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Stigma and HIV/AIDS in South Africa: Exploring Respect and Treatment Adherence

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Authors' contributions

This work was carried out in collaboration between all authors. Author JE helped design the study, undertook interpretation of the data and wrote the final drafts of the paper. Author OL undertook the analyses of the data and wrote the first draft of the manuscript. Author SB helped design the study, provided comments on interpretations and edited drafts of the paper.

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ABSTRACT

Aims: The purpose of this study is to contribute to the study of the relationships between stigma and HIV/AIDS treatment adherence in South Africa.

Study Design: A mixed method investigation employed cross-sectional exit surveys in four sites in South Africa (N=1200) and in-depth interviews with 15 patients from 2 sites, one urban and one rural.

Place and Duration of Study: This paper is part of a 5 year long study on three forms of treatment for conditions with adverse outcomes, TB, maternal delivery and HIV/AIDS. It took place between 2008 and 2012 in four sites in South Africa, two urban – Soweto and Mitchell's Plain and two rural – Bushbuckridge and Hlabisa.

Methodology: The mixed method design used clinic-based exit interviews in multiple sites in the four study areas, selection being based on a stratified approach to include clinics with such characteristics as size, patient flow, geographical accessibility. Patients

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exiting those clinics were randomly selected for inclusion in the study. All participants were required to be 18 years old or over. Qualitative research took place in Soweto and Bushbuckridge only because of resource constraints. A total of 15 people 4 men, 11 women, between the ages of 27 and 59) were interviewed, some twice on the trajectories of their illnesses. Standard analytic packages of SPSS and Atlas-TI were used for analysis.

Results: The interviews established the importance of various forms of stigma in these populations as well as the importance of social and family support. Gaps were identified in the social support system yet there remained a degree of hope and optimism among the patients. In the quantitative analyses, reports of associations are laid out because of the problematic relationship between stigma and adherence noted in the literature. All associations (except for respect from health care providers are significant at 0.05 with wealth associations being highly significant (0.000, 0.003) as are community support measures (0.000, 0.002). The logistic regression results show few significant relationships with only social support (0.000) being significant for missing taking ARV tablets.

Conclusion: The research presented in this paper is largely supportive of other work on stigma as well as on adherence. It puts forward some suggestions, based on associative analyses, on the still perplexing relationship between stigma and adherence.

Keywords: Stigma; respect; adherence; HIV/AIDS; South Africa.

1. INTRODUCTION

Although South Africa still possesses the highest number of people living with HIV/AIDS (PLHA), 5.6 million [1-3] with a prevalence rate of 17.3 percent in 2011 (15.9 percent in 2001) among adults aged 15 to 49), the fourth highest in the world, it shares global improvements in HIV/AIDS identified by many international agencies. The number of newly infected children was halved between 2009 and 2011. The proportion of those receiving anti-retroviral therapy (ART) has increased to over 46 percent of sufferers (2.6 million). Yet challenges remain. The death rate from AIDS continues to rise, albeit slowly. Condom use remains low with surveys indicating 35 percent use (2009). Testing of infants born to HIV+ women stands at 50 percent and worryingly in 2011, among those living with HIV aged 15 to 24, more than twice as many women as men were infected (11.9% to 5.3%). These factors are related to many of the structural forces of South African society, but not necessarily limited to apartheid and post-apartheid conditions, but also high levels of economic distress, gender-based violence, over-stretched health and social services and community stigma. There has been much research on HIV/AIDS stigma in South Africa and while this topic was not a primary interest in designing this study, there emerges a cautionary, counter-intuitive tale about how reducing stigma may result in low levels of treatment adherence.

Stigma and its reduction strategies have been recognized as important dimensions for PLHA and their life circumstances. It has been widely recognized that stigma is a key obstacle for HIV prevention and treatment [4,5]. And it remains a challenging phenomenon, still limiting access to care and treatment adherence [6,7]. The complexity of HIV/AIDS stigma, against the backdrop of diverse cultural settings, has resulted in limited and often varying response on how to address this pervasive phenomenon [8]. In South Africa, anti-stigma policies for PLHA have been piecemeal and secondary, felt by many to be dealt with after structural discriminations are removed. Furthermore, the separation of HIV/AIDS treatment in clinics may add to stigma [9]. And the denial of a link between HIV and AIDS during the years of the Mbeki presidency (1999-2008) resulted in a piecemeal start for treatment in general

[10]. Studies assessing stigma felt by people living with HIV and AIDS (PLHA) fall broadly into the following three categories: perceived stigma, experienced stigma and internalized stigma [11]. Perceived stigma measures how PLHA believe that their partners, friends, family, community or health care workers treat them or would treat them if they were aware of the infected person's status. Experienced stigma is often measured with respect to discrimination, for example, being denied access to health care, or being excluded by one's family or community. Yet it must be recognized that this 'enacted stigma may be accompanied by 'felt' or internalized stigma, a perceived status of being unworthy and disadvantaged [12] which may lead to negative self-image; this includes feelings of shame and guilt for being HIV-positive. Internalized stigma often leads to self-isolation and fear of disclosure. Successful adherence to treatment may reduce these adverse ideas but as our paper argues does this reduction lead to risky and non-compliant behaviours?

