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Authors

Nyamathi, Adeline Ekstrand, Maria Zolt-Gilburne, Jessica et al.

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Correlates of Stigma among Rural Indian Women Living with HIV/AIDS

Adeline Nyamathi,

University of California, Los Angeles, School of Nursing

Maria Ekstrand,

University of California, San Francisco

Jessica Zolt-Gilburne.

George Washington University

Kalyan Ganguly,

Indian Council of Medical Research

Sanjeev Sinha,

All India Institute of Medical Sciences, India

Padma Ramakrishnan,

Indian Council of Medical Research

P. Suresh,

Nellore, India

Mary Marfisee, and

University of California, Los Angeles, School of Nursing

Barbara Leake

University of California, Los Angeles, School of Nursing

Abstract

AIDS-related stigma has received increasing attention in the literature; however, little is known about the devastating impact it has on rural women living with AIDS (WLA) in India. This cross-sectional study (N=68), analyzed from complete baseline data, identified a number of correlates of stigma among rural WLA in South India. Structured instruments were used to capture sociodemographic history, stigma, knowledge of HIV, depressive symptoms along with the recording of CD4 data. A higher level of felt stigma and more AIDS symptoms were related to avoidant coping, while fewer adherence strategies and lower support for ART adherence were also associated with avoidant coping. These findings promote the need for support and resources for rural India WLA.

Keywords

| HIV/AIDS; Rural | Women; Stigma; India | |
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| | | |

INTRODUCTION

The stigma associated with AIDS has long been recognized as a significant obstacle in the worldwide fight against HIV/AIDS (1) and a substantial body of research has documented detrimental physical and mental health consequences of AIDS stigma for patients, both in the US and globally (2,3). AIDS stigma has been shown to inflict hardship and suffering on people living with HIV/AIDS (4,5); it interferes with decisions to seek HIV counseling and testing (6–11), and is a barrier to preventing mother to child transmission (12–17). Stigma also limits HIV-positive individuals' willingness to disclose their infection to others (5,18–20), which can lead to sexual risk to others. Stigma prevents HIV patients from getting adequate medical care by deterring infected individuals from seeking medical treatment for HIV-related problems in local health care facilities or by doing so in a timely fashion (17, 21–23). Stigma also interferes with patient compliance to medication regimens. Patient noncompliance risks treatment failure and the development and transmission of drug-resistant strains (24).

Our conceptual framework (5,25) builds on Scambler's (26) model as well as research by Herek (27–29) and emphasizes four ways in which persons living with HIV/AIDS (PLWHA) experience AIDS stigma as well as strategies used to manage stigma in social interactions. As in Scambler's model, *enacted* stigma here refers to overt acts of discrimination experienced by PLWHA. A number of PLWHA may avoid disclosure due to hearing stories of enacted stigma targeting others in their community. This *vicarious* stigma thus reinforces the belief that disclosing one's status may be harmful.

In our model, we use the term *felt stigma* to refer to the perception of AIDS stigma in one's community and *internalized stigma* to describe a PLWHA's acceptance of societal AIDS stigma as part of his or her personal value system. When this occurs, PLWHA accept their discredited status as valid (28,30). Felt stigma can be expected to motivate PLWHA to take actions to try to avoid enacted stigma, and includes trying to pass as a member of the uninfected majority. In our model, we refer to this behavior as "avoidant coping". By successfully passing as uninfected, PLWHA may reduce their likelihood of experiencing stigma and discrimination (2). However, it can also disrupt their lives, leading to negative health outcomes, reduced quality of life (e.g. 5,25) and increase in psychological distress (26).

Based on research with other stigmatized groups and in other settings, experiencing each of these components of stigma has important consequences for a stigmatized person's overall well-being. Experiencing enacted stigma is likely to increase PLWHA's risk for psychological distress, such as depression (31). It also is likely to affect perceptions of the prevalence of community stigma (felt stigma). Felt stigma, in turn, is expected to lead to avoidant coping, in which WLA monitor and modify their behavior, usually with a goal of trying to avoid future enactments of stigma. Prior research in India has revealed that the primary behavioral modification includes avoiding disclosure of HIV serostatus (19). Finally, internalized stigma is likewise correlated with psychological distress because it prevents PLWHA from seeking social support and other needed resources (32).

