One Year After ART Initiation: Psychosocial Factors Associated with Stigma Among HIV-Positive Mozambicans

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Abstract

The pathways through which stigma is associated with psychological distress remains understudied in Africa. This study evaluates stigma among 277 Mozambicans who were on an antiretroviral therapy (ART) regimens for a full year. Using bivariate and multiple regression analyses, we examine psychosocial factors (disclosure decisions, perceived social support, and depression) associated with stigma, at ART initiation and one year later. We found one year after initiating ART, participants reported no change in stigma, a decreased in perceived social support, and an increase in depressive symptomology. Disclosing HIV status to friends (vs. family or partner) was associated with lower levels of stigma. These findings suggest that HIV care in comparable settings should include counselling, support groups, and peer support, that includes stigma and disclosure concerns prior to and during the first year following diagnosis. Most importantly, assessment and treatment of depression should be incorporated into ongoing HIV care.

Keywords

Stigma; Disclosure; HIV/AIDS; Africa; Depression

> "For persons living with HIV/AIDS, stigma is one of the most insidious barriers affecting access to and provision of health services, particularly in southern Africa" (1).

INTRODUCTION

According to 2008 estimates in Mozambique, over 385,000 of the 1.46 million HIV-positive adults (14% national prevalence) are believed to be eligible for ART (2). Of these about a third (128,000) have initiated treatment provided through the national health system (3). In spite of this success, loss to follow-up between HIV testing and treatment is considerable.(4) Yet, few studies among HIV-positive people in Mozambique have evaluated the association between stigma and psychological distress.

Stigma is viewed as universally occurring, with localized differences that are associated with value and moral structures embedded within a culture (5). Rooted in basic hierarchical social structures within a society's culture, those with an undesired condition become aware of their

differences (perceived stigma) (6), eventually internalizing stereotypes resulting in self stigma (7). Moving into the public domain, enacted stigma results when a discriminatory behavior, such as social exclusion, is experienced and initiated because of the undesired condition (8). Given that culture and society can have such serious impacts on the shape of stigma, investigators must take into account culturally-specific beliefs and societal value systems in order to fully understand stigma processes. For example, studies have shown stigma as a major barrier to utilization of services (9,10). Similarly, several recent studies have linked HIV stigma to diminished adherence to antiretroviral therapy (ART) in people living with HIV, which can directly impact HIV morbidity and mortality (11–13).

Stigma has other negative consequences for health outcomes for people living with HIV, such as lowered self esteem, depression, and anxiety (14,15). Stigma, depression, and disclosure influence one another in a complex web of interaction that is difficult to disentangle (16–18). Furthermore, since adhering to a challenging ART regime often requires social support (19–21), disclosure decisions by patients can be especially important factors in long-term treatment success (22,23). Disclosure carries great risks including social ostracism, family exclusion, loss of material resources such as food and housing, and violence, all of which can contribute to stigma and mental health problems. Conversely, disclosure is necessary to garner social support, and may lift the burden of secrecy thus reducing depression (24–26) and improving mental and physical health (27). While some degree of disclosure is necessary for adherence, stigma may greatly hinder the decision to disclose, limit to whom one will disclose, and thereby restrict options patients believe they have in seeking potential treatment support (28–30).

In this paper, we examine whether stigma among patients in a large hospital in central Mozambique one year after ART initiation is associated with disclosure decisions, social support, and depression. Using validated and tested psychometric measures of stigma and depression, we hypothesized that higher levels of stigma would be associated with limited disclosure and greater levels of depression. Measuring stigma and these associations can contribute to greater understanding of the impact of stigma within this population.

METHODS

Participants and Setting

The present report describes a sub-study of participants undergoing a randomized controlled trial to test the effectiveness of modified directly observed treatment (mDOT) to improve adherence to ART at the HIV treatment clinic in Beira, Mozambique. Detailed methods are described elsewhere (31). Briefly, all persons initiating ART from October 2004 to July 2005 and who met the eligibility criteria (at least 18 years of age, living near the clinic, and free of severe mental illness or dementia, as assessed by clinic staff) were asked to participate. Of the 433 eligible persons, 83 refused (71 too busy, 10 traveled weekly and more than 3 days a week, 2 not interested) and 350 were enrolled into the study.