There is now much research in South Africa and elsewhere which has examined stigma and destigmatization (the reduction or removal of those phenomena leading to stigma). In unequal societies with conservative social dynamics, inequalities often persist as the tension between disclosure and secrecy, because of stigma, has real consequences [4,13]. According to Goffman [14], stigma is an attribute that extensively discredits the individual, reducing him or her "from a whole and usual person to a tainted, discounted one." It has been proposed that stigmatization occurs when an attribute conveys a social identity that is devalued in a particular social context" [15]. These definitions share the assumption that people who are stigmatized have (or are believed to have) an attribute that marks them as different and leads them to be devalued in the eyes of others [16]. In the context of PLHA, this view is strongly internalized [17], especially in more unequal, conservative societies or communities. This context and its likely impact on individual and group interactions has been identified by Joffe [18] and used in recent empirical studies. Campbell et al. [19] confirm that information – often top-down – about HIV is not enough for HIV prevention as non-sufferers may well stigmatize PLHA, although they know it to be wrong, because of lurking concerns about sexual promiscuity and low economic productivity. The bases of stigma are quite arbitrary [20]. Yet it is deep-rooted and heightens social difference [21].

The importance of community support and action for PLHA is widely recognised [22]. Yet some of these issues remain less well researched or point to the need to understand the complexities of stigma production and reduction. Thus Nyblade [11] points to a need for measures at the general population level that clearly define the cause of stigmatizing behaviour, that capture enacted stigma (discrimination) and that can distinguish layered stigma. Some of this need was met by the creation of the people living with HIV stigma index [23]. Since 2008 it has been rolled out to 50 countries, but was not available when this project was undertaken. Knowing HIV status may reduce perceived stigma as treatment appears enhance health status, potentially because of high levels of support from the community and voluntary counselling [24]. Furthermore, there is a need to expand the contexts in which stigma is studied in order to capture the complexity of the phenomenon and ensure effective stigma-reduction programs. Mahajan et al. [8] point to the importance of community-based interventions with respect to HIV stigma reduction and local mobilization. Furthermore, the consequences of reducing stigma must be recognized. This may increase treatment adherence. But it is also possible for adherence to decline if health status is seen to improve. We examine these issues with respect to HIV in four South African communities. Thus the research addresses how stigma and community support affect accessibility (seen as collecting tablets and adherence (seen as related to access by the actual taking of tablets and attending clinics) to antiretroviral treatment in South Africa, using a mixed methods

approach to analyze questionnaire-guided and in-depth field interviews in two urban and rural settings, Soweto and Mitchell's Plain and Hlabisa and Bushbuckridge respectively.

2. METHODS

2.1 Study population

This study is part of a larger, multi-site investigation examining access to health care resources for HIV/AIDS, TB and maternal delivery services. Only the HIV/AIDS part of the study is reported in this paper. The study was based in four localities, two urban and two rural, respectively Mitchell's Plain (Western Cape), Johannesburg (Gauteng) and Bushbuckridge (Mpumalanga), Hlabisa (KwaZulu-Natal). This multi-purpose survey involved both surveys and in-depth interviews. The survey was patient-based administered to around 300 patients in each locale, randomized by HIV/AIDS clinics. Given the interest in access to care, the survey took the form of exit interviews, covering illness state, household characteristics and measures of social status. Economic worth is difficult to assess in sub-Saharan Africa, hence proxies such as house type and water availability were used. Furthermore, given the nature of survey administration no individual without access could be interviewed. Searching out such individuals would be a nearly impossible task, given need to know HIV status, change of cell phone numbers and personal mobility. In this study, patients' attendance at professional medical appointments and collection of antiretroviral treatment were selected as proxy measures of adherence to the ARV tablet regime. A mixed methods approach was used to analyze patients' experiences collecting and adhering to ARVs.

2.2 Interviews

The exit interviews were conducted by locally trained field workers in the sub districts. This sample reflects an urban-rural mix to account for differences in health care delivery across the provinces in South Africa [25]. Within each facility, a random sample of patients was interviewed until the proposed sample size was reached. In total, 300 individuals were interviewed per sub-district, for a projected sample size of 1200. Respondents were included if they were 18 years or older and had been on ARV treatment for at least six months.