Women and Stigma

In Bharat et al's (21,33) groundbreaking study of AIDS stigma in India, evidence was provided that AIDS stigma and discrimination in India are, in some respects, gendered phenomena. She found that women were less likely than men to seek testing, and less able than men to afford treatment. In addition, HIV-positive women were more likely than HIV-positive men to take care of their partners and neglect their own health. Sadly, after having been the primary caregivers for their husbands, women were often asked to leave the house

of their in-laws after the husbands died and denied their inheritance. Moreover, women were often blamed by their in-laws for infecting their husbands by not controlling their husbands' urges to have sex with other women. The quality of care provided to HIV-infected women by family was also significantly poorer than that provided to HIV-positive men. Although Bharat & Aggleton (33) cited a small number of cases in which women abandoned their HIV-infected husbands, more common was the neglect and maltreatment of HIV-positive women by their husbands and in-laws.

Similar results have been found in more recent studies in which HIV-infected Indian women reported that they have had their morality questioned (34,35). As a consequence, many Indian women are afraid to disclose their HIV status, which can result in the use of disclosure avoidant strategies, such as hiding one's medications and lying about the reason for clinic visits. These behaviors have in turn been shown to cause delay in accessing, or suboptimal use of, health-care facilities (36–38). Mothers with HIV face additional challenges related to inheritance issues, access to education for their children, and insensitive treatment by health care professionals in maternity wards (39,40). These issues have all resulted in anxiety and hesitation about disclosing status, even in health care settings.

Fear of AIDS stigma has also been reported in other countries and PLWHA worldwide have developed multiple coping strategies to avoid disclosing their HIV status to family, colleagues and health professionals. For example, PLWHA in Senegal and Indonesia have reported avoiding or delaying treatment for sexually transmitted illness (STI) and HIV infections, out of fear of both public humiliation and discrimination by health care workers (8,41). Similarly, AIDS stigma in Botswana and Jamaica has been associated with delays in testing and treatment services, often resulting in presentation beyond the point of optimal drug intervention (9,42). Even when treatment is obtained, fear of stigma can prevent individuals from following their medical regimens. PLWHA in South Africa, for example, ground pills into powder to avoid taking them in front of others, leading to inconsistent dose amounts (43). In our India antiretroviral therapy (ART) adherence study (5,44), participants reported lying about their condition to friends and family and traveling far to get treatment or medications at clinics and pharmacies where they could be anonymous. One woman reported swallowing her pills with her children's bathwater, since this was her only daily moment of privacy (5,24).

Currently, no quantitative studies exist depicting the stigma experiences of rural Indian women with AIDS. The purpose of this study was to meet this need, by examining the correlates of stigma among rural WLA in South India, as well as the relationship between their stigma experiences and their use of specific disclosure avoidant strategies unique to this setting. Identifying these factors in this population will help health professionals and policy makers to better understand the context of AIDS stigma among rural female PLWHA and could form the basis for strategies that can be used to mitigate some of the negative health consequences of AIDS stigma in this population.

METHODS

Design

This study presents the cross-sectional findings from a baseline questionnaire administered to 68 WLA who participated in a prospective, randomized clinical trial intervention designed to assess the impact of having trained village women, Asha, who interact with health care providers and support WLA compared to usual care group. Human Subjects Protection Committee clearances were obtained both in the US and in India. All data presented here were collected prior to the start of the intervention phase.

Sample and Setting

Inclusion criteria for the study were: a) WLA between the ages of 18–45; b) screened as receiving ART for at least three months, with CD4 levels > 100 while on ART; and c) not a participant of an earlier qualitative study. Two high prevalence HIV/AIDS villages in rural Andhra Pradesh that were demographically alike and served by a Public Health Center (PHC) were randomly selected from a pool of 16 villages.