Procedures

As part of the larger study, enrolled participants were scheduled for assessment appointments on the day they started ART (baseline), and at 6 weeks, 6 months, and 12 months post-ART initiation. Participants were randomly assigned to either the mDOT intervention for 6 weeks or standard care, and completed a 45-minute interviewer-administered questionnaire at all time-points (31,32). Of the 350 participants who were enrolled in the study 55 died, 17 were lost to follow-up, and one dropped out by the end of the study (12 months post-ART initiation). We assessed stigma between the mDOT group and the control group and there was no important differences at baseline, post intervention, or at the 12-month assessment point. Therefore for

the analysis reported in this paper, we used interview data from the 277 participants who provided data at two points, the baseline and 12 month interviews.

Measures

To ensure content and conceptual validity and reliability, most items and all scales were selected from published and validated measures. All items were translated into Portuguese, pretested, and psychometric properties assessed for cultural appropriateness in Mozambique (33).

Stigma—A 21-item stigma scale, reduced from Berger et al 2001 40-item scale, captured the social and emotional aspects of living with HIV(34). We assessed the overall 21-item scale as well as three subscales: social or public stigma (items relating to fear and rejection, such as what "most people think about a person with HIV" or what "most people with HIV can expect when others learn they have HIV"); negative self-image (items expressing "feelings of shame and guilt such as feeling unclean, not as good as others, or like a bad person because of HIV"); and personalized stigma (items relating to personal experiences or fears of rejection for having HIV, such as "losing friends, feeling that people were avoiding him/her, and regrets for having told some people"). Higher scores indicate higher levels of stigma. Scores range from 21 – 84 for the overall combined scale, 10 – 40 for personalized stigma, 6 – 24 for negative self image, and 9 – 36 for social or public stigma. For this sample, the Cronbach alphas for these scales were .90, .88, .79, and .87 for the overall scale, personalized stigma, negative self-image, and public stigma, respectively. The Cronbach alphas for the overall scale and all three domains are within range of the published alphas (35).

Disclosure—Two questions assessed disclosure. The first asked "How many people have you disclosed your HIV status to?" and the second asked to whom they have disclosed (i.e. to partner/spouse, family member, friends, neighbor, and/or coworker). Respondents selected all that applied. Responses represent the total number of persons disclosed to at the time of the assessment.

Demographics and clinical measures—Variables such as gender, age, education (dichotomized at 8 or more years), mean income, employment status (working for pay or not), currently going to school and currently living with a spouse or partner were recorded at baseline via questionnaire. Follow-up questions on income, employment, student status, and living with a spouse/partner were asked again at the 12 month assessment. Adherence was assessed using a one item self report measure "How many of your HIV medication doses did you miss in the last 7 days?"(36); medical reports were reviewed to capture regimen dosing, and then percent of doses taken was calculated. We conducted a chart review to collect the closest CD4 test result within 2 months of each assessment point.

Depressive symptoms—Depression was measured using the short-version (10- item) Centers for Epidemiological Studies Depression (CESD) Scale, (37,38) a nondiagnostic screening measure for examining the prevalence of nonspecific psychological distress in community samples. Possible scores range from 0 – 30 with a score of 10 or greater indicating depression. Cronbach's alpha for this sample was .74, lower than the published range of .85 to .92 (37).

Social Support Measures—Social support was measured using the Medical Outcomes Study-Social Support Scale (MOS-SSS) that assesses perceptions of support in the past 30 days. The 18-item scale distinguishes among 4 domains of support (affirmational, score range 0–24; informational, score range 0–32; tangible, score range 0–40; and emotional score range 0–24) and has demonstrated good reliability (α = .78 to .89) (39,40). At the 12 month

assessment for the present sample, Cronbach's alpha for the overall scale was .94 and each domain was .76, .83, .82, and .82, respectively.

Data Analysis

Descriptive statistics (proportions, means, and standard deviations) for one year after ART were used to characterize the study sample. Associations between categorical data were assessed using Pearson chi-square tests to compare proportions and *t*-tests with unequal variance to compare continuous variables. When assessing associations with stigma scores and the number of people to whom participants disclosed, we used Pearson correlations for continuous variables.

To assess change between baseline and one year measures, differences in continuous variables were tested using two-sided paired *t*-tests or Wilcoxon rank sum tests if the data were highly skewed. Associations between categorical data variables were assessed using McNemar test to compare proportions. When assessing factors associated with stigma scores and number of people to whom participants disclosed, we used independent *t*-test, Pearson chi-square, and correlation as appropriate.