Patient exit interview questionnaires were developed to collect demographic and socioeconomic data as well as information on health service use, direct costs associated with health care and other aspects of access to health care. The questionnaire was administered by trained interviewers in the language of the respondent's choice. Completed questionnaires were checked for accuracy by data collection coordinators within each site and double entered into a data entry platform specifically designed for this purpose in Epidata.

2.3 Analytic approaches

Data were analysed using SPSS. Univariate statistical analyses were used to discover associations between the independent variables and outcomes of missing ART tablets and visits. To control for confounding factors, binary multivariate logistic regression was performed. The variables included in the models were those found to be significantly associated with treatment adherence ($P < 0.05$) in the univariate analysis along with important socioeconomic and socio-demographic variables.

Descriptive statistics and chi-squared tests were developed to assess the association between self-reported adherence and socioeconomic, demographic, and service related characteristics. Associative analyses were performed with respect to economic and social support indicators for current employment and type of house as a measure of wealth. They were also carried out for social support and stigma: measured by being respected by healthcare workers, being judged by people in the community, queues being too long at the clinic, healthcare workers too busy to see patients, some staff not treating patients with respect, having partner support, having support from family, having support from friends, being part of a support group and having ever belonged to a support group. These measures of stigma are commonly found in the literature [26]. Given the broad purpose of the investigation, a stigma scale/index could not be employed to minimize respondent burden. Logistic regression was used to explain variations in outcomes (adherence) in terms of variations in the independent variables.

Qualitatively, 15 in-depth interviews (4 men and 11 women, aged between 27 and 59 and with poor economic status) with patients on ARV treatment in two of the four sites (Bushbuckridge and Soweto, Johannesburg) included in the quantitative phase were undertaken as resource constraints restricted this part of the study. Again, exiting the treatment facility was the way in which patients were engaged. Patients were purposively selected to reflect a range of patient treatment experiences (i.e. ART successful, partial user and defaulter). Providers facilitated the recruitment of patients within the facilities. Interview guides covered a range of issues exploring patient's life histories (i.e. social support systems, education, income, migration, work), illness trajectories (i.e. from illness onset to diagnosis and treatment, treatment seeking, stigma) and experiences with the health system (i.e. barriers constraining access and engagements with health care providers). The life and illness histories were told as narratives that related to how HIV and ARV treatments affected their lives.

Patients were interviewed by trained field workers in their first language. Follow-up interviews were conducted with three of the patients and provided an opportunity for either clarification or exploration or both. Interviews were audio-taped, transcribed and translated into English. All patients were assigned pseudonyms to protect confidentiality.

The transcripts were thematically coded using a Microsoft macro, MS-Excel v.12.0. Upon reading the transcripts, an initial set of codes, from which emerged several major themes, such as family and spousal support, adherence and transport costs. These major themes were then grouped into four central themes: 1) family and community support, 2) adherence, 3) access to treatment, 4) stigma and 5) coping. Coding was compared with that produced by other team researchers and continued until no new themes emerged. Table 1 gives a detailed description of how the transcripts were coded under these themes. Some quotations were coded to more than one theme.

2.4 Ethics

Ethical approval for the study was granted by committees at the University of Cape Town, the University of the Witwatersrand and the University of KwaZulu-Natal. Permission from health department officials and individual facility managers was obtained to conduct the study in the selected facilities. Written informed consent to participate in the study was obtained from each participant and respondents from both the survey and in-depth interviews were informed of their rights of withdrawal at any time without their care being affected.

Table 1. Coding for qualitative stigma analysis

1. Family and community support	2. Adherence	3. Access to Treatment	4. Stigma	5. Coping
1.1 Financial support	2.1.Partial Adherence (e.g. taking medication off and on, when it is convenient or safe)	3.1. Treatment from health care workers (e.g. health care workers see them immediately, health care workers yell at them, fair treatment, health care workers explain treatment clearly)	4.1.Anticipated (perceived) stigma (e.g. stereotypes, prejudice)	5.1 Acceptance (e.g. simple acceptance, hope...)
1.2. Physical and emotional support (e.g. taking care of PLWH, allowing them to live in their house)	2.2.Non-Adherence (e.g. missed doses, stopped treatment)	3.2. Queues (e.g. long queues, fighting in queues, having to queue)	4.2. Internalized (self) stigma (e.g. enacted or perceived – reflected appraisals of others, disclosure concerns, avoidance of HIV testing/treatment/safe sex, withdrawal from situation, reduction of self esteem)	5.2. Family or community helps me cope
1.3. Treatment support (Helping pick up treatment/accompanying them to clinic/ reminding them to take treatment)	2.3 Complete Adherence	3.3. Transport (e.g. trouble financing transport, finding someone to give them a ride, walking to the clinic)	4.3. Experienced stigma (discrimination) (e.g. being thrown out of the house, being turned down by health care providers, being treated differently by family and friends)	5.3 Difficulty coping (e.g. anxious, depressed...)
1.4. Being part of a support group		3.4. Picking up treatment (e.g. being able to see everyone you want, picking up all treatment in one visit, picking up the right treatment)		5.4 Religion
				5.5. Risky sexual behaviour (e.g. using condoms or not)

