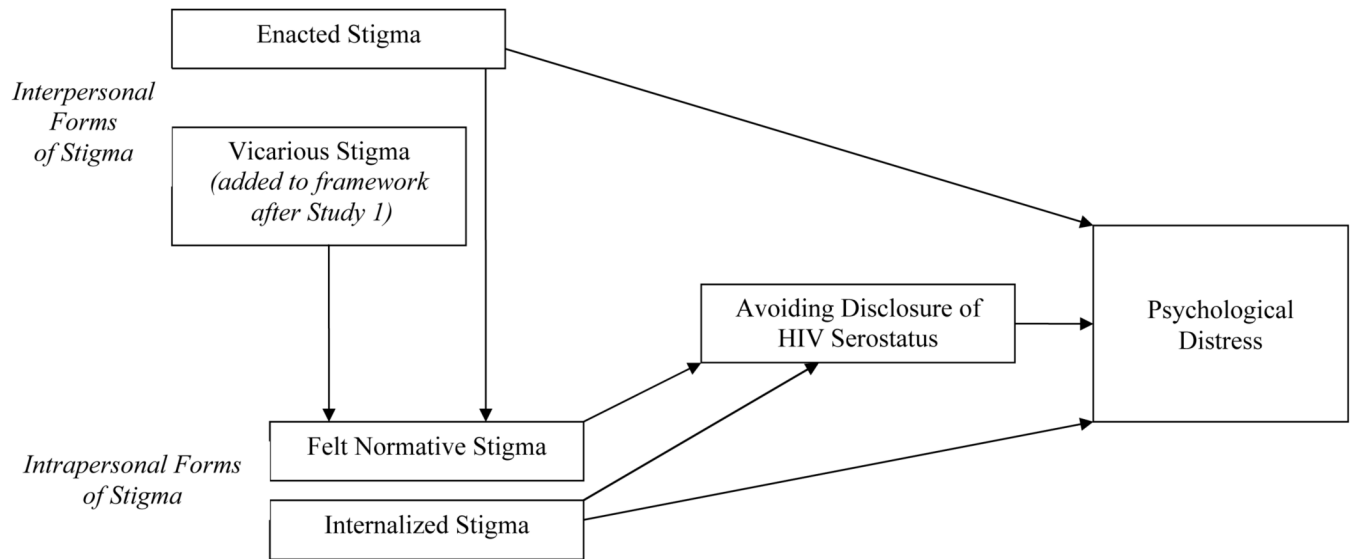
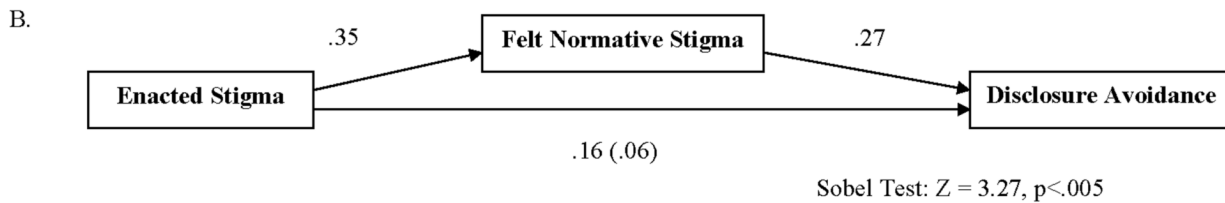
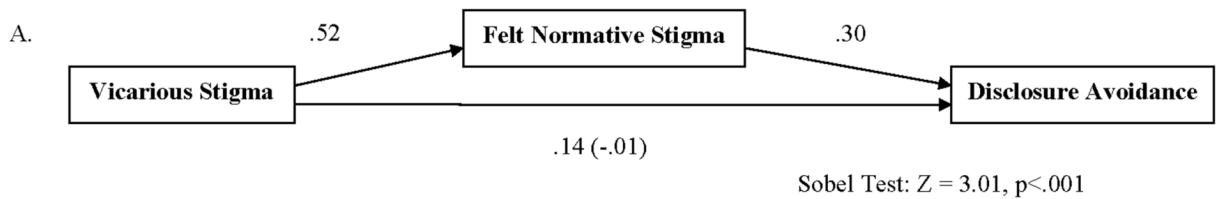
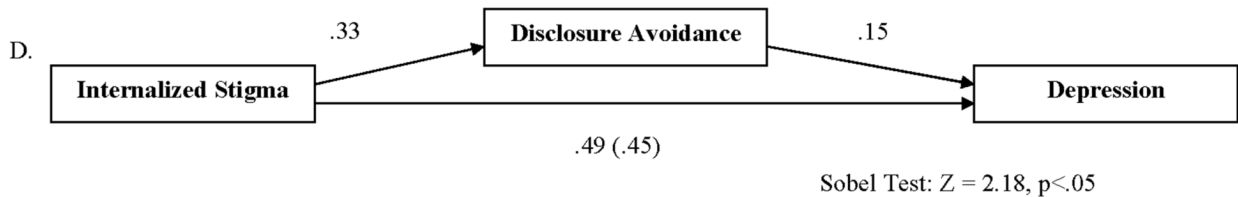
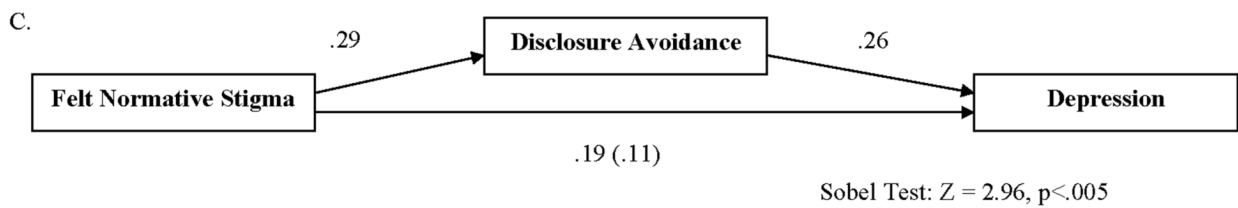