We examined factors associated with stigma by fitting an ordinary least squares multivariable regression model including disclosure as a covariate. Potential confounding factors were included in the regression models. To minimize the potential for colinearity, we verified that no pair of variables included in the regression model was highly correlated ($r = .40$). To refine the model we used all variables significant at the $p = .10$ level (disclosure was included regardless of *p*-value). In the multiple regression analysis we report the beta coefficients and the standardized beta coefficients. The standardized regression beta coefficients are measured on the same scale, with a mean of 0 and a standard deviation of 1. The coefficients are then technically directly comparable to one another, with the largest coefficient indicating which independent variable has the greatest influence on the overall stigma score (41). All analyses were conducted using two-sided tests and a significance level of .05.

RESULTS

Of the 277 participants at 12 months after initiating ART, 56.3% were female, and 80% were either employed or attending school. The mean (*M*) age was 35.8 (standard deviation [*SD*] = 8.9, range 18–70) and CD4 count was $M = 308.2$ [*SD* = 156.7] range 27 – 915). Men (as compared to women) were more likely to be working or going to school (100% vs. 65%, $\chi^2(1) = 52.0, p \leq .001$), were on average 7 years older (39.7 vs. 32.7, $t = 6.83, p \leq .001$), perceived less informational support (11.3 vs. 13.5, $t = 2.69, p \leq .01$), and had lower personalized stigma scores (23.7 vs. 25.3, 3.3, $t = p \leq .001$).

At both assessment points (data not shown in tables), women disclosed to more people than men (men: 2.7 persons at ART initiation and 4.5 persons at 12 months; women: 4.5 persons at ART initiation and 6.3 persons at 12 months, $p \leq .05$). One year after ART initiation, women were more likely to disclose to a family member (87.9% vs. 62.8%, $p \leq .001$), where as men were more likely to disclose to a co-worker (16.5 vs. 8.3, $p \leq .05$). There were no sex differences in disclosure to partner/spouse (men 59.5%, women 48.7%) or friends (men 31.4%, women 22.4%). There were no other sex differences from ART initiation to 12 months after ART initiation for depression, perceived social support, or in stigma scores.

Although the overall mean perceived social support scores ranked at 52.8 percentile, mean scores for the sub domains of informational and emotional perceived support were low, falling into the 37.5% percentile. Stigma scores (overall as well as for the three domains) were high with mean scores in all three domains falling within 64th–68th percentile.

Table 1 illustrates the comparison of socio-demographic and clinical characteristics, and stigma, depression, and social support scores, among study participants at ART initiation and 12 months later. There were several important changes in psychosocial factors from ART initiation to 12 months after ART initiation. Specifically, perceived social support decreased (mean score 61.7 vs. 55.3, $t = 4.87$ $p < .001$), depression increased (3.7 vs. 6.2, $t = 9.18$ $p < .001$), and there were several slight but significant increases within the 3 stigma domains.

In regards to associations between stigma and disclosure 12 months post initiating ART (see Table 2 and Table 3), lower overall stigma score was significantly associated with disclosing to more people ($r = -0.21$, $p \leq .001$), specifically to friends (55.8 vs. 51.9, $t = 4.52$, $p \leq .001$), or co-workers (55.2 vs. 51.6, $t = 2.99$, $p \leq .01$); however there was no difference in the overall stigma score when disclosing to a spouse or partner (54.5 vs. 55.0, $p \leq .51$). There were no significant associations between stigma and self-reported adherence or CD4 count. Additionally, at the 12-month assessment, there were no important differences between stigma and socio-demographic characteristics such as education, income, currently working or going to school, or living with a spouse or partner.

Finally, as illustrated in Table 4, after controlling for all significant associations with the overall stigma scale at the significance level of .10, we found, compared to the other variables studied, depression was significantly related to and contributed most to stigma (standardized beta = .23, $t = 4.12$ $p \leq .001$). In addition, our results indicated that, rather than the number of people to whom the person disclosed, the type of person to whom the person disclosed was associated with lower overall stigma. Rather than spouse, partner or other family member, disclosing one's HIV status to a friend was significantly associated with lower overall stigma (standardized beta = 0.18, $t = 2.86$, $p \leq .05$).

