Published in final edited form as:

AIDS Care. 2009 November ; 21(11): 1357–1362. doi:10.1080/09540120902862576.

The Impact of Taking or Not Taking ARVs on HIV Stigma as Reported by Persons Living with HIV Infection in Five African Countries

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Abstract

Aim—This study examined the impact of taking or not taking antiretroviral (ARV) medications on stigma, as reported by people living with HIV infection in five African countries.

Design—A two group (taking or not taking ARVs) by three (time) repeated measures analysis of variance examined change in reported stigma in a cohort sample of 1,454 persons living with HIV infection in Lesotho, Malawi, South Africa, Swaziland, and Tanzania. Participants self-reported taking ARV medications and completed a standardized stigma scale validated in the African context. Data were collected at three points in time, from January 2006 to March 2007. Participants taking ARV medications self-reported a mean CD4 count of 273 and those not taking ARV self-reported a mean CD4 count of 418.

Results—Both groups reported significant decreases in total HIV stigma over time; however, people taking ARVs reported significantly higher stigma at Time 3 compared to those not taking ARVs.

Discussion—This study documents that this sample of 1,454 HIV infected persons in five countries in Africa reported significantly less HIV stigma over time. In addition, those participants taking ARV medications experienced significantly higher HIV stigma over time compared to those not taking ARVs. This finding contradicts some authors' opinions that when clients enroll in ARV medication treatment it signifies that they are experiencing less stigma. This work provides caution to health care providers to alert clients new to ARV treatment that they may experience more stigma from their families and communities when they learn they are taking ARV medications.

Keywords

HIV/AIDS; stigma; antiretrovirals; Africa

Introduction

AIDS stigma and discrimination have considerable influence on people living with HIV infection, particularly in sub-Saharan Africa, where the burden of AIDS is so significant (Phaladze et al., 2005). Stigma has developed into a major barrier to HIV prevention and care (Weiss & Ramakrishna, 2001). It is a deterrent to testing and treatment (Newman, 2002), which may result in delays to seek care and possibly increasing suffering and mortality. Many experts have concluded that programs must address stigma in order to be successful (L. R. Uys, 2000).

The development of antiretroviral (ARV) medications in the late 1990s altered the face of HIV/AIDS, transforming it from a fatal disease into a chronic illness. Many believed that as more people gained access to ARV treatment, and as the disease itself was transformed, stigma would decline. Such has been the case in Brazil, where a study of young people living with HIV (Abadia-Barrero & Castro, 2006) showed that access to ARV treatment reduced stigma. Thus, universal access has become an important intervention against stigma.

For some, however, the opposite has been true. Taking medications may indicate that someone is HIV-positive, so someone who does not wish to disclose his/her status may avoid taking medications. In a qualitative study with 25 adolescents and young adults (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007), half of the participants had missed medication doses for fear of disclosing their status and possible subsequent stigma. In a study of 204 HIV-positive people in the United States, Rintamaki and colleagues (Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006) similarly found that worry about disclosing one's HIV status was a significant predictor of adherence to medications. However, a study in Botswana (Nam et al., 2008) found that acceptance of one's HIV-status helped people avoid internalizing stigma and they were more adherent to their medications. These studies report the conflicting relationship between HIV stigma and outcome variables.

Various studies have also documented the negative impact of both treatment side effects and stigma on an individual's ability to be adherent to medications (Hardon et al., 2007; Weiser et al., 2003). Not only can the side effects of ARVs be bothersome, but they can also cause visible side effects, or "stigma symbols," which add to existing stigma that one may perceive or receive as a person living with HIV infection (Holzemer, Uys, Makoae et al., 2007). In a study of HIV-positive men and women on ARVs in Rwanda, participants noted visible body fat redistribution as a side effect of their treatment. The body fat redistribution negatively affected their quality of life, and could result in stigma and, ultimately, poorer medication adherence (Mutimura, Stewart, & Crowther, 2007).

Although the literature reports a great deal of research on adherence and stigma in various settings, there is little research on understanding the relationships between taking ARV medications or not, and HIV stigma in persons living with HIV infection. Program managers may assume that ARV therapy will improve people's lives. However, if the side effects and potential resulting stigma are significant, people may decide to delay initiation of ARV therapy, or even forgo it altogether. If the second phase of The President's Emergency Plan for AIDS Relief (PEPFAR) is to be successful in sub-Saharan Africa with further "roll out" of ARVs, program planners and managers need a greater understanding of the relationship between HIV stigma and taking ARV medications. The purpose of this study, therefore, was to examine whether there are differences in HIV stigma over time between persons who are taking ARV medications and those not taking ARV medications in five African countries.

