

## Loneliness and Secrecy: ART adherence in Maputo – the importance of Education and of Health Professionals

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### Abstract

This study aims to explore socio-demographic characteristics of ART patients in the city of Maputo, including differences on age, gender and schooling level, on their family and health professionals support relationships, on their previous knowledge about HIV and ART, on their fear to be recognized as HIV and on the impact of the discrimination experiences on the ART adherence. The sample consists of 602 ART patients living in Maputo district, Mozambique, between 21 and 56 years old.

The findings reveal that most of the patients have never interrupted the treatment. More men than women reported doing it, warning us for the impact of male avoidance of the treatment and of the treatment appointments on compromising their life quality and expectancy. Those who have none support relationship or the health professionals as figures of support adhere more than those who have family, activists or friends as support relationships. Those who reported that have never interrupted the treatment have more previous knowledge about HIV and the treatment. Most of those who have interrupted the treatment have already been discriminated by nurses or friends. The majority of the participants did the test because were already feeling sick. All participants that did the test because were suspecting of the partner, have already interrupted the treatment, what calls attention to the value of this variable on treatment adherence. The study reveals that those who have self-reported treatment interruption mostly have suspicious about the partner having another relationships (secrets) and those who have never interrupted in majority are dealing to what the study variables address as exposure.

The study pulls attention to the role of information and of health education access to ART patients attempting to the loneliness, the fear of discrimination and a social support perceived as present elements of influence on the adherence to the ART. Health Professionals are seen in the study as differentiated elements with a positive role on participants ART adherence.

### Introduction

Sub-Saharan Africa is still on of the most affected regions by AIDS [1]. According to the national report [2] in 2009 the HIV prevalence in Mozambicans age 15-49 was 11,5%. Being lower in the north of the country and higher and even with a tendency to suppurate the values in the Centre and

South of the country. In Maputo district the percentage of infected people is one of the highest in the country, 19,8%, and in Maputo city 16,8% of the habitants are infected by HIV. Gender differences on infection overrule reveal that are more women (13,1% of the population) infected by HIV than men (9,2%), and for both, men and women HIV prevalence increases with education and with age. HIV treatment adherence is one of the main concerns of research in the field [2,3]. Literature on ART adherence has been growing and addressing different influences that have implications on patients ability to maintain a consistent therapeutic program [4,5]: cultural factors, risk behaviours, stereotyped group risks (as sex workers and drug addicted ART patients), medication accesses as well as characteristics of ART medication and the influence of demographic and social factors [6-8],

Gender is another factor that studies have demonstrated that have implications on coping with HIV. Literature reveals how males and females present their differences on searching for help of others, or for information about health. Studies have also presented a discrepancy in adherence to antiretroviral medications between HIV-infected men and women presenting women lower values on ART adherence [9].

Relationships between social support and outcomes such as physical morbidity and mental health have been presented for several years, with the strongest relationships typically involving perceived emotional support [10]. Focusing attention on HIV infection context several studies have indicated that people are most likely to work collectively to achieve in the context of trusting and supportive relationships; the sense of not being excluded but of still being part of the group, of feeling included, and of being in touch with social support have been related to better coping [11-16] , better treatment adherence , and slower progression to AIDS (17-20).

The *perceived* social-emotional support have been presented as a factor that definitely influences mental health outcomes but not exclusively positively as it is not always perceived as helpful by the recipient [10,21]. Well-intentioned support attempts may be seen as oppressive and constraining by their recipients, and social network members may react with criticism and hostility to what they feel and evaluate as insufficient progress in adjustment to stress [22,23]. In development of these factors patients can start to feel judgment by those who are functioning as their social support base [21]. Feelings of loneliness restrict the personal emotional openness and improves isolation and fears of stigma and discrimination. These are also factors that studies have revealed that impacts ART adherence, reducing it [24-29].