3. RESULTS

Qualitative findings are first reported as there is much in common with other recent research and the quantitative ones, in this case, provide a more nuanced account of stigma and adherence.

The qualitative findings were derived from 15 participants, drawn from Bushbuckridge (n=8) and Johannesburg (n=7). Five of the patients were 'successful' users (i.e. were adhering to the treatment), five were 'defaulters' (i.e. did not adhere to the treatment), three were 'partial' users (i.e. adhered to the treatment on an irregular basis) and for two patients, their adherence patterns were unclear or undefined. Almost half of the participants were co-infected with TB (n=8). Eleven of the fifteen participants were unemployed, the other four either being self employed (n=1) or employed by someone else (n=3). Thus, the majority of the participants relied on grants as their source of income. Five of the participants received a Child Support Grant and four of the participants receive a Disability Grant. It was unclear from the interview transcripts whether the other six were receiving grants. In the absence of these social grants, most participants are depending on their partners, parents, siblings or friends for financial assistance.

3.1 Stigma

Patients reported feeling stigma, especially from their family and community, which often limits their ability to disclose their status and adhere to treatment. Internalized (felt) stigma (e.g. enacted or perceived – reflected appraisals of others, disclosure concerns, avoidance of HIV testing/treatment/safe sex, withdrawal from situations, reduction of self esteem was noted and reduced adherence:

This lady didn't tell these white people we are working for that she is HIV positive because if they knew they would make our lives a living hell. You are not supposed to touch anything. They will tell you to go and wash your hands, use soap and make sure that you wash them thoroughly.

—ART partial user in the Thulamahashe Clinic (rural)

Furthermore, internalized (felt) stigma affected family and community relations, resulting in worsening living conditions:

I am afraid because he would leave me [if I told him I am taking ARVs].

– ART Defaulter at the Mpilo ART Clinic (urban)

I didn't tell my mother, sometimes when I have to go to the clinic my mother would ask me to tell her and I would just come up with a story because I'm avoiding to tell her and she would tell me to tell her the truth but I wouldn't because I'm scared she might want to tell my other siblings and we will start having unnecessary fights and they would bring up my status stigmatizing me because when you have this illness people don't like you.

– ART partial user at the ThulamahasheClinic:

[When I was sick] They did talk about me... people were talking badly, even at home they would talk.

– Unsuccessful ART user in Rixile. (rural):

I passed through a lot of discrimination at my location... I will pass and two girls are standing there you will hear them keep quiet when I cross and when I've passed you will hear them start gossiping. – Successful ART user from Baragwanath (urban)

3.2 Family and Community Support

Family and community support emerged as a very important factor to adhering to treatment and consistently attending clinic visits. As the majority of the participants were unemployed, many had to rely on social support grants as their main source of income. Thus, they often speak of a dependency on family or friends in order to help them financially with respect to transport, or physical to pick up the treatment:

My father was the one who was supporting me financially in terms of going to the clinic and hospital. He used to hire a care to take me to the clinic.

– ART defaulter from Mpilo ART clinic:

I was helped by my sister because even the money I was receiving for social grant was cut off.

–ART partial user from Thulamahasheclinic:

My sister and my brother were supportive of me so much that sometimes when I was not able to come to the clinic to collect my treatment I would ask my sister to collect it for me.

– ART partial user at Thulamahashe.

In the absence of financial support from family and friends, patients often need to find other means to obtain their treatment:

I ran out of treatment and I had no money to come to the clinic and there was no one to support me financially that's the reason I asked to be referred to Thulamahashe health Center because it will be easy for me to go there when I have no money.

– Unsuccessful ART user from Rixile Clinic:

Although financial support allows the patients to physically obtain their treatment, it's really the emotional support from their family and friends that helps them maintain their them cope with the disease:

When you are living with HIV, you need a good support, to be well treated and counseling, and find someone to talk to in order to forget all the problems and when feel upset and thinking about your status and not treated very well you feel rejected things like that.

– ART partial user from RixileClinic:

I get [support] from my sister-in-law and from my daughter. It's because when I am not able to face my brother I tell my sister in law and then she will tell him.