Figure 1. Theoretical Framework Linking Facets of Stigma, Avoidance of HIV Serostatus Disclosure, and Psychological Distress



Note: The numbers next to the arrows represent regression beta-weights. Below the horizontal arrow in each model, the first number represents the regression weight when the mediator is not included in the model and the second number (in parentheses) represents the weight when mediator is included in the model.



Note: The numbers next to the arrows represent regression beta-weights. Below the horizontal arrow in each model, the first number represents the regression weight when the mediator is not included in the model and the second number (in parentheses) represents the weight when mediator is included in the model.

Figure 2.
Mediation Analyses Examining Associations Among Stigma, Disclosure Avoidance, and Depression

Table 1

Demographic profile of the cohort participants

<u>Gender</u>	<u>N (%)</u>	<u>Employment Status</u>	<u>N (%)</u>
Male	159 (69.4%)	Not employed	66 (28.8)
Female	70 (30.6%)	Currently employed	163 (71.2%)
<u>Marital Status</u>	<u>N (%)</u>	<u>Religion</u>	<u>N (%)</u>
Married	175 (76.4%)	Hindu	202 (88.2%)
Never married	26 (11.4%)	Muslim	9 (3.9%)
Divorced/separated	2 (0.9%)	Christian	17 (7.4%)
Widowed	26 (11.4%)	Jain	1 (0.4%)
<u>Education</u>	<u>N (%)</u>	<u>Interview language</u>	<u>N (%)</u>
≤ 9 years	70 (30.6%)	Kannada	181 (79.0%)
10 years	69 (30.1%)	Tamil	14 (6.1%)
Vocational training	63 (27.5%)	Telugu	29 (12.7%)
At least some college	27 (11.8%)	English	5 (2.2%)
<u>Age</u>		<u>Income/month (in rupees)</u>	
Mean: 37.6		Mean: 4510.99	
Range: 23-74		Range: 0-22,000	