The aim of the present study is to explore socio-demographic characteristics of ART adherence on patients who live in Maputo district in Mozambique, including differences on: age, gender and schooling level, on their family and health professionals support relationships. Knowledge about HIV and ART and the fear to be recognized as HIV and on the impact of the discrimination experiences on the ART adherence are also variables in account as a second aim of the study.

### **Study Setting**

This exploratory study was conducted in Maputo district in Mozambique among a convenience sample of patients in the Military Hospital (HIV Cohort) and DREAM NGO. The Military Hospital is an urban public hospital and the only one which still has the HIV clinic, and Dream NGO is the largest single provider of HIV care in Maputo City, receiving patients from all district. The Institutional Review Board approved this study. After having received authorization, we solicited voluntary participants to fill out the questionnaires and explained the study's aim. To protect participants and their anonymity, no information regarding identity is required on the questionnaire. Participants, one by one, answered the questionnaire, sitting in a desk alone with the researcher, thus guaranteeing confidentiality. The fact that the investigator is unknown to the patients, that he is not a member of the health care team is a guarantee of patient's anonymity limits this bias (e.g. the patients were not afraid of being criticized for poor adherence). This study strictly followed the guidelines for human rights protection.

### **Participants**

Person in antiretroviral (ART) therapy for HIV aged 18 years and above who attended the clinic for a routine clinical care appointment between September 2011 and May of 2012 were eligible for the study. Patients were not compensated for participation. Patients unable to provide informed consent (e.g. participants with severely impaired cognitive functioning) or those who could not speak Portuguese were excluded from the study. The sample consists of 602 ART patients living in Maputo district between 21 and 56 years old.

## Measures

A questionnaire was developed to access to the elements on research: socio-demographic characteristics, family disclosure and support relationships, relationship with the HIV diagnose, relationship with ART, relationship with the Health Team, Sexuality, Social discrimination and Violence, general knowledge about TARV.

Socio-demographic characteristics were assessed through the following items - gender (male/female), age (included as a continuous variable), schooling (None, 1<sup>st</sup> Cycle (1 to 4 years of school), 2<sup>nd</sup> Cycle (5 to 6), 3<sup>rd</sup> Cycle (7 to 9), Secondary School (10-12), University Degree, Others), marital status (single, married, unmarried cohabitation, divorced, widower), household (live alone, live only with children, live only with life partner, live with children and life partner, live with children and other relatives, live with relatives).

From the questionnaire the following questions were specifically chosen for this study: (1) Did you interrupt the treatment at least once (yes/no), (2) Which one is your primary support relationship (family, friends, health professionals, activists, health associations, none, other), (3) Which reason took you to do the HIV test (started to feel sick, was hospitalized and tested, my partner did it, my partner is HIV+, suspected that my partner was having other partners, doctor's advice, was joining a friend or relative), (4) Previous knowledge about HIV before doing the test (yes/no), (5) Discriminated as HIV+ (yes/no), (6) By whom have you been discriminated (doctors, nurses, relatives, friends, work colleagues), (7) fear of being recognized as HIV+ (yes/no).

## Data analysis

The data were analyzed using the Statistical Package for Social Sciences (SPSS) version 19.

Chi-square ( $\chi^2$ ) test and adjusted residuals was used to analyze the differences between those who have or have not interrupted the treatment. The level for statistical significance was set at  $p < .05$ . Only significant results were discussed.

## Results

Demographic characteristics of these individuals are shown in Table 1. The amount of women (74,8%) and men (25,2%) are differently represented in the sample, being women almost three quarts of it. Most participants have between 21 and 29 years old (33,2%) and have completed the Second Cycle of School (33,1%). Only 6,3% of the individuals have never completed any school level and none (0%) have completed any University degree. More than half of our sample have the relatives (55,1%) as the primary support relationship, 22,8% have the activists, and 15% have the health professionals. A minority of 3% have friends as primary support and 4,2% of our sample don't have any support relationship.