– HIV+ patient from Jabavu Clinic (urban):

My sister inspired me [to keep taking treatment] because she was on treatment and she has survived from the illness. – Successful ART user from Rixile Clinic.

Finally, the role that support groups play in treatment adherence also emerged as an integral part of the treatment and coping and de-stigmatizing process:

When I have attended the support group I was feeling very great.

–Successful ART patient from Rixile Clinic.

[I cope with my illness because] I'm a member of a support group, at the support group they always bring people who are coming teach us with the treatment and the side effects and how to live a positive life. – ART defaulter from Vasubantu Clinic (urban)

But gaps remain:

3.3 Gaps in the Social Support System

While patients identify that support from their family and friends as integral to their accessibility to ART, they also identify weaknesses within the support programs and education offered by the clinics. One patient stopped going to support groups because she felt there was an overlap between what she learned at the clinic and what she learned at the support group:

Is that the lessons those they are giving us while attending the support groups in the clinic when we go to collect our treatment were the same as thosein the support groups... So [this reason] made me stop to attend the support group. --- ART Partial User from Rixile Clinic

The following patients expressed gaps in the information and support they receive from the health care workers with respect to their treatment regime and financial aid:

I then started understand that it means that these pills do work the only problem is that the doctor didn't educate me about them. – ART partial user from RixileClinic

Yes, they are treating us very well but when we explain our problems in regards of shortage of money they need to help us in registering us to receive disability grant in order to help ourselves and to come to collect the treatment. – ART Defaulter from the Mpilo ART clinic.

Yet from the qualitative findings, hope and optimism remain strong:

3.4 Hope and Optimism

Despite the challenges that patients face on a daily basis with respect to accessing their ARV treatment, there is an overwhelming sense of hope, optimism, acceptance and confidence that prevails through the stories of each individual's experience with the disease:

Even when people talk or look at me knowing that I am sick, I have no problem with that because I am living my own life and I didn't step down and everybody knows that I am ill.
 – Successful ART user from Baragwanath

Well I didn't see [the illness] as a problem because I didn't know how it came about, I just accepted it and told myself that I'm fine, as long as I had gotten the relevant treatment to treat these ailment, I know that if I take them properly I was going to survive this illness. – Successful ART user from Rixile

And for me, my life began after I was diagnosed with HIV because that's when I learnt to eat healthy, that's when I learnt to take extreme good care of me, that is when I learnt be happy, that is when I learnt to listen to other people when they were talking to me because everybody was telling the right things. – Successful ART patient from Baragwanath.

3.5 Associative and Multivariate Analyses

The associative analyses with respect to the outcomes and economic and social support status are reported first. Table 2 summarizes the characteristics of the ARV patients in the sample according to socioeconomic and demographic variables and treatment characteristics. The overall sample included 1,267 individuals, of whom 5.4% (n=68) and 13.8% (n=175) reported missing clinic visits and missing tablets respectively. There was a higher percentage of females than males (26.3%) in the group and a majority of the individuals were unemployed (77.7%) and achieved a level of education of “some high school” (45.2%).

Table 2. Characteristics of ARV users, in total and by self-reported adherence measures

	All respondents (n=1,267)	Respondents reporting missed visits (n=68; 5.4)	Respondents reporting missed tablets (n=175; 13.8)
Variables:			
Age (mean)	37.93	---	---
Male sex	26.3%	7.2	14.8
Unemployed	77.7%	6.8	21.0
Some or complete primary education	24.7%	4.5	10.5
Some high school	45.2%	5.8	14.5
Matriculation	18.7%	5.9	21.6
Diploma or degree	1.3%	14.3	14.3

Table 3 shows the chi-squared analysis of the employment and wealth outcomes with respect to missing ARV treatments apart from the last three days. Wealth was measured based on the type of housing that the individual inhabited. Race was also examined with ARV adherence outcomes, but was not statistically significant, partially explainable by the skewed distribution of this variable with virtually all respondents being black. Current employment (Table 3.1) was statistically significant for missing taking tablets. Of the full-time work participants (n=157), 21.7% (34) had missed their tablets; of the part-time work participants (n=124), 13.7% (n=17) had missed their treatment. Compared to the unemployed participants (n=981), of whom, only 9.9% (n=97) missed their treatment, it

seems as though those in employment are more likely to miss taking their ARV tablets other things equal, this being examined further in the regressions.

Economic status (Table 3.2) is also a statistically significant factor in treatment compliance. Those who live in a dwelling/house/flat/room in backyard (n=88), those in informal dwellings/shack in backyard (n=113) and those who live in workers hostels (n=10) are most likely to miss their tablets (21.6%, 21.2% and 20% respectively). Clearly lower economic status seems to suggest lower treatment adherence.