Table 2
Items Selected for Use in the Stigma Assessments

Enacted Stigma Index^a

- Has a hospital worker mistreated you because of your HIV
 Have people looked at you differently because you have HIV?
 Has a healthcare worker not wanted to touch you because you have HIV?
 Have you been told not to share your food or utensils with family because of your HIV?
 Have you been asked not to touch or care for children because of your HIV?
 Have you been refused medical care or denied hospital services because of your HIV?
 Have family members forced you to move out of your home because you have HIV?
 Has a hospital worker made your HIV infection publicly known by marking HIV on your medical record?
 Has someone threatened to hurt you physically because you have HIV?
 Have you been refused housing because people suspect you have HIV?
 Vicarious Stigma (all items begin with the words, "How often have you heard stories about...")^b
 ... a healthcare worker not wanting to touch someone because of his or her HIV?
 ... people being mistreated by hospital workers because of their HIV?
 ... people being refused medical care or denied hospital services because of their HIV?
 ... a healthcare provider talking publicly about a patient with HIV?
 ... someone being refused care from their family when they were sick with HIV?
 ... people being forced by family members to leave their home because they had HIV?
 ... a hospital worker making someone's HIV infection known by marking HIV on their medical records?
 ... families avoiding any relative who has HIV?
 ... people looking differently at those who have HIV?
 ... a village/community ostracizing someone because they had HIV?
 Felt Normative Stigma Scale (all items begin with the words, "In your community...")^c
 ... how many mothers would *not* want someone with HIV to hold their new baby?
 ... how many mothers would *not* want an HIV-infected person to feed their children?
 ... how many people would *not* share dishes or glasses someone who has HIV?
 ... how many people think that HIV-infected people have brought shame on their families?
 ... how many people avoid visiting the homes of people with HIV?
 ... how many people think that if you have HIV you have done wrong behaviors?
 ... how many people would *not* want an HIV-infected person cooking for them?
 ... how many people think that people with HIV should feel guilty about it?
 ... how many people think that a person with HIV is disgusting?
 ... how many people think people with HIV are paying for their karma or sins?
 Internalized Stigma Scale (all items begin with the words, "How much do you feel...")^{d,e}
 ... that you should avoid holding a new infant because of your HIV?
 ... that you should avoid feeding children because of your HIV?
 ... that you should avoid sharing dishes or glasses just in case someone might catch HIV from you?
 ... that you have brought shame to your family because you have HIV?
 ... that you should avoid visiting people because of your HIV?
 ... that you have HIV because you have done wrong behaviors?
 ... that you should avoid cooking for people because you have HIV?
 ... guilty about having HIV?
 ... disgusting because of your HIV?
 ... that you are paying for karma or sins because you have HIV?
-

^a Responses were "No" (0) or "Yes" (1)

^b Ratings were made on a 4-point scale ranging from *Never* (0) to *Frequently* (3)

^c Ratings were made on a 4-point scale ranging from *No One* (0) to *Most People* (3).

^d Ratings were made on a 4-point scale ranging from *Not At All* (0) to *A Great Deal* (3).

^e By design, internalized stigma items parallel items in the Felt Normative Stigma Scale.

Table 3
Correlations Among Stigma Instruments, HIV Serostatus Disclosure Avoidance, and Depression

	Enacted Stigma	Vicarious Stigma	Felt Normative Stigma	Internalized Stigma	Disclosure Avoidance	Depression (BDI)
Enacted Stigma	1.00					
Vicarious Stigma	0.46**	1.00				
Felt Normative Stigma	0.35**	0.52**	1.00			
Internalized Stigma	0.07	-0.02*	0.30**	1.00		
Disclosure Avoidance	0.16*	0.14*	0.29**	0.33**	1.00	
Depression (BDI)	0.19**	0.05	0.19**	0.49**	0.29**	1.00

*
 $p < .05$

**
 $p < .01$