The analysis of the treatment interruption presented statistical significant differences.

Most patients that have interrupted the treatment: are men (36,8%;  $\chi^2 (1) = 20,038$ ;  $p = .000$ ); are participants who have between 48 and 56 years old (37,3%;  $\chi^2 (3) = 94,152$ ,  $p = .000$ ), who have finished the 1st Cycle of schooling (36,3%;  $\chi^2 (4) = 52,794$ ,  $p = .000$ ); who have done the HIV test cause was feeling sick (79,8%; ( $\chi^2 (6) = 207,152$ ;  $p = .000$ ) or who have suspected the partner (9,3%); who have friends (9,3%) and activists (33,2%) as primary support relationships ( $\chi^2 (4) = 106,209$ ,  $p = .000$ ), who have already been discriminated as seropositive (78,8%,  $\chi^2 (1) = 6,860$ ,  $p = .009$ ), who have been discriminated by friends (46,7%) and nurses (35,5%;  $\chi^2 (4) = 52,763$ ,  $p = .000$ ).

Considering those who have never interrupted the treatment, we have more: women (80,2%); ART patients with ages between 21 and 29 years old (41,3%); patients who have never completed a cycle of studies (9,3%) or who have only finished the Secondary school (34%); who have done the test cause the partner was HIV+ (13,7%), was hospitalized (12,5%), the partner did it (6,8%), was joining a friend or a relative (3,4%); who have health professionals (22%) as primary support relationship or none support relationship (6,1%); who didn't have previous knowledge about HIV (46,1%;  $\chi^2(1) = 5,415$ ,  $p = .02$ ); who have never been discriminated as seropositive (31,5%), or was discriminated by doctors (14,3%), relatives (16,8%) and work colleagues (20,4%); and fear being discriminated as HIV+ (75,3%;  $\chi^2(1) = 22,535$ ;  $p = .000$ ).

Table 1 – Differences between ART interruption

	Yes (N=)		No (N=)		Total (N=)		$\chi^2$
	N	%	N	%	N	%	
Gender							20,038
Female	122	63,2	<b>328</b>	80,2	450	74,8	
Male	<b>71</b>	36,8	81	19,8	152	25,2	
Age							94,152
From 21 to 29	31	16,1	<b>169</b>	41,3	200	33,2	
From 30 to 38	45	23,3	125	30,6	170	28,2	
From 39 to 47	45	23,3	83	20,3	128	21,3	
From 48 to 56	<b>72</b>	37,3	32	7,8	104	17,3	
Schooling Level							52,794
None	0	0	<b>38</b>	9,3	38	6,3	
1st Cycle	<b>70</b>	36,3	91	22,2	161	26,7	
2nd Cycle	72	37,3	127	31,1	199	33,1	
3rd Cycle	51	26,4	103	25,2	154	25,6	
Secondary School	0	0	<b>50</b>	34	50	8,2	
University Degree	0	0	0	0	0	0	
Other	0	0	0	0	0	0	
Support Relationship							106,209
Relatives	111	57,5	221	54	332	55,1	
Friends	<b>18</b>	9,3	0	0	18	3	
Health Professionals	0	0	<b>90</b>	22	90	15	
Activists	<b>64</b>	33,2	73	17,8	137	22,8	
None	0	0	<b>25</b>	6,1	25	4,2	
Previous Knowledge							5,415
Yes	194	53,9	<b>261</b>	63,8	365	60,6	
No	<b>89</b>	46,1	148	36,2	237	39,4	
Reason to do the HIV test							207,152
Feel Sick	154	79,8	121	29,6	275	45,7	
Was hospitalized	0	0	51	12,5	51	8,5	
Partner did it	0	0	28	6,8	28	4,7	
Partner HIV+	0	0	56	13,7	56	9,3	
Partner suspicious	18	9,3	0	0	18	3	
Joining friend or relative	0	0	14	3,4	14	2,3	
Other	21	10,9	139	34	160	26,6	
Discriminated as HIV+							6,860