With respect to stigma and community support and ART adherence, Table 4 reports the statistically significant associations for the stigma and community outcomes, with respect to missing tablets and missing ARV visits. Table 4 groups the support outcomes. Table 4.1 shows that of those who did not have the support of their partner, 17.4% missed their tablets as compared to 11.8% who did have the support from their partner. Family support was also statistically significant for missing tablets. Of those who did not have the support of their family, 18.2% missed their tablets, compared to 12.8% who did have their family's support. With respect visiting the ARV clinic, support from friends seems to be significant: of those who did not have support from their friends, 7.0% missed their visit, as compared to 3.7% who did have support.

Following the support gained by personal relationships, belonging to a support group is also an integral part of treatment adherence. Table 4.1 also shows that belonging to a support group was negatively associated with missing tablets. Of those who do not belong to a support group, 15.9% missed their tablets, as compare to only 9.3% who do belong to a support group. But the opposite outcome emerges when individuals were asked whether they had ever belonged to a support group. Of those who never belonged to a support group, 12.6% missed their tablets as compared to the 30.4% of those who have belonged to support groups.

Table 3. Employment and Wealth crossed with ARV tablet adherence
3.1 Current employment and missing tablets, except for the last three days

Employment Status		Number and proportion of those who, except for the last three days, have ever missed taking any tablets			
			Never missed	Missed	Total
Current Employment	Yes, full-time	Count	123	34	157
		Percentage	78.3	21.7	100.0
	Yes, part-time	Count	107	17	124
		Percentage	86.3	13.7	100.0
	No employment	Count	884	97	981
		Percentage	90.1	9.9	100.0
Total	Count	1114	148	1262	
	Percentage	88.3	11.7	100.0	
Pearson Chi Square Test of independence to show whether paired observations are independent of one another		p=0.000			

3.2 Housing and missing tablets, except for the last three days

Type of Housing					
Housing Type	House or brick structure	Count	581	72	653
		Percentage	89.0	11.0	100.0
	Traditional dwelling/hut	Count	51	4	55
		Percentage	92.7	7.3	100.0
	Flat or apartment	Count	172	13	185
		Percentage	93.0	7.0%	100.0
	Town/cluster/semi-detached	Count	10	1	11
		Percentage	90.9	9.1	100.0
	Unit in retirement village	Count	1	0	1
		Percentage	100.0	.0%	100.0
	Dwelling/house/flat/room in backyard	Count	69	19	88
		Percentage	78.4	21.6	100.0
	Informal dwelling/shack IN backyard	Count	89	24	113
		Percentage	78.8	21.2	100.0
	Informal dwelling/shack NOT in backyard	Count	127	13	140
		Percentage	90.7	9.3	100.0
	Room/flatlet not in backyard	Count	7	0	7
		Percentage	100.0	.0	100.0
	Workers' hostel	Count	8	2	10
		Percentage	80.0	20.0	100.0
Other (specify)	Count	1	0	1	
	Percentage	100.0	.0	100.0	
Total	Count	1116	148	1264	
	% within type of house in which you live	88.3	11.7	100.0	
Pearson Chi-Square		p=0.003			

Table 4.2 reports the relationship that the patients have with the healthcare workers. It reports on whether patients feel as though health care workers *do not* treat them with respect. Interestingly, of those who agreed that they were not being treated with respect, 3.9% missed their visit, as compared to 6.7% who disagreed. This means that those who feel as though they are being treated with respect are more likely to miss their tablets than those who do not. Being able to talk to the doctors and nurses in private was shown to also be statistically significant. Of those who could not talk to the health care providers in private, 17.2% missed their tablets, as compared to 12.2% who were able to speak to the health care workers in private. Finally, another interesting outcome emerged with respect to disclosing to healthcare workers about missed pills. Of those who could not disclose to their missed pills, only 13.7% missed, whereas 19.2% missed when they were able to disclose.

The final outcome, feeling judged by the community (Table 4.3), examined the perceived stigma that patients felt. Of those who felt judged, only 2.4% missed their visit, as compared

to those who did not feel judged, 6.4% missed. These outcomes all suggest that factors that influence adherence are complex suggesting a nuanced relationship between support, trust, and adherence. Not all relationships trend in the same direction.

