Antiretroviral treatment: adherence and the influence of depression in users with HIV/Aids treated in primary care

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ABSTRACT Adherence to treatment is one of the major challenges to HIV (Human Immunodeficiency Virus) treatment, being depression a factor that impacts on it. The research aimed to identify if depression interferes with adhesion. A multi-approach method for adherence, open interview and Beck Depression Inventory were used for depression screening. The relationship between depression and nonadherence was not found, although the prevalence of depression reached 22.24%. Some patients assume fear of stigma and difficulty in following antiretroviral treatment due to the drug adverse effects. Also a social protection network was perceived as crucial as was the necessity to build a care network.

KEYWORDS HIV. Medication adherence. Depression. Primary Health Care. Social support.

RESUMO *A adesão ao tratamento é um dos maiores desafios ao tratamento de HIV (Vírus da Imunodeficiência Humana), e a depressão, um fator de impacto. Objetivou-se identificar se a depressão interfere na adesão. Para tanto, utilizou-se um método de multiabordagem de adesão, entrevista aberta e o Inventário de Depressão de Beck para rastreamento de depressão. A relação entre depressão e não adesão não se verificou, apesar de a prevalência de depressão ser de 22,24%. Os pacientes admitiram medo do estigma e dificuldade em seguir o tratamento antirretroviral em decorrência dos efeitos adversos do medicamento. Detectou-se a importância da rede social de proteção e evidenciou-se a necessidade da construção de uma rede de cuidados.*

PALAVRAS-CHAVE *HIV. Adesão à medicação. Depressão. Atenção Primária à Saúde. Apoio social.*

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Introduction

The Acquired Immunodeficiency Syndrome (Aids) is an advanced clinical manifestation of the disease caused by the Virus of Human Immunodeficiency (HIV). Its distinguishing trait is a disturbance of cellular immunity resulting in higher susceptibility to opportunistic infections and neoplasias[1]. The transmission of this syndrome is predominantly sexual, in spite of there being other forms of exposure to HIV such as blood and vertical transmission[1].

In Brazil, there were, in 2015, 830.000 people living with the HIV, and there were 32.321 new notifications of infection by HIV in that year[2].

Since 1996, according to Law # 9.313/96, the Brazilian government guarantees the distribution of antiretroviral drugs in the environment of the Unified Health System (SUS), being the first developing country to adopt a public policy of access to Antiretroviral Therapy known as ART[3]. In 2013, a new approach to stopping the Aids epidemics became possible by means of the decision to treat every person living with the HIV, regardless of what their CD4 count could reveal about their immune state, making primary care centers responsible for treatment and for increasing the coverage of HIV testing among key populations[4].

This access to ART assured by the Brazilian government and by international initiatives in the same sense made possible the improvement in survival and quality of life rates of patients, leading to the understanding of Aids as a chronic disease. Yet the use of antiretroviral drugs (ARVs) also came along with significant side effects, which led to an adherence problem. In this context, matters related to adopting standards to promote adherence to the services and to ART became not only a priority but required a continuous and long lasting focus[5].

The HIV positive patient who abandons a drug therapy or follows it incorrectly can make room for opportunistic infections. Therefore, adherence to treatment ends up having quite evident social and political implications, both in terms of the investment made by the Brazilian government and in terms of controlling the epidemics[5]. Recent studies stress the need for policies aiming at tackling the epidemics to improve quality of care and promote adherence to therapy[3]. From the viewpoint of public health, non-adherence is both an individual and collective threat[5].

The combination of two or more adherence methods is necessary for purposes of monitoring, but none of the methods presents enough accuracy to define the real situation regarding the use of medication[6].

In spite of the knowledge that the viral load is subject to the influence of clinical complications, vaccines and drug interaction[7], the only measurement good for assuring that the patient is actually taking the ARV is that of gauging the presence of the medication in the bloodstream[8]. That is why the quantification of HIV in the bloodstream, also known as Viral Load (VL), is used for monitoring the response to the antiretroviral treatment and for early detection of virological failure[1].

Self-reporting has been the most used method for monitoring adherence both in research and in daily healthcare[6]. It is considered a low cost method that does not require much time, and allows to hear patients and solve problems related to the ingestion of the ARVs. However, there are also problems related to this method considering the differences between the adherence measurement methods and the tendency of patients to overestimate their behavior when under medication[6,9].

Among the variables that interfere in the adherence to ART, depression is acknowledged for its capacity to lead to negative outcomes such as reduction in adherence to medication, in quality of life and possible worsening of disease progression and mortality[10]. Depression is knowingly a pathology presenting a high level of improvement when treated, and this improvement can reduce unnecessary use of healthcare centers, bring down mortality and extend patient survival[11].