METHODS

Design

A purposive convenient sample of 1,454 people living with HIV infection in Lesotho, Malawi, South Africa, Swaziland, and Tanzania was followed for one year in a longitudinal design that examined stigma change. Participants self-reported taking ARV medications, and completed a standardized stigma scale, which had been validated in the African context. The data were collected in three assessment periods, about six months apart, between January 2006 and March 2007. A two-group (taking or not taking ARVs) by three (time) repeated measures analysis of variance examined change in HIV stigma over time. This is part of a larger study on HIV/AIDS-related stigma in Africa (Dlamini et al., 2007; Greeff et al., 2008; Holzemer, Uys, Makoae et al., 2007; Holzemer, Uys, Chirwa et al., 2007; Kohi, 2006; Makoae et al., 2008; Naidoo et al., 2007; L. Uys et al., 2005).

Protection of Human Subjects

The study protocol was reviewed and approved by all seven of the universities involved (see author list), providing protection of human subjects. As appropriate, permission for the study was also obtained from central and local government authorities. Participants received information about the background of the study, were informed that participation was completely voluntary, and were also told that they could withdraw at any time. They were also assured of the confidentiality of the information obtained. After receiving this explanation – in the local language of their country – each person who agreed to participate signed a written consent form. The participants received reimbursements for their transportation, and lunch was provided. The surveys were conducted either in English or in the local languages: English and Tswana in South Africa; Chichewa in Malawi; SeSotho in Lesotho; Swazi in Swaziland; and Kiswahili in Tanzania. Most participants completed the self-report surveys with some assistance from the research staff.

Settings and Sample

Each of the five sites had a goal of collecting data from 300 persons living with HIV infection, at three points in time over approximately 12 months (baseline, six months, and 12 months). Potential participants were recruited from HIV support groups or HIV clinics. If the person agreed to participate, the field worker made an appointment to meet at a convenient place and time to collect that data.

Measures

The participants completed a survey booklet with a series of instruments at each of the three points in time. Two instruments were used for the analysis reported here:

1) Demographic Questionnaire—The multiple-item Demographic Questionnaire was used to obtain demographic and illness background data from the participants. These items included age, gender, education level, marital status, number of children, number of people living in the same home, work for pay, whether they were currently taking ARV medications, and the year of HIV diagnosis.

2) HIV/AIDS Stigma Instrument – PLWA (HASI-P) (Holzemer, Uys, Chirwa et al., 2007)—The HASI-P is a 33-item instrument that measures six dimensions of HIV-related stigma (verbal abuse, negative self-perception, health care neglect, social isolation, fear of contagion, workplace stigma) and total HIV stigma. The Cronbach alpha reliability coefficients for the scale scores range from 0.76 to 0.90. The instrument was developed based upon qualitative interviews with persons living with HIV infection in each of the five participating sites. Sample items from each of the six factors are presented in Table 4.

Data Analysis

Responses to the questionnaires were entered into Statistical Package for the Social Sciences (SPSS) for Windows Version 15.0 software. Descriptive statistics (i.e., means, standard deviations, frequencies, and percents) were used to examine demographic characteristics of the sample and stigma. A two-group repeated measures analysis of variance was conducted to determine the relationship between taking and not taking ARVs and HIV stigma.

RESULTS

Sample

The total sample size was 1,454 and was approximately equally distributed by country (See Table 1). When comparing the people taking ARVs with those not taking ARVs with regard to demographic variables, the two groups differed significantly on age, marital status and setting. Younger participants, those not married, and those living in urban areas were less likely to be taking ARV medications. CD4 counts were self-reported. Those not on ARVs reported a mean CD4 count of 418 (SD=225, n=314) and those taking ARVs reported a mean CD4 count of 273 (SD=196, n=440; $t = 9.403$, $df = 752$, $p < 0.000$).

Attrition

The overall participant attrition rate (see Table 1) or loss during the study was 31% (n=447) over the one year period. The attrition percentages varied by country with Swaziland losing the most and South Africa losing the least. Participant loss generally occurred between the second and third assessment period. A comparative analysis of participants who stayed and those who left the study over time demonstrated no differences in gender, age, marital status, taking and not taking ARVs, or setting.

