

STIGMA AND HIV/AIDS IN SOUTH AFRICA: A CAUTIONARY TALE OF RESPECT AND ADHERENCE

Abstract

The situation with respect to HIV/AIDS is improving but some challenges remain. A great deal of policy and academic work has been undertaken on many elements of this health issues. The stigmatization of sufferers is seen as a stumbling block to disclosure and treatment adherence. In this mixed method study focusing on two urban and rural sites in South Africa, we contribute to this debate in part by confirming the findings in previous studies but providing insight through careful examination of associative as well as regression analyses. These suggest that for some higher levels of support and respect, indicators of destigmatization, result in lower levels of treatment adherence. We comment on this finding with respect to policy practice in South Africa.

Key Words: stigma, respect, adherence, HIV/AIDS, South Africa

Introduction

Although South Africa still possesses the highest number of people living with HIV/AIDS (PLHA) – 5.6 million (UNAIDS 2012, South Africa 2012, CIA 2013), 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. New infections among those aged 15 and older has declined from over half a million in 2001 to 350000 in 2011. 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.

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 (see Campbell et al.2005, Gilbert and Walker 2010). 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 (Mahajan et al., 2008). Much of the literature on measuring stigma (Earnshaw & Chaudoir, 2009; Nyblade, 2006; Mahajan et al., 2008; Link & Phelan, 2001) identifies the lack of clarity in conceptualizing stigma as a major barrier to HIV prevention and treatment efforts. 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 (Nyblade, 2006). Perceived stigma measures how PLHA see 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 (see Lekas et al. 2011) 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 more risky and less compliant behaviours?

There is now much research in South Africa which has examined stigma and destigmatization. In unequal societies with conservative social dynamics, inequalities often persist as Campbell et al. 2005) note while the tension between disclosure and secrecy, because of stigma, has real consequences (see Li et al. 2012). According to Goffman (1963, p. 3), stigma is an attribute that extensively discredits the individual reducing him or her “from a whole and usual person to a tainted, discounted one.” Crocker et al. (1998) proposed that stigmatization occurs when an attribute conveys a social identity that is devalued in a particular social context” (p. 505). 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 (see Major and O’Brien 2005). In the context of PLHA, this view is strongly internalized (see Simbayi et al. 2007), especially in unequal, conservative societies or communities. This context and its likely impact on individual and group interactions has been identified by Joffe (1999) and used in recent empirical studies. Campbell et al. (2007) 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 lack of economic productivity. They further recognize the importance of community support and action by PLHA (see also Bos et al 2008). 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 (2006) 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. Knowing HIV status may reduce perceived stigma as treatment will enhance health status, potentially because of high levels of support from the community and voluntary counselling (see Mall et al 2013). 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. (2008) 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, not only with respect to greater adherence but to its reduction if health status is also 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.

Methods

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. Social stigma was explored using interview questions that gauged the support patients received from their social networks, including partners, friends, family and community support groups. These outcomes were compared against quantitative data to determine a correlation between stigma experiences and ARV treatment adherence.

Quantitatively, questionnaire-guided exit interviews were conducted by locally trained field workers in the sub districts of Bushbuckridge (Mpumalanga), Mitchell’s Plain (Western Cape), Johannesburg (Gauteng) and Hlabisa (KwaZulu-Natal). This sample reflects an urban-rural mix to account for differences in health care delivery across

the provinces in South Africa (see Cleary et al. 2012)). 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.

Data were analysed using SPSS. Univariate statistical analyses were used to analyze associations between the independent variables and outcomes of missing ART tables 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 with respect to current employment and type of house as another measure of wealth.. social support and stigma: being respected by healthcare workers (recoderespect2), being judged by people in the community (recodejudge), queues being too long at the clinic (recodequeue), healthcare workers too busy to see patients (recodebusy), some staff not treating patients with respect (recoderespect), having partner support (support), having support from family (supfam), having support from friends (supfriend), being part of a support group (supgp) and having ever belonged to a support group (supgever). To explore, the relationships between the independent variables and the outcomes, logistic regressions were carried out.).