Screening Procedure

The study was publicized by means of flyers posted in the PHCs of the two study villages. A full description of the study was provided by the research team to WLA in a private setting in the PHCs. After all questions were answered, WLA who continued to be interested signed an initial informed consent. Subsequently, research staff administered a brief two-minute structured questionnaire that elicited information about age and other socio-demographic characteristics about HIV and ART status. These questions helped to determine eligibility for the proposed study and provided basic sociodemographic information on later refusals. To complete the eligibility review, blood was drawn to assess CD4 levels. Research staff stationed at the designated site four days later provided test results. All respondents were paid \$5 for completion of these screening procedures. WLA who met eligibility criteria and wished to participate then underwent another informed consent procedure and were enrolled in the study. The administration of the baseline questionnaire then followed, prior to any intervention.

Instruments

Several of the instruments have been previously tested with WLA in the US (45–47) and in India (48).

Socio-Demographic information—A structured questionnaire was used to collect sociodemographic information, and included age, birthday, education, employment status, marital status and number of children.

Health History—We collected self-reported information on HIV- and TB-related physical symptoms, history of opportunistic infections (OIs), ART adherence history, including strategies and support services. The perceived symptoms checklist was based upon the ACTG checklist (49) and was modified to include responses that patients frequently reported in India.

Biologic Health Status—CD4 counts were assessed as part of the screening procedure. Blood samples were sent to the district hospital lab for CD4 determination by flow cytometry. The absolute numbers of CD4 cells were obtained by multiplying percent CD4 from flow cytometry by total white blood cell count (determined by Act Diff Coulter).

Knowledge about HIV—Thirteen items from a modified 21-item CDC knowledge questionnaire were used to measure HIV/AIDS knowledge (50). Modifications to the CDC instrument have been detailed elsewhere (51). The internal consistency of the HIV Knowledge scale in a sample of Indian homeopathy physicians was .81. In our current study, the Cronbach alpha was .90.

Stigma—Stigma scales developed by Ekstrand and her team (5,25,52), provided four constructs: a) Vicarious Stigma; b) Felt Stigma; c) Enacted Stigma; and d) Internalized Stigma. Scale items were based on previous research (53–57) and were subsequently modified based on qualitative interviews in India (5,21) to ensure that the content was

relevant and appropriate. The process of developing these scales has been described in detail by Steward et al. (5).

Vicarious Stigma—These ten items were similar to those assessed by the Enacted Stigma scale, but measured whether participants had heard stories about other people living with HIV/AIDS being mistreated because of their infection. A sample item is: "How often have your heard stories about people being refused medical care or denied hospital services because of their HIV?" Each item has a four-point response set that ranges from (1) never to (4) frequently. Internal consistency reliability, as measured by Cronbach's alpha, was .85 for the scale in this sample. One item "People looking differently at those with HIV" was dropped from the scale since its item-total correlation was below .3.

Felt Stigma—This 10-item scale measures perceived levels of stigma in one's community, such as the attitudes that people living with HIV/AIDS deserve their infections or have brought shame on their families. A sample item in Felt Stigma is: "In your community, how many people think that HIV-infected people have brought shame on their families?" Items were measured on a four-point scale ranging from (1) no one to (4) most. One item "In your community, how many mothers would not want someone with HIV to hold their new baby" was dropped due to low item-total correlation. Cronbach's alpha for the remaining nine items in this sample was .84.

Enacted Stigma—Assesses whether participants have experienced specific discriminatory acts due to their HIV infection, such as being asked not to share utensils or plates with other family members. Ten items in this scale measured enacted stigma using a yes/no format. An example of an item in this scale is: "Have you been told not to share your food or utensils with your family because of your HIV?". Reliability for the scale was .90.

Internalized Stigma—This 10-item scale parallels the Felt Stigma scale, but assesses the extent to which respondents believe that, as HIV-infected people, they deserved to be stigmatized. Each item has a four-point response format varying from (1) not at all to (4) a great deal. For example, an item is: "How much do you feel that you deserve to have HIV?" Reliability in this sample was .89.