Stigma

The mean summed scores for total HIV stigma over time for people taking and not taking ARVs are reported in Table 3. At Time 1, those not taking ARVs reported more HIV stigma ($M = 0.471$) than those taking ART ($M = 0.425$). At Times 2 and 3, however, those not taking ARVs reported less HIV stigma ($M = 0.410$ and $M = 0.250$ respectively) than those taking ARVs ($M = 0.423$ and $M = 0.314$, respectively) (see Table 3). Repeated measures ANOVA showed that there were significant differences in overall stigma levels over time ($F=52.91$; $df = 2, 928$; $p<.0001$), and there was a significant interaction between stigma and taking ARV medications ($F=5.81$; $df = 2, 928$; $p<.006$).

Stigma Change by Factor Scores

Six separate analyses of variance (ANOVAs) were conducted to explore where the change over time in HIV stigma occurred (See Table 4). Five of the six factors had a significant main effect of time, demonstrated by decreased total HIV stigma over time. Factor 6, Workplace Stigma, did not change over time. Three of the factor scores (Verbal Abuse, Negative Self-Perception, and Social Isolation) showed significant interactions, demonstrating that those taking ARVs reported higher scores on these three factors. There were no differences for the factors Health Care Neglect or Fear of Contagion. Since there was no significant main effect of change over time for Workplace Stigma, the interaction cannot be interpreted.

Stigma Change Within-Subjects

Total stigma scores were examined across time. HIV stigma was significantly different between Time 1 and 3 ($p <.000$) and Time 2 and 3 ($p <.000$) (see Table 3). The interaction between stigma and ARV use was significant between Time 1 and 3 ($p <.001$). The interaction of time and HIV stigma between the two groups is graphically presented in Figure 1. Participants not taking ARVs initially reported higher levels of stigma but, one year later, those participants taking ARVs reported greater stigma.

DISCUSSION

The results of this study indicate that the roll-out of ARV treatment is not a magic cure for HIV stigma, as many expected. However, based upon self-reported CD4 levels, this five country sample appears to have been appropriately treated with ARVs, given the significant difference in self-reported CD4 counts. HIV stigma significantly decreased over time for both groups, but those taking ARVs did report higher levels of total HIV stigma by Time 3. This might be related to the fact that it is difficult to hide one's status when taking ARVs. Taking ARV medications requires regular visits to health care providers and daily intake of several pills. Frequent clinic visits, blood draws, and taking pills are aspects of antiretroviral therapy that are difficult to hide. The model of HIV stigma by Holzemer and colleagues (2007) outlines triggers that can identify a person as being HIV-positive and lead to HIV stigma. Given this theoretical work, it is not surprising that taking ARV medications increases HIV stigma for some individuals.

Another factor that might increase the stigma reported by those taking ARVs is the belief in communities that you only take ARVs when you are already very sick. Taking medications is seen as an indication of severity of illness that might, in itself, increase stigma, since it increases fear. This is a perception that needs to be addressed by health care providers doing health education. Taking ARV medication should imply that the individual is participating in appropriate health monitoring and seeking treatment to retard illness progression.

The finding that significantly more older people are taking ARVs can be explained by the fact that the medication is only taken in more advanced stages of the illness. There are a number

of factors that might influence the finding that fewer people who were never married are using ARVs. One could speculate that single people are younger, and that this finding is linked to the previous one. Another factor is that many of the countries require a person who comes for ARV treatment to bring a “treatment partner.” Such a partner is probably easier to find for a person who is in a more permanent relationship. Being in a more permanent relationship might also motivate a person to be tested and get onto medication, while single people might find it easier to remain untested and not to confront their own status. It is more difficult, however, to explain why fewer people living in urban areas are on ARVs. This may be related to a sampling error, since more rural people than urban and peri-urban were lost from the sample.

Another interesting result of the study was the general decline in HIV stigma as reported by people living with HIV infection in the five countries. This is good news for all affected and infected and for the health services in general.

ARV treatment is currently the only medical hope for people infected with HIV who require therapy. To help people have a better quality of life with the disease in the long term, we must recognize that taking ARVs may increase HIV stigma and this increased stigma may create a barrier to continuing the treatment if it is not addressed by health care providers. Although community-level stigma may be decreasing, it may not be true at the individual level for persons taking ARVs who are identified because of their medications and thus become targets for stigma and discrimination. More information is needed about whether a fear of stigma may be keeping some HIV-positive people from seeking care and treatment.

Acknowledgments

This work was supported by NIH Research Grant #R01 TW06395 funded by the Fogarty International Center, the National Institute of Mental Health, and the Health Resources and Services Administration, U.S. Government.