DISCUSSION

The pathways through which stigma influences psychological distress for people with HIV remain understudied in Africa. To enhance understanding of stigma among persons on ART, we assessed stigma and several psychosocial factors among 277 Mozambicans on an ART regimen. One year after initiating ART, there was no change in stigma. However participants reported an increase in depression (no difference between men and women), a decrease in perceived social support, and an increase in disclosure, with women disclosing their HIV status to more people than men. Additionally, we found no associations between stigma and self-reported adherence, CD4 count, or socio-demographics indicators. In the final multivariate analysis, stigma increased with depression and decreased when HIV status was disclosed to friends.

We found stigma was related to overall well-being in terms of depression and perceived social support and it was not a matter of disclosing to more people, but to whom one disclosed that was associated with stigma. Initially disclosing to one's family may be important to garner support to address HIV illness, access care, and take medications (42,43), but as individuals begin living longer with their HIV status, disclosing to individuals outside the realms of family (i.e., to friends) may make a difference in stigma. However, recommending that health care providers counsel patients to disclose should be approached with caution. A recent study linked disclosure of HIV status to friends, family, and community members to extensive physical and verbal abuse (44). Health care providers need special training and resources to provide assistance in addressing disclosure concerns (45). While disclosing to family and friends may reduce stigma, other coping behaviors used by some HIV positive persons include seeking counseling and joining support groups (46).

We found an increase in depression symptomology 12 months after initiation of ART. These results suggest the need that long term HIV care must incorporate the assessment and treatment of depression (16). Studies have demonstrated that depression can be successfully treated among HIV-positive individuals, and that treatment of depression leads to improved health outcomes (47–51). A review of the literature on the treatment of depression in the context of HIV (52) reported that both psychosocial and psycho-pharmacologic treatments of depression appear to be effective for individuals with HIV.

Additionally, while depression increased among participants in this study, social support decreased. Several other studies have documented a relationship between depression and social support as well (53–55). These findings suggest that one way to intervene to decrease rates of depression could be to increase social support for people with HIV in the form of group support or peer or buddy support. However, increasing social support is usually tied to encouraging people to disclose their HIV status, and as previously discussed this should be done cautiously.

One limitation of this study is that, as a sub analysis, it was not specifically designed to evaluate the psychosocial factors of patients on ART, and causal inferences cannot be made. However, because of the longitudinal nature of the study, we were able to show associations among these important psychosocial factors and how they changed over time, thereby illustrating the need for future studies to specifically examine stigma and depression over time. Additionally, as this study included only one site in the second largest urban center in Mozambique, the results may not be generalizable to rural areas or other urban centers with differing infrastructure or cultural beliefs.

We found that although persons living on ART for a year disclosed to more people, stigma did not change and there was a sense of less social support. However, disclosing to a friend may actually serve as a protective factor. Finally and most noticeably was the increase in symptoms of depression over time. These findings highlight how important it is for policy makers and clinicians to recognize that living with HIV is a dynamics process, and HIV care in comparable settings should include counselling prior to and throughout treatment that includes stigma and disclosure concerns. More importantly, on going assessment of depression symptomology and treatment for depression should be incorporate into HIV care.

Acknowledgments

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Table 1

Comparison in Socio-demographic, Perceived Social Support, Stigma, Disclosure and Clinical Characteristics among 277 HIV-Positive Mozambicans at ART Initiation and 12 Months after ART Initiation

	ART Initiation		12 Months after ART Initiation		Test Statistic
	n	%	n	%	$\chi^2=$
Socio-demographic					
Working or going to school	186	67.2	223	80.5	23.20***
Living with spouse or partner	141	50.9	147	53.1	1.29
Education 8 or more years	111	40.1	111	40.1	
Relationship of person disclosed to					
Spouse or partner	114	41.3	148	53.4	17.29***
Family	169	61.2	198	72.0	12.90***
Friends	35	12.7	73	26.4	22.40***
Co-worker	21	7.6	33	11.9	5.14*
	Mean (SD)		Mean (SD)		$t=$
Number of person disclosed HIV status to Clinical	2.97	3.39	5.53	8.69	5.43***
Adherence to ART in the last 7 days(%)	97.3	0.13	96.7	0.14	0.55
CD4 cell count 10^6 cells/L	131.5	81.3	308.2	156.7	17.96***
Depression	3.7	4.1	6.2	3.0	9.18***
Perceived Social Support					
Overall score	61.7	20.7	55.3	22.7	4.87***
Affirmational	16.0	6.8	15.6	0.4	0.90
Informational	13.5	6.0	12.5	6.6	2.41**
Tangible	22.1	7.1	20.6	8.4	2.99**
Emotional					
Stigma					
Overall Stigma score	53.6	10.2	54.8	6.6	1.92
Personalized stigma	23.6	5.3	24.7	4.0	3.31***