Avoidant Coping—This scale was based on our previous "Disclosure Avoidance" scale (5), and was adapted to meet the needs of our study population. This 14-item scale assesses the frequency with which participants use various coping strategies to avoid disclosing that they have HIV. Examples of avoidant coping included hiding one's HIV medications and describing one's illness as TB, rather than HIV. Responses vary from (1) never to (4) often. Cronbach's alpha for this scale was .90. Scale scores for all stigma measures and for stigma coping were constructed by summing the individual item responses.

Depressive Symptomatology—The CES-D, a 20-item scale, measured frequency of depressive symptoms on a 4-point continuum. The CES-D has well-established reliability and validity and has been used with a variety of populations (58). Scores on the CES-D range from 0–60, with higher scores representing greater depressive symptomatology. Internal consistency for the scale in this sample was .91.

Data Analysis

Frequencies and percents, or means and standard deviations, were used to delineate stigma in this sample and describe background characteristics. Because the stigma scales were highly skewed, associations of stigma with socio-demographic, health and health history measures were examined with Spearman correlations. Analysis of variance and Pearson

correlations were used to assess correlates of avoidant coping; potential correlates included all four stigma scales dichotomized at their medians.

Variables that were associated with avoidant coping at the .15 level were used as predictors in a linear regression model; those that were not significant at the .10 level were successfully removed. The final model was assessed for multicollinearity.

RESULTS

Sociodemographic Factors

A total of 68 WLA were identified as eligible to participate in the study and were administered the structured questionnaire. The age of the women ranged from 20 to 45; mean age was 31.2 (SD 5.3). As depicted in Table 1, approximately half (52%) of the women were married, over 40% were widowed, and nearly two-thirds reported being Hindu. More than three-quarters lived with children, but less than half (44%) lived with a spouse. Over one-third of the women (39%) had received no education, but about three-quarters reported employment. WLA on average had been taking ART for just under two years (22 months). The mean number of visits made to health care providers was 7.5 over the past three months.

Vicarious Stigma

Table 2 depicts responses to individual items of the stigma scales. Stories about how PLWHA had been mistreated were commonly heard by the participants; the range of "frequently" heard items ranged from 40% to 63%. For example, stories of how PLWHA were forced to leave home by family members and ostracized by their community were reported "frequently" by over 60% of the women. Moreover, about half the sample had heard stories of persons living with HIV/AIDS being mistreated by hospital workers, not being touched voluntarily by hospital workers, and of health care providers talking publicly about patients with HIV. Over 40% of the participants also frequently heard of persons living with HIV/AIDS who were avoided by their families, looked at differently, or had to suffer with HIV being written on their medical record. The median of vicarious stigma was 3.4

Felt Stigma

Participants reported similarly high levels felt stigma, which assessed perceived levels of stigma in the women's communities. The frequency of perceiving discriminating thoughts from "most" of their community ranged from 49% to 69%. More than two-thirds of participants perceived that most people in their community would not want a woman living with HIV/AIDS to feed other people's children, and that HIV-infected persons were paying for a sin committed in the past. Two-thirds of the sample thought that most people would not want to share dishes with an HIV-infected person. About two-thirds perceived that most people felt that those with HIV should feel guilty about a past event and slightly under two-thirds regarded such persons as disgusting. About half of the participants perceived that most of their community would avoid entering homes of persons living with HIV/AIDS and thought such persons brought shame on their families. The median for felt stigma was 3.6.

Internalized Stigma

Frequencies of endorsing the selected discriminatory beliefs "a great deal" were also high, and ranged from 49% to 71%. More than two-thirds of the women believed they were paying for Karma or sin and felt guilty and disgusting about having HIV. Slightly less than two-thirds thought they should avoid feeding children (62%) or holding a new infant (60%). Over half thought they had brought shame to their families and that they should avoid

cooking for others. Slightly less than half (49%) avoided visiting people. The median value for the scale was 3.7.