<i>In</i> –	Yes	<b>152</b>	78,8	280	68,5	482	71,8	<i>bold</i> 52,763	
	No	41	21,2	<b>129</b>	31,5	170	28,2		
	Discriminated by								
	Doctors	12	7,9	<b>40</b>	14,3	52	12		
	Nurses	<b>54</b>	35,5	64	22,9	118	27,3		
	Relatives	1	0,7	<b>47</b>	16,8	48	11,1		
	Friends	<b>71</b>	46,7	72	25,7	143	33,1		
	Work colleagues	14	9,2	<b>57</b>	20,4	71	16,4		
	Fear of being identified as HIV +								22,535
	Yes	177	91,7	<b>308</b>	75,3	485	80,6		
	No	<b>16</b>	8,3	101	24,7	117	19,4		

values that correspond to an adjusted residual  $\geq |1.9|$ .

## Discussion

The level of self-reported adherence evaluated as treatment non-interruption, is superior on women than on men. Our results attempting gender adherence contrast the literature, where is presented that usually women are less likely to adhere to ART than men [11]. These results improve our awareness to the fact that HIV infected men are facing different barriers to adherence than do their female counterparts [30,31]. According to the difference between the infected female and male in the country, 13,1% and 9,2%, respectively, [3] was expected to have a higher number of men in this study sample, than it has (less than 25% of the sample were male participants) attempting to the fact that it was an accidental sample. This data calls attention to the role that women is taking in her own health and on her ART program adherence and the difference of the one that is being taken by men. As results show, male avoidance of the treatment and of the treatment appointments might be compromising their information about HIV and ART as also as their role and involvement on the treatment, on their health, on their life expectancy and on their family's subsistence according to the economical role that they take part in their families. Along the years, studies have demonstrated that the efficacy of ART is strictly related to a high (more than 95-99%) adherence to the treatment. ART good adherence allows the HIV infected patients to have a better quality of life (less health complications, more resistance to AIDS...) than those who are not so well committed to the treatment, allowing patients to have a safe and strong daily life routine. In addition to this information, this study results calls our attention to where are the infected men of Maputo district? Health policies have to become closer to men when ART adherence is the concern. Infected HIV men need specific interventions and specific strategies have to be developed to approach and involve them more effectively.

Results on age and schooling level need to be addressed together. Results reveal that treatment is more interrupted by elders than by youths (21 to 29 years old have never interrupted the treatment). Factors involved in longer treatment exposures, as higher exposure to life adversities, to treatment stressors and to treatment coping strategies failure, tend to develop a major role on long term treatment adherence, making it harder for elders or/and as long as the years are going, to which this study results might be synchronized with. Attempting to the study participants characteristics, Mozambicans schooling level with age between 48 and 56 years old tend to be lower (1<sup>st</sup> cycle) than the one of the youths (secondary school). Our results are according to literature in the influence of patient disease literacy on treatment adherence. Patients with low literacy tend to have the highest reported rate of non-adherence (52.2% of our participants) and individuals with marginal literacy skills were the least likely to self-report missing any doses of antiretroviral medications (19.5% of our participants) [32,33].

The results about the reason to do the HIV test increase our interest on the theme of Secrecy. Beside the fact that participants majority (45%) did the test because was already feeling sick, the data about



doing the test because was suspecting of the partner, calls attention to the value of this variable on treatment adherence, once all of the participants that pointed this reason to do the test have already interrupted the treatment. The study reveals that those who have self-reported treatment interruption mostly have suspicious about the partner having another relationships (secrets) and those who have never interrupted in majority are dealing to what the study variables address as exposure: from the partner who reveals or the seropositive state or that have done the test; or from a relative or a friend who asks for joining to do the test. Despite the fact that doing the test because was hospitalized doesn't involve a special voluntary movement to take the decision, a required element on planned behaviour theories [34], we still must verify that does who did it revealed less interruption, what pulls our attention to the important role developed by health professionals. Our awareness lands on the importance of the possibility of the good relationship between the health care system and the ART adherence behaviour when patients discover their serostatus hospitalized.