Qualitatively, 15 in-depth interviews with patients on ARV treatment in two of the four sites (Bushbuckridge and Soweto, Johannesburg) included in the quantitative phase were undertaken as there were resource constraints in the study. 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 in 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)

122 adherence, 3) access to treatment, 4) stigma and 5) coping. Table 1 gives a detailed description of how the
123 transcripts were coded under these themes. Some quotations were coded to more than one theme.

124 Ethical approval for the study was granted by committees at the University of Cape Town, the University of the
125 Witwatersrand and the University of KwaZulu-Natal. Permission from health department officials and individual
126 facility managers was obtained to conduct the study in the selected facilities. Written informed consent to
127 participate in the study was obtained from each participant.

128 Results

129 We report the qualitative findings first as there is much in common with other recent research and the quantitative
130 ones, in this case, provide a more nuance account of stigma and adherence.

131 The qualitative findings were derived from 15 participants ranged in age from 27 to 59 years; 11 women and 4 men
132 participated. The interviews were drawn from Bushbuckridge (n=8) and Johannesburg (n=7). Five of the patients
133 were ‘successful’ users (i.e. were adhering to the treatment), five were ‘defaulters’ (i.e. did not adhere to the
134 treatment), three were ‘partial’ users (i.e. adhered to the treatment on an irregular basis) and for two patients, their
135 adherence patterns were unclear, or undefined. Almost half of the participants were co-infected with TB (n=8).
136 Eleven of the fifteen participants were unemployed, the other four either being self employed (n=1) or employed by
137 someone else (n=3). Thus, the majority of the participants relied on grants as their source of income. Five of the
138 participants received a Child Support Grant and four of the participants receive a Disability Grant. It was unclear
139 from the interview transcripts whether the other six were receiving grants. In the absence of these social grants,
140 most participants are depending on their partners, parents, siblings or friends for financial assistance.

141 Stigma

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

146 *This lady didn’t tell these white people we are working for that she is HIV positive because if they knew they would*
147 *make our lives a living hell. You are not supposed to touch anything. They will tell you to go and wash your hands,*
148 *use soap and make sure that you wash them thoroughly.*—ART partial user in the Thulamahashe Clinic

149

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

152 *I am afraid because he would leave me [if I told him I am taking ARVs].* – ART Defaulter at the Mpilo ART Clinic

153 *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*
154 *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*
155 *because I’m scared she might want to tell my other siblings and we will start having unnecessary fights and they*
156 *would bring up my status stigmatizing me because when you have this illness people don’t like you.* – ART partial
157 user at the Thulamahashe Clinic

158 [When I was sick] *They did talk about me... people were talking badly, even at home they would talk.* –
159 Unsuccessful ART user in Rixile.

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

163 *Family and community support*

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

168 *My father was the one who was supporting me financially in terms of going to the clinic and hospital. He used to*
169 *hire a care to take me to the clinic.* – ART defaulter from Mpilo ART clinic

170 *I was helped by my sister because even the money I was receiving for social grant was cut off.* –ART partial user
171 from Thulamahashe clinic:

172 *My sister and my brother were supportive of me so much that sometimes when I was not able to come to the clinic*
173 *to collect my treatment I would ask my sister to collect it for me* – ART partial user at Thulamahashe

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

176 *I ran out of treatment and I had no money to come to the clinic and there was no one to support me financially*
177 *that's the reason I asked to be referred to Thulamahashe health Center because it will be easy for me to go there*
178 *when I have no money.* – Unsuccessful ART user from Rixile Clinic

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

181 *When you are living with HIV, you need a good support, to be well treated and counseling, and find someone to talk*
182 *to in order to forget all the problems and when feel upset and thinking about your status and not treated very well*
183 *you feel rejected things like that.* – ART partial user from Rixile Clinic

184 *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*
185 *tell my sister in law and then she will tell him.* – HIV+ patient from Jabavu Clinic