Enacted Stigma

The range of "yes" responses to discrimination experienced by participants ranged from 40% to 84% (Table 3). Over 80% of the women were told not to touch or care for children and were looked at differently than women without HIV/AIDS. Three quarters or more were forced to leave their homes by family members, were told not to share food or utensils, and were refused housing. Over 70% reported having been physically threatened and observed that healthcare workers were afraid to touch them. At least two-thirds reported that they had been denied medical/hospital care and had been mistreated by hospital workers. Fewer women (40%) observed their HIV status in their medical record. The median of enacted stigma was 8.5.

Avoidant Coping

Close to half the sample reported frequent use of all coping strategies, with the exception of leaving their village to get medication (38%). The most common coping strategy was making up reasons other than HIV for seeing the doctor (62%), followed closely by hiding their medication (59%) (data not shown).

Unadjusted Associations

Felt and enacted stigma had the fewest correlates of the four stigma variables and no correlates among socio-demographic measures (Table 4). Higher AIDS knowledge, greater use of avoidant coping and poorer quality of life were related to almost all of the four stigma measures. Enacted stigma was the only stigma scale that was not related to fewer perceived ART benefits and felt stigma was the only scale that was unrelated to fewer sources of support for ART adherence. Lower CD4 cell counts were associated with higher levels of internalized stigma and vicarious stigma. Lower educational level was related to a higher level of both internalized and vicarious stigma. Age, living situation, work status and depressive symptomatology were not related to any of the stigma measures.

Adjusted Associations with Avoidant Coping

In a multiple linear regression analysis for avoidant coping (Table 5) a higher level of felt stigma and more AIDS symptoms were related to greater avoidant coping, while fewer adherence strategies and lower support for ART adherence were associated with less avoidant coping.

DISCUSSION

The pervasive all-encompassing stigma faced by WLA in our study reflects the myriad challenges these women face in coping with their illness. They faced not only actual acts of stigmatization, but also a hostile environment flush with stories about acts of stigmatization faced by other WLA. It is not surprising that these women also struggled with a large amount of felt and internalized stigma.

Prior studies have found that felt, vicarious, and internalized stigma are more prevalent than enacted stigma (38). The high rate of enacted stigma (i.e., discriminatory acts) in our sample may reflect the fact that our participants were rural women. It also suggests a hostile living environment derived not only from the women's perceptions of how the community viewed them, but also from the community's and healthcare professionals' actions. Women were not allowed to share food, utensils or even care for children. Enacted stigma had low-to-moderate correlations with AIDS-related measures, such as good AIDS knowledge, quality

of life, support for ART adherence, and Avoidant coping. The high level of enacted stigma, and yet, its relatively low associations with AIDS-related measures, supports results in other studies that the most detrimental forms of stigma are not specific acts (5,38).

As in this sample, enacted stigma within the healthcare system against women living with HIV/AIDS is prevalent in India (39). Physician-enacted stigma can take the form of not touching patients, sitting far away from them and even wearing masks (39). Anecdotally, these stigmatizing actions have been a major barrier to WLA in accessing appropriate care. In fact, women in India have stated that they just want "caring healthcare providers" (40). Yet, enacted stigma had no significant association with CD4 count, recent health care visits, adherence with ART, or perceived benefits of ART.

Interestingly, vicarious stigma (hearing of other WLA being mistreated) was not only prevalent, but it also had more significant associations with socio-demographic and AIDS-related variables than other forms of stigma. Vicarious stigma has been viewed as a way of evaluating enacted stigma (5) and was more closely associated with quality of life than enacted stigma. One main reason for low enacted stigma in other studies is because people have heard of others being mistreated and, as a consequence, have chosen to hide/not disclose their own infections. Without disclosure, PLWHA are much less likely to experience discrimination. Higher AIDS knowledge was most likely protective against heard stigma because it allowed WLA to know the facts. On the other hand, a high level of vicarious stigma was associated with increased avoidant coping as mentioned above. Predicted positive outcome from disclosure is a key factor in whether or not WLA will disclose their HIV status (19). Therefore, the frequent use of avoidant coping strategies by WLA in this study may indicate perceptions of both futility and fear toward disclosing their HIV/AIDS serostatus.