Table 4. Community support and stigma outcomes with respect to adherence and accessibility to ART

4.1 Social support and missing ART

Social support statements		Number and proportion of those who have ever missed ART			Total
			Never Missed	Missed	
I have all the support from my partner that I need to cope with my illness	Disagree	Count	256	54	310
		Percentage	82.6	17.4	100.0
	Agree	Count	588	79	667
		Percentage	88.2	11.8	100.0
Total		Count	844	133	977
		Percentage	86.4	13.6	100.0
Pearson Chi-Square		0.018			
I have all the support from my family that I need to cope with my illness	Disagree	Count	153	34	187
		Percentage	81.8	18.2	100.0
	Agree	Count	896	131	1027
		Percentage	87.2%	12.8%	100.0%
Total		Count	1049	165	1214
		Percentage	86.4	13.6	100.0
Pearson Chi-Square		0,046			
I belong to a support group	No	Count	730	138	868
		Percentage	84.1	15.9	100.0
	Yes	Count	359	37	396
		Percentage	90.7	9.3	100.0
Total		Count	1089	175	1264
		Percentage	86.2	13.8	100.0
Pearson Chi-Square		0.002			
Did you ever belong to a support group?	No	Count	536	77	613
		Percentage	87.4	12.6	100.0
	Yes	Count	112	49	161
		Percentage	69.6	30.4	100.0
Total		Count	648	126	774
		Percentage	83.7	16.3	100.0
Pearson Chi-Square		p=0.000			

4.2 Relationship with healthcare workers and missing clinic visits

Healthcare relations statements		Number or proportion of those who have ever missed a clinic visit			Total
			Never Missed	Missed	
Respect from providers	Agree	Count	345	14	359
		Percentage	96.1	3.9	100.0
	Disagree	Count	721	52	773
		Percentage	93.3	6.7	100.0
Total		Count	1066	66	1132
		Percentage	94.2	5.8	100.0
Pearson Chi-Square			0.059		
Privacy in settings providers	Disagree	Count	336	70	406
		Percentage	82.8	17.2	100.0%
	Agree	Count	739	103	842
		Percentage	87.8	12.2	100.0
Total		Count	1075	173	1248
		Percentage	86.1	13.9	100.0
Pearson Chi-Square			0.016		
Ability to inform providers	Disagree	Count	226	36	262
		Percentage	86.3	13.7	100.0
	Agree	Count	569	135	704
		Percentage	80.8	19.2	100.0
Total		Count	795	171	966
		Percentage	82.3	17.7	100.0
Pearson Chi-Square			p=0.049		

4.3 Community judgment and missing clinic visits

Judgment statement		Number and proportion of those who have ever missed a clinic visit			Total
			Never Missed	Missed	
Felt judged by community	Yes	Count	207	5	212
		Percentage	97.6	2.4	100.0
	No	Count	808	55	863
		Percentage	93.6	6.4%	100.0
Total		Count	1015	60	1075
		Percentage	94.4	5.6	100.0
Pearson Chi-Square			p=0.000		

To control for confounding factors and to compare stigma and treatment adherence and visit frequency, logistic regressions were run; these are summarized in Table 5. The logistic regression for “missed tablets” (Table 5.1) shows that having ever belonged to a support group is the only significant factor in explaining variations in tablet adherence, ($p < 0.05$). Those who have ever attended a support group are 30 percent less likely to report having ever missed their ARV tablets. At a 90% CI, we can report feeling judged by the community and having family support as significant as well ($p = 0.094$, $p = 0.081$, respectively). At this level, those who feel judged by the community are 43 percent less likely to miss their tablets; similarly, those who have family support are 1.77 times less likely to miss their tablets.

The logistic regression for having “missed clinic visits” (Table 5.2) did not show any statistically significant outcomes at a 95% CI. However, at a 90% CI, feeling as though some staff do not treat the patient with respect and ever having being part of a support group were both statistically significant ($p=0.056$ and $p=0.064$ respectively). At this level, those who feel as though the staff do not respect them are 29 percent less likely to miss their clinic visits and those who have ever belonged to a support group were 45 percent less likely to miss their clinic visits. In all analyses, no statistically significant differences were found between urban and rural residents.

Table 5. Multivariate Analyses of “Have you ever missed any tablets, except for the past three days?” and “Have you ever missed a clinic visit?”
5.1 Multivariate analysis of “Have you ever missed any tablets, except for the past three days?”

	1	2	3	4	5	6	Confidence Intervals (95% for Exp(B))	
							Lower	Upper
Respect from providers	.648	.596	1.183	1	.277	1.911	.595	6.141
Being judged by community	-.833	.497	2.813	1	.094	.435	.164	1.151
Having to queue	-.079	.306	.067	1	.796	.924	.507	1.683
Health workers too busy	.091	.340	.071	1	.790	1.095	.562	2.134
Community support	.394	.273	2.081	1	.149	1.483	.868	2.533
Family support	.550	.315	3.036	1	.081	1.733	.934	3.215
Support from friends	-.290	.278	1.092	1	.296	.748	.434	1.289
Belong to support group	.693	1.201	.333	1	.564	2.000	.190	21.037
Ever belonged to support group	-1.194	.277	18.551	1	.000	.303	.176	.522
Constant	1.651	.782	4.457	1	.035	5.213		
Hosmer and Lemeshow Test Simulated goodness of fit statistic to show how model Fits the data	0.466							