References

- Abadia-Barrero CE, Castro A. Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Social Science and Medicine* 2006;62(5):1219–1228. [PubMed: 16099573]
- Dlamini PS, Kohi TW, Uys LR, Phetlhu RD, Chirwa ML, Naidoo JR, et al. Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries. *Public Health Nursing* 2007;24(5):389–399. [PubMed: 17714223]
- Greeff M, Phetlhu R, Makoae LN, Dlamini PS, Holzemer WL, Naidoo JR, et al. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative Health Research* 2008;18(3):311–324. [PubMed: 18235155]
- Hardon AP, Akurut D, Comoro C, Ekezie C, Irunde HF, Gerrits T, et al. Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa. *AIDS Care* 2007;19(5):658–665. [PubMed: 17505927]
- Holzemer WL, Uys L, Makoae L, Stewart A, Phetlhu R, Dlamini PS, et al. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing* 2007;58(6):541–551. [PubMed: 17484748]
- Holzemer WL, Uys LR, Chirwa ML, Greeff M, Makoae LN, Kohi TW, et al. Validation of the HIV/AIDS Stigma Instrument - PLWA (HASI-P). *AIDS Care* 2007;19(8):1002–1012. [PubMed: 17851997]
- Kohi T, Makoae L, Chirwa M, Holzemer WL, Phetlhu DR, Uys Leana, Naidoo J, Dlamini PS, Greeff M. HIV and AIDS stigma violates human rights in five african countries. *Nursing Ethics* 2006;13(4):405–414.
- Makoae LN, Greeff M, Phetlhu RD, Uys LR, Naidoo JR, Kohi TW, et al. Coping with HIV-related stigma in five African countries. *Journal of the Association of Nurses in AIDS Care* 2008;19(2):137–146. [PubMed: 18328964]

- Mutimura E, Stewart A, Crowther NJ. Assessment of quality of life in HAART-treated HIV-positive subjects with body fat redistribution in Rwanda. *AIDS Res Ther* 2007;4:19. [PubMed: 17877798]
- Naidoo J, Uys L, Greeff M, Holzemer W, Makoae L, Dlamini P, et al. Urban and rural differences in HIV/AIDS stigma in five African countries. *African Journal of AIDS Research* 2007;6(1):17–23.
- Nam SL, Fielding K, Avalos A, Dickinson D, Gaolathe T, Geissler PW. The relationship of acceptance or denial of HIV-status to antiretroviral adherence among adult HIV patients in urban Botswana. *Social Science and Medicine*. 2008
- Newman, P.; Grusky, O.; Roberts, SJ.; Rivkin, I. Organizational factors in the early detection of HIV. The XIV International AIDS Conference; 2002; 2002.
- Phaladze NA, Human S, Dlamini SB, Hulela EB, Hadebe IM, Sukati NA, et al. Quality of life and the concept of “living well” with HIV/AIDS in sub-Saharan Africa. *J Nurs Scholarsh* 2005;37(2):120–126. [PubMed: 15960055]
- Rao D, Kekwaletswe TC, Hosek S, Martinez J, Rodriguez F. Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care* 2007;19(1):28–33. [PubMed: 17129855]
- Rintamaki LS, Davis TC, Skripkauskas S, Bennett CL, Wolf MS. Social stigma concerns and HIV medication adherence. *Aids Patient Care and STDS* 2006;20(5):359–368. [PubMed: 16706710]
- Uys L, Chirwa M, Dlamini P, Greeff M, Kohi T, Holzemer W, et al. Eating plastic, winning the lotto, joining the WWW: Descriptions of HIV/AIDS in Africa. *Journal of the Association of Nurses in AIDS Care* 2005;16(3):11–21. [PubMed: 16433113]
- Uys LR. Confidentiality and HIV/AIDS in South Africa. *Nursing Ethics* 2000;7(2):158–166. [PubMed: 10986941]
- Weiser S, Wolfe W, Bangsberg D, Thior I, Gilbert P, Makhema J, et al. Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndromes* 2003;34(3):281–288. [PubMed: 14600572]
- Weiss MG, Ramakrishna J. Conference examines need for more study of AIDS stigma. *AIDS Policy Law* 2001;16(18):4. [PubMed: 11591006]

Figure 1.
ARV Medication Use and Stigma Over Time

Table 1

Sample Size by Time for Each of the Five Countries

Country	Time 1 % (n)	Time 2 % (n)	Time 3 % (n)	% sample loss
Lesotho	18.8% (273)	20.1% (251)	17.4% (175)	33%
Malawi	17.7% (258)	19.9% (246)	20.4% (206)	20%
South Africa	21.8% (317)	24.1% (299)	28.3% (285)	10%
Swaziland	21.0% (304)	15.4% (191)	15.8% (159)	48%
Tanzania	20.7% (302)	20.5% (255)	18.1% (182)	40%
Totals	100% (1,454)	100% (1,242)	100% (1,007)	31% (447)

Table 2

Sample Characteristics Comparing Participants who were on ARVs and those not on ARVs.