Vicarious stigma may have had more associations than enacted stigma because it reflects not just individual acts, but an individual's amalgamation of stories she has heard about her community. Vicarious stigma may give the WLA a deeper sense of the attitudes within her community and thus may have more associations with negative consequences of HIV infection.

Internalized stigma and the WLA's perception of deserving to be stigmatized had significant associations with both AIDS-related measures and sociodemographic measures. A high level of internalized stigma was associated with a lower quality of life. A woman with a high level of internalized stigma may deprive herself of social support (38). Since social support can be an important predictor of ART adherence (20), it is not surprising that women who had a high level of internalized stigma had lower CD4 levels. These levels may partially reflect adherence to medications for some time prior to the study when they were not being observed. Internalized stigma may also be due, in part, to misconceptions about HIV/AIDS. Compared to women who reported a lower level of internalized stigma, those who reported a higher level were less educated about AIDS and had less formal schooling. Misconceptions among WLA are not surprising given a pervasive lack of knowledge about sex, sexual practices and STD's in India (33). Misunderstanding of how HIV/AIDS is spread is apparent in examples of enacted stigma, such as refusing to let WLA hold a child, share dishes or cook for others. Internalized stigma grounded in misconceptions about HIV/AIDS among WLA is not surprising if enacted stigma is pervasive within the community. On the other hand, basic education about HIV/AIDS protects WLA not only in coping with their own illness, but also in coping with their husbands' illness (40).

Overall felt stigma, while prevalent in our sample, was not associated with sociodemographic factors and had few associations among AIDS-related factors. High levels of

felt stigma suggest that individuals perceive that they live in an environment that would not be supportive to their situation. WLA in our study often perceived that most people in their communities supported the discriminatory feelings and actions that were presented to them, which is consistent with previous studies that also found high levels of felt stigma (5,38). Yet, despite a high association with avoidant coping and modest associations with AIDS Knowledge, perceived ART benefits, and quality of life, felt stigma had no other associations in this study. It is reasonable that people who feel they are living in a hostile/unsupportive environment go to great lengths to hide their infections. Felt stigma may be the form of stigma with the fewest associations because it is not related to specific actions or even hearing about specific actions, but rather an osmotic sense of the attitudes of the community.

Interestingly, none of the stigmatization measures were related to depressive symptoms. This may be due to the way that we evaluated depressive symptoms. Felt stigma, for example, has been linked to depressive symptoms because it leads to disclosure avoidance that may ultimately lead to the depressive symptoms (5).

Quality of life was associated with higher levels of internalized stigma. Previous studies have found no correlation between quality of life and internalized stigma other than gender (38). Stigma, however, can have a negative effect on quality of life (38). Stigma negatively effects quality of life because of the way it causes PLWHA to interact with their community and take care of themselves (38). Our study confirmed a relationship between avoidant coping and higher levels of felt stigma, which is consistent with previous studies that have looked at disclosure. The importance of being able to anticipate a supportive response after disclosing one's serostatus has been found to be a fundamental determinant in whether or not an individual discloses (19,39). Our data clarifies the relationship between support for ART adherence and avoidant coping mechanisms, while affirming the importance of support for ART adherence (39,59). Previous studies have suggested that reliance on disclosure avoidance techniques are not related to "the proportion of people in their [WLA] social networks who knew of their infections" (5). Instead, disclosure avoidance has been linked to overall support, not necessarily from within the WLA social circle. Further research is needed to articulate exactly what form of support is most effective at preventing reliance on avoidant coping mechanisms.

Limitations

There are a number of limitations to this paper. Since the sample contains a small number of rural WLA, the generalizability to all rural WLA is limited. Moreover, the cross-sectional design prevents an assumption of causality between independent predictors and dependent variables. Most importantly, since this is not a longitudinal intervention study, we cannot distinguish between predictors and outcome variables.

CONCLUSIONS

The present study has demonstrated the systemic stigmatization that WLA in two villages in India face. These women face a hostile environment where they are overtly stigmatized, but also where the undercurrent from village gossip causes high levels of heard and felt stigma and finally a high level of internalized stigma. The next step is to look at interventions at the contextual level, dealing with members of the community and healthcare personnel to decrease stigmatization and potentially improve quality of life and treatment outcomes for these women.