1. Values of equation predicting dependent variable from the independent variable
2. Standard error associated with the coefficients
3. Chi-square value to test null hypothesis
4. Degrees of freedom for each test
5. 2-tailed p-value
6. Odds ratio for predictors

5.2 Multivariate analysis of “Have you ever missed a clinic visit?”

	1	2	3	4	5	6	Confidence Intervals (95% for Exp(B))	
							Lower	Upper
Being judged by community	-18.522	4786.882	.000	1	.997	.000	.000	.
Having to queue Health workers too busy	-.094	.455	.043	1	.836	.910	.373	2.219
Being respected	.641	.495	1.681	1	.195	1.899	.720	5.008
Community support	-1.230	.643	3.651	1	.056	.292	.083	1.032
Family support	-.556	.439	1.605	1	.205	.574	.243	1.355
Support from a friend	.339	.465	.533	1	.465	1.404	.564	3.493
Belonging to a support group	.509	.428	1.414	1	.234	1.664	.719	3.851
Ever belonging to support group	18.543	15060.062	.000	1	.999	1.130E8	.000	.
Constant	-.789	.426	3.432	1	.064	.454	.197	1.047
Hosmer and Lemeshow Test	39.620	9446.145	.000	1	.997	1.609E17		
See Table 5.1	0.910							

Note: See Table 5.1 for headings

4. DISCUSSION AND CONCLUSION

From this study of stigma and treatment adherence in South Africa it is clear that community support and stigma are factors that influence adherence to ART and matter in both urban and rural settings. This supports much recent research [27-29]. But other studies [30] show there is no statistically significant relationship between stigma and adherence. This South African study can contribute to raising questions about this relationship which requires further investigation. It is commonplace to ignore or reject associative analyses and influence of the variables is more robustly treated in regressions. Yet a great deal remains unknown about the relationship between stigma and adherence so the univariate analyses are used to point not only to well-known economic relationships between wealth and adherence but to suggest some greater non-compliance in the presence of support and respect. It is difficult to explain why those who have never belonged to a support group appear to have higher adherence than those who belong. Is it different self-motivation? Or did not attend meetings regularly? Or a response aberration? This requires further research. But it can be noted that being employed, being treated with respect in health care settings, not being judged and being able to disclose missing tablets were all associated with lower levels of adherence, although the proportions feeling this way are relatively low. The health care system is to be congratulated on the respect with which it treats patients. Privacy and the possible adverse response to disclosing non-adherence seen negatively but close on a fifth of the population. It must be recognised that privacy, respect, trust and so on may have multiple means but these are used in the UNAIDS stigma survey and suffer as do all self-reported responses. But sample size is sufficiently large for idiosyncratic responses to be insignificant. But there remain circumstances where support and respect between sufferer and provider and community are present but appear to result in lower than expected levels of adherence, given these circumstances. From other associative analyses, lower

proportions of adherence are found among those in full-time employment and those living in shacks in backyards. This can only be suggestive but is it possible to speculate that here is a degree of comfort which derives from social and family support that permits sufferers to not follow treatment protocols? The paternalistic, arms-length treatment regimes of some health care providers may find some rationale in this finding. In other words, is it possible that a top-down approach to guiding patients to treatment may bring some benefit in greater adherence? This is speculation at this point. But there remains a dearth of evidence of how to increase adherence, given stigma [31,32] and a recent review comments that more studies are needed to clarify these matters [33]. Many actions by the South African health care system have led to positive perceptions of privacy, respect and trust. Yet policies to reduce or remove HIV/AIDS stigma need to be more broadly based to include the education of employers and work colleagues and emphasise efforts among the most disadvantaged – those living in backyard shacks, a difficult group with whom to communicate. Stigma, although felt by the patient, is also ‘enacted’ and external with its source often in social structures and contexts. Improving and sustaining adherence therefore requires not only better availability of treatment, support and education but also recognition of the complicated role of all these interactions.

CONSENT

All clinics were provided with written and oral presentations on the nature of the project and consented to be included. All patients with an informed consent document present discussed their participation in the project in their own language with a trained field worker. They were required to sign the consent form before any questions could be asked.

ETHICAL APPROVAL

Ethical approval for this research was given by the University of Witwatersrand and the University of Cape Town’s ethics research boards. The national and provincial ministries of health also granted ethical approval. This approval was also obtained from various hospital and clinic boards.

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COMPETING INTERESTS

The authors have no competing interests to report.

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