The study's results suggest that HIV serostatus disclosure influences adherence to ART regimens for HIV+ patients. According to literature was expected to have less self-reports of interruption on patients who have activists, family and friends as primary support relationships [35, 36] as these relationships tend to promote an optimal context for an effective dialogue in a safe social space and a sense of belonging and responsibility for tackling HIV/AIDS [37]. In fact, these study results reveal that those who self-reported treatment interruption are those who have friends (9,3%) and activists (33,2%) as primary support relationships. The opposite of what was expected. Peer-education, and activist's role are described in literature as an empowerment movement and a promising investment on HIV mitigation and ART adherence by the use of selected local facilitators to help people identify obstacles to effective HIV-prevention and AIDS-care and discuss how they can work together to tackle these [38-40]. According to this, these study results pulls our awareness as well as a deeper concern on the role of activists support, and on activists needs and practices supervision in attention to the importance and the impact of the role this members are having on ART adherence. On the other hand, our results reveal that those who have never interrupted the treatment have health professionals (22%) as their primary support relationship, what indicates that a good physician-patient relationship is associated with better adherence to antiretroviral regimens for HIV infection and is consistent with literature [41-49].

Multiple studies indicate the influence of the role of the knowledge of treatment regimens and cognitive demands related to the complexity of ART pharmacotherapy, as factors that may influence the level of adherence, and results indicated that personal HIV knowledge and appointment adherence were associated [50, 51]. Surprisingly our results are not consistent with literature, revealing that patients who have never interrupted the treatment are those who didn't have any previous knowledge about HIV/AIDS before doing the test. Although this results might bring our attention to the role that the first HIV appointment has as a good first moment of providing correct information about the virus and the treatment, and also as past beliefs about the treatment might have been influencing negatively the ART adherence of our participants.

Discrimination and stigma show concordant values in our research. Those who have interrupted the treatment at least once are those who have already been discriminated as seropositive (78,8%), and those who have never interrupted the treatment are those who live more in the fear of being identified as seropositive (75,3%). Several studies have reported the role of social support in increasing or decreasing the stigma and effect of it on ART adherence. Curiously our participants who majority interrupted the treatment, were those who were discriminated by friends (46,7%). Past experiences, experienced by the self or beliefs internally constructed by the social environment reports or expectations, have an impact on our future reactions [34] and the adherence behaviour is not an exception [52]. These study results suggests that the fear of being identified as seropositive is present but is not a sufficient condition to improve the flight response on ART patients, the treatment interruption response [53]. Otherwise, pulls our attention to the effect of the vivid experience of having been discriminated as a seropositive on the production of the avoidance of the health behaviour, the ART adherence, and requires the need of deeper research on the impact of the

discrimination on ART adherence.

These results increase our awareness to the importance of developing studies and interventions that improve Art adherence knowledge according to gender, age, social support network and health professionals educational presence and role.

### Study Limitations

This study has some limitations. First, because of the sensitive nature of the survey, findings are subject to social desirability bias. Second, an additional objective method (e.g. a count of returned pills) would have helped to improve the estimation of adherence level.

### Future Directions

The results emphasize the need to understand the negative, as well as the positive, aspects of social relationships when examining responses to stressful circumstances. Consistent with previous research, conflict aspects of social relationships were empirically, as well as conceptually, distinct from perceived available social support. Further studies should address the comparison between specific knowledge of ART and the impact on treatment adherence. On future research we also expect to deepen the knowledge on the role of discrimination in treatment's non-adherence, and on the role of the relationship with health professionals in the impact on the ART adherence behaviour.

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