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 $\label{eq:Table 1} \textbf{Table 1}$ Sample Characteristics (N=68)

| Measure | Mean | (SD) |
|--|-------|--------|
| Age | 31.21 | (5.3) |
| Number of Children | 1.57 | (1.0) |
| Mean Time Taking HIV medication in Months (SD) | 22.3 | (17.6) |
| Mean Visits Past 3 months (SD) | 7.53 | (3.5) |
| | N | % |
| No Formal Education | 26 | 38.8 |
| Marital Status | | |
| Married | 35 | 51.5 |
| Widowed | 28 | 41.2 |
| Other | 5 | 7.4 |
| Religion | | |
| Hindu | 44 | 65.7 |
| | N | % |
| Christian | 17 | 25.4 |
| | N | % |
| Muslim | 6 | 9.0 |
| People Living with: | | |
| Children | 52 | 76.5 |
| Spouse | 30 | 44.1 |
| Facilities/Providers Visited Past 3 Months | | |
| Government Hospital | 68 | 100.0 |
| Pharmacist | 46 | 67.7 |
| Primary Health Center (PHC) | 44 | 64.7 |
| Medical Assistant | 35 | 51.5 |
| Private Hospital | 31 | 45.6 |
| Private Practitioner | 27 | 39.7 |
| HIV Care Clinic | 11 | 16.2 |
| Non Governmental Organization/Voluntary Counseling and Testing (NGO/VCT) | 10 | 14.7 |

Table 2

Vicarious Stigma

| Stigma Items | Never | Rarely | Sometimes | Frequently |
|--|-------|--------|-----------|------------|
| Forced to Leave Home by Family Members | - | 2.9 | 33.8 | 63.2 |
| Ostracized by Community | 1.5 | 10.3 | 26.5 | 61.8 |
| Refused Care by Family | 1.5 | 10.3 | 48.5 | 39.7 |
| Looked at differently | - | 11.8 | 47.1 | 41.2 |
| Avoided by Family | - | 8.8 | 45.6 | 45.6 |
| Refused Medical Services | - | 10.3 | 50.0 | 39.7 |
| Mistreated by Hospital Workers | 2.9 | 16.2 | 29.4 | 51.5 |
| Healthcare Worker not Wanting to Touch | 2.9 | 16.2 | 30.9 | 50.0 |
| Healthcare Provider Talking Publicly | 16.2 | 5.9 | 29.4 | 48.5 |
| HIV Written on Medical Record | 27.9 | 8.8 | 19.1 | 44.1 |

| Felt Stigma | No one | Very Few | Some | Most |
|-------------------------------------|--------|----------|------|------|
| HPP* Shouldn't Hold Others New Baby | 2.9 | 1.5 | 33.8 | 61.8 |
| HPP Shouldn't Feed Other's Children | 1.5 | 1.5 | 29.4 | 67.7 |
| Won't Share Dishes with HPP | - | 1.5 | 32.4 | 66.2 |
| Don't Want HPP Cooking for Them | 1.5 | - | 42.7 | 55.9 |
| Avoid Home of HPP | 1.5 | 1.5 | 48.5 | 48.5 |
| HPP Brings Shame on Family | - | 4.4 | 44.1 | 51.5 |
| HPP has Done Wrong Behaviors | - | 4.4 | 33.8 | 61.8 |
| HPP Paying for Karma or Sin | 1.5 | 2.9 | 26.5 | 69.1 |
| Think HPP Should Feel Guilty | 1.5 | 4.4 | 29.4 | 64.7 |
| Think HPP is Disgusting | - | 7.4 | 29.4 | 63.2 |