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

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

190 *When I have attended the support group I was feeling very great.* –Successful ART patient from Rixile Clinic

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

194 But gaps remain:

195

196

197 Gaps in the social support system

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

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

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

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

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

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

213 Hope and optimism

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

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

219 *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*
220 *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*
221 *properly I was going to survive this illness.* – Successful ART user from Rixile

222 *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*
223 *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*
224 *when they were talking to me because everybody was telling the right things.* – Successful ART patient from
225 Baragwanath

226 Quantitative findings

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

233 Table 3 shows the chi-squared analysis of the employment and wealth outcomes with respect to missing ARV
234 treatments apart from the last three days. Wealth was measured based on the type of housing that the individual
235 inhabited. Race was also examined with ARV adherence outcomes, but was not statistically significant, partially
236 explainable by the skewed distribution of this variable with virtually all respondents being black. Current
237 employment (Table 3.1) was statistically significant for missing taking tablets. Of the full-time work participants
238 (n=157), 21.7% (34) had missed their tablets; of the part-time work participants (n=124), 13.7% (n=17) had missed
239 their treatment. Compared to the unemployed participants (n=981), of whom, only 9.9% (n=97) missed their
240 treatment, it seems as though those in employments are more likely to miss taking their ARV tablets other things
241 equal, this being examined further in the regressions.

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

246 With respect to stigma and community support and ART adherence, Table 4 reports the statistically significant
247 associations for the stigma and community outcomes, with respect to ever missing tablets and missing ARV visits.
248 Table 4.1 groups the support outcomes. Table 4.1.1 shows that those who did not have the support of their partner,
249 17.4% missed their tablets as compared to 11.8% who did have the support from their partner. Family support
250 (table 4.1.2) was also statistically significant for missing tablets. Of those who did not have the support of their
251 family, 18.2% missed their tablets, compared to 12.8% who did have their family’s support. With respect visiting
252 the ARV clinic, support from friends (table 4.1.3) seems to be significant: of those who did not have support from
253 their friends, 7.0% missed their visit, as compared to 3.7% who did have support.

254 Following the support gained by personal relationships, belonging to a support group is also an integral part of
255 treatment adherence. Table 4.1.4 shows that belonging to a support group was negatively associated with missing
256 tablets. Of those who do not belong to a support group, 15.9% missed their tablets, as compare to only 9.3% who
257 do belong to a support group. But the opposite outcome emerges when individuals were asked whether they had
258 *ever* belonged to a support group (Table 4.1.5). Of those who never belonged to a support group, 12.6% missed
259 their tablets as compared to the 30.4% of those who have belonged to support groups.

260 Tables under 4.2 report the relationship that the patients have with the healthcare workers. Table 4.2.1 reports on
261 whether patients feel as though health care workers *do not* treat them with respect. Interestingly, of those who
262 agreed that they were not being treated with respect, 3.9% missed their visit, as compared to 6.7% who disagreed.
263 This means that those who feel as though they are being treated with respect are more likely to miss their tablets
264 than those who do not. Being able to talk to the doctors and nurses in private was shown to also be statistically
265 significant (table 4.2.2). Of those who could not talk to the health care providers in private, 17.2% missed their

266 tablets, as compared to 12.2% who were able to speak to the health care workers in private. Finally, another
267 interesting outcome emerged with respect to disclosing to healthcare workers about missed pills. Of those who
268 could not disclose to their missed pills, only 13.7% missed, whereas 19.2% missed when they were able to disclose.

269 The final outcome, feeling judged by the community (Table 4.3.1), examined the perceived stigma that patients felt.
270 Those who felt judged were less likely to miss their clinic visits; of those who felt judged, only 2.4% missed their
271 visit, as compared to those who did not feel judged, 6.4% missed. These outcomes all suggest that factors that
272 influence adherence are complex suggesting a nuanced relationship between support, trust, and adherence. Not all
273 relationships trend in the same direction.