Variable	Not Taking ARVs N=488	Taking ARVs N=443	Sample Size N=931	Significance
Age	M=35.05 SD=8.28	M=36.97 SD=8.51	904	F=.011, df=902, p=0.451
Years HIV	M= 3.1 SD=2.6	M=3.32 SD = 2.74	924	F=1.06 df=922, p=0.211
Sex	Female= 54.2% Male= 47.7%	Female= 45.7% Male= 52.3%	931	X ² =0.69, df=1, p=0.041
Marital status				
Never married	66.8%	33.2%	325	X ² =55.83, df=4, p=0.00
Married	42.5%	57.9%	254	
Widowed	41.1%	58.9%	209	
Divorced	41.9%	58.1%	74	
Cohabiting	67.2%	32.8%	58	
Work for pay	No = 53% Yes = 49.2%	No = 46.5% Yes = 50.8%		X ² =1.36, df=1, p=0.263
Setting				
Urban	57.7%	42.3%	388	X ² =12.45, df=2, p=0.002
Peri-urban	52%	48%	298	
Rural	43.1%	56.9%	232	
Highest education qualification				
Certificate	49.2%	50.8%	197	X ² =5.12, df=4, p=0.275
Diploma	37.5%	62.5%	24	
Advanced	0	100%	3	
Degree	50%	50%	2	
Post-grad	75%	25%	4	
Self-Reported CD4 Counts				
	M=418 SD=225 n=314	M=273 S=196 n=440	N754	T=9.403 df=752 p=<0.000

Table 3

Mean and SD Differences in Stigma Level Among Participants Taking and Not Taking ARVs Over Time (n=904)

	Time 1 Mean (SD)	Time 2 Mean (SD)	Time 3 Mean (SD)
Off ARVs	.47 (.49)	.41 (.45)	.24 (.36)
On ARVs	.43 (.45)	.42 (.48)	.31 (.41)

Table 4

Six separate ANOVAS with one between factor (ARVs -on/off) by one within factor (Time -3 levels) with the six stigma mean factor scores as dependent variables.

Factor	Time 1	Time 2 (Mean Scores)	Time 3	Main Effect Time	Interaction Time by ARV
1) Verbal Abuse (8 items, $\alpha=0.89$) "someone scolded me"					
Taking ARVs	0.58	0.59	0.44	F=37.65 df=2 p=0.000	F=4.07 df=2,927 p=0.017
Not Taking ARVs	0.58	0.51	0.29		
2) Negative Self Perception (5 items, $\alpha=0.91$) "I felt completely worthless"					
Taking ARVs	0.79	0.78	0.57	F=56.52 df=2 p=0.000	F=7.55 df=2,916 p=0.016
Not Taking ARVs	1.03	0.84	0.53		
3) Healthcare Neglect (7 items, $\alpha=0.83$) "I was denied healthcare"					
Taking ARVs	0.14	0.12	0.09	F=9.67 df=2 p=0.000	F=0.24 df=2,916 p=0.790
Not Taking ARVs	0.13	0.12	0.07		
4) Social Isolation (5 items, $\alpha=0.89$) "People cut down on visiting me"					
Taking ARVs	0.56	0.28	0.26	F=59.86 df=2 p=0.000	F=10.16 df=2,925 p=0.000
Not Taking ARVs	0.56	0.42	0.22		
5) Fear of Contagion (6 items, $\alpha=0.79$) "I was told to use my own eating utensils"					
Taking ARVs	0.20	0.24	0.17	F=12.26 df=2 p=0.000	F=1.46 df=2,925 p=0.234
Not Taking ARVs	0.22	0.22	0.13		
6) Workplace Stigma (2 items, $\alpha=0.76$) "Someone tried to get me fired at work"					
Taking ARVs	0.18	0.13	0.17	F=0.83 df=2 p=0.437	F=3.63 df=2,904 p=0.03
Not Taking ARVs	0.15	0.17	0.10		