| Internalized Stigma | Not at ALL | A Little | A Fair Amount | A Great Deal |
|---------------------------------|------------|----------|---------------|--------------|
| Avoid Holding a New Infant | 4.4 | 4.4 | 30.9 | 60.3 |
| Avoid Feeding Children | 5.9 | 4.4 | 27.9 | 61.8 |
| Avoid Sharing Dishes/Glass | 5.9 | 8.8 | 33.8 | 51.5 |
| Avoid Cooking for Others | 9.0 | 4.5 | 34.3 | 52.2 |
| Avoid Visiting People | 7.4 | 5.9 | 38.2 | 48.5 |
| Bringing Shame to you Family | 8.8 | 2.9 | 33.8 | 54.4 |
| Guilty of Wrong Behaviors | 16.2 | - | 26.5 | 57.4 |
| Paying for Karma or Sin | 10.3 | 1.5 | 20.6 | 67.7 |
| Feeling Guilty About having HIV | 4.4 | - | 25.0 | 70.6 |
| Feeling Disgusting | 7.4 | - | 25.0 | 67.7 |

^{*}HIV-Positive Person

Table 3

Enacted Stigma

| Enacted Stigma | Yes |
|---------------------------------------|------|
| Forced to Leave Home by Family | 76.5 |
| Told not to Touch/Care for Children | 80.9 |
| Looked at Differently | 83.8 |
| Physically Threatened | 70.6 |
| Told not to Share Food/Utensils | 79.4 |
| Refused Medical/Hospital Care | 66.2 |
| Mistreated by Hospital/Worker | 69.1 |
| Healthcare Workers Reluctant to Touch | 70.6 |
| HIV Put on your Medical Record | 39.7 |
| Refused Housing | 75.0 |

^{*} HIV-Positive Person

 Table 4

 Spearman Correlations of Stigma with Socio-demographic and AIDS-Related Measures

| Socio-demographic | Internalized Stigma | Felt Stigma | Vicarious Stigma | Enacted Stigma |
|--------------------------|---------------------|-----------------|------------------|-----------------|
| Age | 06 | 06 | 01 | 05 |
| Married | .15 | .11 | 12 ^a | .04 |
| Education | 45 ^C | 16 | 28 ^a | 14 |
| Living with Spouse | .10 | .04 | 06 | .06 |
| Living with Parent | 07 | .05 | 19 | .01 |
| Living with Children | .01 | .03 | .20 | .06 |
| Hindu Religion | .04 | .02 | 08 | 04 |
| Working | .001 | .03 | .14 | 02 |
| Depressive symptoms | .03 | 03 | .15 | 07 |
| AIDS-Related | | | | |
| CD4 Count | 30 ^a | 09 | 30 ^a | 04 |
| HIV Symptoms | .21 | .12 | .31 <i>b</i> | .23 |
| Recent Healthcare Visits | .13 | 02 | .24 ^a | 07 |
| Perceived ART Benefits | 53 ^c | 31 ^a | .55 ^c | 16 |
| ART Support | 40 ^C | 14 | 49 ^C | 28 ^a |

| AIDS-Related | Internalized Stigma | Felt Stigma | Vicarious Stigma | Enacted Stigma |
|--------------------|---------------------|------------------|------------------|------------------|
| Adherence with ART | 19 | 20 | 14 | 18 |
| Avoidant Coping | .52 ^c | .49 ^c | .53 ^c | .25 ^a |
| AIDS Knowledge | 42 ^C | 40 ^C | 43 ^c | 28 ^a |
| Quality of Life | .44 ^C | .25 | .49 ^c | .28 ^a |

ap < .05

b p < .01

c p < .001

Table 5

Linear Regression for Avoidant Coping (N = 68)

| В | s.e | P value |
|-------|--------------------|--|
| 0.52 | 0.13 | .001 |
| 12 | 0.03 | .001 |
| 0.06 | 0.02 | .004 |
| -0.13 | 0.05 | .021 |
| | 0.52 12 0.06 | 0.52 0.13 12 0.03 0.06 0.02 |

^aUpper median for felt stigma

 $^{^{}b}$ Sum of HIV adherence strategies

 $^{^{}c}_{\#}$ of AIDS symptoms

 $[\]emph{d}_{\#}$ of people reminding patient to take HIV medication