274 To control for confounding factors and to compare stigma and accessibility outcomes with treatment adherence and
275 visit frequency, logistic regressions were run; these are summarized in Table 5. The logistic regression for “ever
276 missed tablets” (Table 5.1) shows that having ever belonged to a support group is the only significant factor in
277 tablet adherence, at a 95% CI ($p=0.000$). Those who have ever attended a support group are 30 percent less likely
278 to ever miss their ARV tablets. At a 90% CI, we can report feeling judged by the community (“recodejudge”) and
279 having family support (“supfam”) as significant as well ($p=0.094$, $p=0.081$, respectively). At this level, those who
280 feel judged by the community are 43 percent less likely to miss their tablets; similarly, those who have family
281 support are 1.77 times less likely to miss their tablets.

282 The logistic regression for having “missed ARV tablets” (Table 5.2) did not show any statistically significant
283 outcomes at a 95% CI. However, at a 90% CI, feeling as though some staff do not treat the patient with respect
284 (“recoderespect”) and ever having being part of a support group (“supgever”) were both statistically significant
285 ($p=0.056$ and $p=0.64$ respectively). At this level, those who feel as though the staff do not respect them are 29
286 percent less likely to miss their clinic visits and those who have ever belonged to a support group were 45 percent
287 less likely to miss their clinic visits.

288 Discussion and Conclusion

289 These regressions suggest that respect from healthcare workers, feeling judged, support from family, and especially
290 being part of a support group significantly influence treatment adherence and clinic visits. Thus, it is clear that
291 community support and stigma are factors that influence adherence to ART. The regressions also suggest that when
292 collectively controlling for all independent variables, some of the adverse outcomes on missing tablets and clinic
293 visits disappear. But the associative analyses point not only to well-known economic relationships between wealth
294 and adherence but some greater non-compliance in the presence of support and respect. This paper suggests therefore
295 that the regression analyses may cloud some important relationships in relation to adherence, support, trust and
296 stigma. Support is usually seen as a necessary element in stigma reduction. Our regressions support that. But we
297 must also note there are some circumstances where support and respect between sufferer and provider and
298 community are present but appear to result in lower levels of adherence. Is there a comfort which derives from
299 support that permits sufferers to not follow treatment protocols as they do not fear scolding? The paternalistic,
300 arms-length treatment regimes of some health care providers may find some rationale in this finding. Should
301 support lead to equity between patient and provider in their relationships? It is certainly true that equity is a key
302 policy discourse in post-apartheid South Africa. But there may be unintended consequences. And if this is the case
303 with HIV/AIDS where there is massive public education and priority for the distribution of resources, what does
304 this mean for other devastating diseases, such as TB which has less public education and community awareness?
305 For TB and HIV/AIDS, policies to remove stigma need to be broadly based since although felt by the patient, it is
306 also ‘enacted’ and external with its source often in social structures and contexts. Improving and sustaining

adherence therefore requires not only better availability but also recognition of the complicated role acceptability to patient, provider and community for support, trust and stigma reduction.

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347 **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		5.4 Religion

you want, picking up
all treatment in one
visit, picking up the
right treatment)

**5.5. Risky sexual
behaviour**
(e.g. using condoms or
not)

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%

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364 **Table 3: Employment and Wealth crossed with ARV tablet adherence**

365 **3.1 Current employment * apart from the last three days, have you ever missed taking any tablets**

Crosstab			apart from the last three days, have you ever missed taking any tablets		Total
			No	Yes	
Current Employment	Yes, full-time	Count	123	34	157
		% within current employment	78.3%	21.7%	100.0%
	Yes, part-time	Count	107	17	124
		% within current employment	86.3%	13.7%	100.0%
	No	Count	884	97	981
		% within current employment	90.1%	9.9%	100.0%
Total		Count	1114	148	1262
		% within current employment	88.3%	11.7%	100.0%

Chi-square tests	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	18.628 ^a	2	.000
Likelihood Ratio	16.170	2	.000
Linear-by-Linear Association	18.199	1	.000
N of Valid Cases	1262		

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Chi-square tests	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	26.231 ^a	10	.003
Likelihood Ratio	24.846	10	.006
Linear-by-Linear Association	1.514	1	.219
N of Valid Cases	1264		

a. 7 cells (31.8%) have expected count less than 5. The minimum expected count is .12.