	ART Initiation		12 Months after ART Initiation		Test Statistic
	n	**%**	**n**	**%**	**χ²=**
Negative self-image	15.4	2.4	16.1	1.8	4.49 ***
Social or public stigma	22.3	3.8	23.0	3.8	3.00 **

Note. † Depression is on a 10 item scale. Possible score range from 0 -30, score 10 or higher is considered depressed.

χ^2= McNemar Chi2 (1 degree of freedom) for categorical data

t = two-sided paired t-test for continuous data

SD = standard deviation

*
p < 0.05,

**
p < 0.01,

***
p < 0.001

Table 2

Correlations (r) of Perceived Social Support, Clinical Characteristics and Disclosure with Stigma among 277 HIV-Positive Men and Women Mozambicans 12 Months after ART initiation

	Overall Stigma Score	Stigma Domains		
		Personalized Stigma	Negative Self-image	Social/ Public Stigma
Clinical				
Adherence to				
ART in the last 7 days	0.04	0.02	0.02	0.01
CD4 cell count 10^6 cells/L	−0.08	−0.09	0.03	0.03
Depression	0.24***	0.26***	−0.13*	−0.22***
Perceived Social Support				
Overall score	−0.12*	−0.11	−0.12*	−0.13*
Affirmational	−0.08	−0.07	−0.11	−0.11
Informational	−0.07	−0.05	−0.09	−0.09
Tangible	−0.17**	−0.16**	−0.16**	−0.18**
Emotional	−0.11	−0.12*	−0.07	−0.12*
Number of person disclosed				
HIV status to	−0.17**	−0.14*	−0.24***	−0.21***

Note. r = Pearson product-moment correlation coefficients.

*
$p < 0.05$

**
$p < 0.01$

***
$p < 0.001$

Table 3

Relationship with Person's Disclosed to with Stigma among 277 HIV-Positive Men and Women Mozambicans 12 Months after ART initiation

| | Overall Stigma Score | t statistic | Stigma Domains | | | | | |
			Personalized Stigma	t statistic	Negative Self-image	t statistic	Social/Public Stigma	t statistic
Mean stigma scores of those who disclosed (compared to those who did not disclose):								
Spouse or partner	54.5 (55.1)	0.66	24.4 (25.0)	1.27	16.0 (16.1)	0.25	22.7 (23.2)	1.14
Family member	54.4 (55.9)	1.70 *	24.5 (25.0)	0.90	15.8(16.60	3.41 ***	22.7(23.6)	1.80 *
Friend	51.9 (55.8)	4.52 ***	23.3 (25.1)	3.48 ***	15.3 (16.3)	4.21 ***	21.5 (23.5)	3.88 ***
Co-worker	51.6 (55.2)	2.99 **	23.5 (24.8)	1.76	15.2(16.2)	3.01 **	21.4 (23.2)	2.53 **

Note. Significance test were conducted using a two sided t test.

*
p < 0.05

**
p < 0.01

***
p < 0.001

Table 4

Summary of Regression Analyses for Variables Predicting Perceived Stigma at 12 Months after ART Initiation (N=277)

	B	SE (B)	β	t statistic
Female	1.35	0.77	0.10	1.76
Depression	0.52	0.13	0.23	4.12 ***
Number of person disclosed HIV status to	−0.87	0.04	−0.11	−1.82
Disclosed to:				
Family member	−0.91	0.88	−0.06	−1.03
Friend	−2.65	0.93	−0.18	−2.86 *
Co-worker	−1	1.21	−0.05	−0.82
Perceived Social Support				
Tangible	−0.12	0.76	−0.15	−1.6
Emotional	−0.05	0.14	−0.37	0.39
R^2		15.3		
F (8,265)		7.14		

Note. B = unstandardized beta, β = standardized beta, SE(B) = standard error beta