3.2 Type of house in which you live * apart from the last three days, have you ever missed taking any tablets			apart from the last three days, have you ever missed taking any tablets		Total
			0	1	
Crosstab					
type of house in which you live	House or brick structure ...	Count	581	72	653
		% within type of house in which you live	89.0%	11.0%	100.0%
	Traditional dwelling/hut...	Count	51	4	55
		% within type of house in which you live	92.7%	7.3%	100.0%
	Flat or apartment ...	Count	172	13	185
		% within type of house in which you live	93.0%	7.0%	100.0%
	Town/cluster/semi-detached ...	Count	10	1	11
		% within type of house in which you live	90.9%	9.1%	100.0%
	Unit in retirement village	Count	1	0	1
		% within type of house in which you live	100.0%	.0%	100.0%
	Dwellig/house/flat/room in backy	Count	69	19	88
		% within type of house in which you live	78.4%	21.6%	100.0%
	Informal dwelling/shack IN backy	Count	89	24	113
		% within type of house in which you live	78.8%	21.2%	100.0%
	Informal dwelling/shack NOT in b	Count	127	13	140
		% within type of house in which you live	90.7%	9.3%	100.0%
	Room/flatlet not in backyard but	Count	7	0	7
		% within type of house in which you live	100.0%	.0%	100.0%
	Workers hostel	Count	8	2	10
		% within type of house in which you live	80.0%	20.0%	100.0%
	Other (specify)	Count	1	0	1
		% within type of house in which you live	100.0%	.0%	100.0%
Total		Count	1116	148	1264

373 community support and stigma outcomes with respect to adherence and accessibility to ART

374 **4.1 Support**

375 **4.1.1. I have all the support from my partner that I need to cope with my illness * evermissedregression**

Crosstab					
			evermissedregression		Total
			yes	no	
I have all the support from my partner that I need to cope with my illness	Disagree	Count	54	256	310
		% within I have all the support from my partner that I need to cope with my illness	17.4%	82.6%	100.0%
	Agree	Count	79	588	667
		% within I have all the support from my partner that I need to cope with my illness	11.8%	88.2%	100.0%
Total		Count	133	844	977
		% within I have all the support from my partner that I need to cope with my illness	13.6%	86.4%	100.0%

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Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	5.594 ^a	1	.018		
Continuity Correction ^b	5.130	1	.024		
Likelihood Ratio	5.401	1	.020		
Fisher's Exact Test				.021	.013
Linear-by-Linear Association	5.588	1	.018		
N of Valid Cases	977				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 42.20.

b. Computed only for a 2x2 table

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389 **4.1.2. I have all the support from my family * evermissedregression**

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Crosstabs			evermissedregression		Total
			yes	no	
I have all the support from my family	Disagree	Count	34	153	187
		% within I have all the support from my family	18.2%	81.8%	100.0%
	Agree	Count	131	896	1027
		% within I have all the support from my family	12.8%	87.2%	100.0%
Total		Count	165	1049	1214
		% within I have all the support from my family	13.6%	86.4%	100.0%

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Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.966 ^a	1	.046	.049	.033
Continuity Correction ^b	3.518	1	.061		
Likelihood Ratio	3.705	1	.054		
Fisher's Exact Test					
Linear-by-Linear Association	3.963	1	.047		
N of Valid Cases	1214				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 25.42.

b. Computed only for a 2x2 table

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395 **4.1.3. I have all the support from my friends * recodearvmissvisit**

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Crosstabs			recodearvmissvisit		Total
			Yes	No	
I have all the support from my friends	Disagree	Count	29	384	413
		% within I have all the support from my friends	7.0%	93.0%	100.0%
	Agree	Count	21	546	567
		% within I have all the support from my friends	3.7%	96.3%	100.0%
Total		Count	50	930	980

Crosstabs			recodearvmissvisit		Total
			Yes	No	
I have all the support from my friends	Disagree	Count	29	384	413
		% within I have all the support from my friends	7.0%	93.0%	100.0%
	Agree	Count	21	546	567
		% within I have all the support from my friends	3.7%	96.3%	100.0%
Total		Count	50	930	980
		% within I have all the support from my friends	5.1%	94.9%	100.0%

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Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	5.434 ^a	1	.020	.027	.015
Continuity Correction ^b	4.770	1	.029		
Likelihood Ratio	5.349	1	.021		
Fisher's Exact Test					
Linear-by-Linear Association	5.428	1	.020		
N of Valid Cases	980				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 21.07.

b. Computed only for a 2x2 table

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4.1.4. do you belong to a support group * evermissedregression

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Crosstabs			evermissedregression		Total
			yes	no	
do you belong to a support group	No	Count	138	730	868
		% within do you belong to a support group	15.9%	84.1%	100.0%
	Yes	Count	37	359	396
		% within do you belong to a support group	9.3%	90.7%	100.0%
Total		Count	175	1089	1264
		% within do you belong to a support group	13.8%	86.2%	100.0%

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Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	9.796 ^a	1	.002	.002	.001
Continuity Correction ^b	9.255	1	.002		
Likelihood Ratio	10.418	1	.001		
Fisher's Exact Test					
Linear-by-Linear Association	9.789	1	.002		
N of Valid Cases	1264				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 54.83.

b. Computed only for a 2x2 table

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4.1.5. did you ever belong to a support group * evermissedregression

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Crosstabs			evermissedregression		Total
			yes	no	
did you ever belong to a support group	No	Count	77	536	613
		% within did you ever belong to a support group	12.6%	87.4%	100.0%
	Yes	Count	49	112	161
		% within did you ever belong to a support group	30.4%	69.6%	100.0%
Total		Count	126	648	774
		% within did you ever belong to a support group	16.3%	83.7%	100.0%

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Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	29.889 ^a	1	.000	.000	.000
Continuity Correction ^b	28.592	1	.000		
Likelihood Ratio	26.480	1	.000		
Fisher's Exact Test					
Linear-by-Linear Association	29.850	1	.000		
N of Valid Cases	774				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 26.21.

Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	29.889 ^a	1	.000	.000	.000
Continuity Correction ^b	28.592	1	.000		
Likelihood Ratio	26.480	1	.000		
Fisher's Exact Test					
Linear-by-Linear Association	29.850	1	.000		
N of Valid Cases	774				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 26.21.

b. Computed only for a 2x2 table

4.2. Relationship with healthcare workers

4.2.1. Respect: *recoderespect* * *recodearvmissvisit*

Crosstabs			recodearvmissvisit		Total
			Yes	No	
recoderespect	agree	Count	14	345	359
		% within recoderespect	3.9%	96.1%	100.0%
	disagree	Count	52	721	773
		% within recoderespect	6.7%	93.3%	100.0%
Total		Count	66	1066	1132
		% within recoderespect	5.8%	94.2%	100.0%

Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.569 ^a	1	.059	.075	.037
Continuity Correction ^b	3.073	1	.080		
Likelihood Ratio	3.824	1	.051		
Fisher's Exact Test					
Linear-by-Linear Association	3.566	1	.059		
N of Valid Cases	1132				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 20.93.

b. Computed only for a 2x2 table

4.2.2.Privacy: recodeprivate * evermissedregression

Crosstabs			evermissedregression		Total
			yes	no	
recodeprivate	disagree	Count	70	336	406
		% within recodeprivate	17.2%	82.8%	100.0%
	agree	Count	103	739	842
		% within recodeprivate	12.2%	87.8%	100.0%
Total		Count	173	1075	1248
		% within recodeprivate	13.9%	86.1%	100.0%

Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	5.755 ^a	1	.016	.018	.011
Continuity Correction ^b	5.343	1	.021		
Likelihood Ratio	5.585	1	.018		
Fisher's Exact Test					
Linear-by-Linear Association	5.750	1	.016		
N of Valid Cases	1248				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 56.28.

b. Computed only for a 2x2 table

4.2.3 .informing providers: recodetellmiss * evermissedregression

Crosstabs			evermissedregression		Total
			yes	no	
recodetellmiss	disagree	Count	36	226	262
		% within recodetellmiss	13.7%	86.3%	100.0%
	agree	Count	135	569	704
		% within recodetellmiss	19.2%	80.8%	100.0%
Total		Count	171	795	966
		% within recodetellmiss	17.7%	82.3%	100.0%

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428

Chi-square tests	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.873 ^a	1	.049	.058	.029
Continuity Correction ^b	3.508	1	.061		
Likelihood Ratio	4.038	1	.044		
Fisher's Exact Test					
Linear-by-Linear Association	3.869	1	.049		
N of Valid Cases	966				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 46.38.

b. Computed only for a 2x2 table

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432 **4.3. Community stigma**

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434 **4.3.1. Being Judged: *recodejudge* * *recodearvmissvisit***

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Crosstab			recodearvmissvisit		Total
			Yes	No	
recodejudge	yes	Count	5	207	212
		% within recodejudge	2.4%	97.6%	100.0%
	no	Count	55	808	863
		% within recodejudge	6.4%	93.6%	100.0%
Total		Count	60	1015	1075
		% within recodejudge	5.6%	94.4%	100.0%

436

437 **Table 5: Logistic Regressions Analyses of ever missing tablets and clinic visits**

438 **5.1 *Ever missed tablets***

Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	7.673	8	.466

439

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Variables in the Equation

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
recoderespect2	.648	.596	1.183	1	.277	1.911	.595	6.141
recodejudge	-.833	.497	2.813	1	.094	.435	.164	1.151
recodequeue	-.079	.306	.067	1	.796	.924	.507	1.683
recodehwbusy	.091	.340	.071	1	.790	1.095	.562	2.134
recoderespect	-.164	.323	.256	1	.613	.849	.451	1.600
support	.394	.273	2.081	1	.149	1.483	.868	2.533
supfam	.550	.315	3.036	1	.081	1.733	.934	3.215
supfriend	-.290	.278	1.092	1	.296	.748	.434	1.289
supgp	.693	1.201	.333	1	.564	2.000	.190	21.037
supgpever	-1.194	.277	18.551	1	.000	.303	.176	.522
Constant	1.651	.782	4.457	1	.035	5.213		

le(s) entered on step 1: recoderespect2, recodejudge, recodequeue, recodehwbusy, recoderespect, support, supfam, supfriend, supgp, er.

452

453 **5.2 Missed ARV visits**

454

Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	3.355	8	.910

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Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
								Lower	Upper
Step 1 ^a	recoderespect2	-17.966	8143.427	.000	1	.998	.000	.000	.
	recodejudge	-18.522	4786.882	.000	1	.997	.000	.000	.
	recodequeue	-.094	.455	.043	1	.836	.910	.373	2.219
	recodehwbusy	.641	.495	1.681	1	.195	1.899	.720	5.008
	recoderespect	-1.230	.643	3.651	1	.056	.292	.083	1.032
	support	-.556	.439	1.605	1	.205	.574	.243	1.355
	supfam	.339	.465	.533	1	.465	1.404	.564	3.493
	supfriend	.509	.428	1.414	1	.234	1.664	.719	3.851
	supgp	18.543	15060.062	.000	1	.999	1.130E8	.000	.
	supgpever	-.789	.426	3.432	1	.064	.454	.197	1.047
	Constant	39.620	9446.145	.000	1	.997	1.609E17		

Variable(s) entered on step 1: recoderespect2, recodejudge, recodequeue, recodehwbusy, recoderespect, support, supfam, supfriend, supgp, supgpever.