Depression is the psychiatric disturbance prevalent among HIV infected individuals[12].

Although there are studies considering a variation in the prevalence of depression among People Living with HIV/Aids (PLHA) ranging from 0% to 42%, the consensus is that it is most frequent among this group than among the population in general, the difference being of 30% on one side and of 11% on the other, respectively[12].

Thus, this study aimed at analyzing adherence to treatment among HIV positive patients, identifying patients diagnosed with depression and verifying the interruption of ART due to depression symptomatology.

Methodology

The study took place at the Germano Sinval Faria School Health Center (CSEGSF) of the Oswaldo Cruz Foundation, in Rio de Janeiro in the year of 2016, a choice made for its accumulated experience in the assistance to HIV positive patients in the environment of primary care since 1999.

This work made use of the mixed investigation method, characterized by the combined use of qualitative and quantitative investigation, as we understand it to be more adequate for analyzing the complex phenomena inherent to social and health sciences[13,14].

The phases of the research followed the identification of patients who began the ART program in 2014, the revision of the medical history of those patients and the implementation of the Beck Depression Inventory, as well as of a semi-structured interview process.

The criteria for inclusion encompassed cases of HIV/Aids among individuals of 18 years of age and above who started the ART program in the period between January and December 2014 at the CSEGSF, where their reference doctor worked, and who accounted for two levels of viral load when beginning treatment.

For identification of patients, the System for Logistical Control of Medication (Siclom) of the Pharmacy Service was useful. Physicians were in charge of recruiting their patients for

the study during their appointments there.

Once the patient was identified, a revision of his medical records was made in order to find his socio-demographic information, the date of his HIV/Aids diagnosis, and the viral load measured from his beginning at the ART program up until March 30 2016. There was tracing of any information related to complications that could lead to interrupting or changing treatment. Attention was paid to depression diagnosis, usage of alcohol and drugs or to any account of a prior follow-up of patient by mental health professionals, even more so in the case of a correlated drug prescription.

Interviews were performed according to the availability of patients. At first, patients answered the Beck Depression Inventory II (BDI II). Semi-structured interviews were conducted with the purpose of finding out how they came to know they were ill; the impact of the disease in their life; how the treatment began, how it felt to follow the ART program, and whether depression interfered somehow in the ingestion of medication.

Developed by Beck et al.[15], the BDI II consists of a self-reporting instrument made of 21 questions encompassing items related to depression symptomatology. This instrument is regularly used in polls and studies on depression among HIV/Aids patients.

For adherence measurements, the choice was made for a multi-approach method[6,8,9] combining the self-reporting of the interviews and the objective measurements provided by the viral load records and the System for Logistical Control of Medication (Siclon) for removal of ARVs.

The first adherence measurement made for the purpose of this study was the percentage of days on ARV medication. An adopted standard of adherence was the ingestion of 95% of the prescribed doses, being this the same standard adopted by the Ministry of Health (MH). The Siclom data, based on the dates of removal of medication and on the number of tablets prescribed, allowed seeing how regularly medication would be taken from the pharmacy and

whether patients had enough medication for fulfilling or not the adherence standard established by the MH.

The percentage of days on medication was calculated according to the following equation: total of days on medication divided by the follow-up time. For the purpose of calculating the days encompassed by the follow-up time, March 30 2016 was taken as a reference date and was subtracted from the date in 2014 when the patient registered at the Siclom.

In that sense, all patients who remained 95% or more of their time on medication, according to the follow-up information, were considered adherent to the ART program.

The second method, that of the viral load count, considered adherent every patient who attained viral suppression up until 24 weeks from the beginning of the ART program. Suppression is understood as a viral load with a maximum of 50 copies/ml of blood[7].

Self-reporting, the third adherence criterion, to be verified during the interview, identified as an adherent patient anyone who informed having made the correct use of the ARV medication as prescribed.

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Results and discussion

Chart 1 shows the number of subjects in each phase of the study, along with the analysis of losses and variables.

Chart 1. Number of subjects in each phase of the study, analyzed losses and variables

Study population and variables	Phases of study		
	SICLOM	**MEDICAL RECORD**	**INTERVIEW AND BDI II**
Initial patient	34	28	28
Loss	6	0	10
Patient under study	28	28	18
Variables	Initial registry, ARV withdrawal dates	Socio-demographic data, information on depression and mental health, viral load measurements.	Discovery of diagnosis, experience with ART, interruption or abandonment of ARV treatment or symptomatology compatible with depression.

ARV- Antiretroviral; BDI II- Beck II Depression Inventory; Siclon- System for Logistical Control of Medication; ART- Antiretroviral Therapy.

Among the 34 initial patients, six were ruled out for different reasons: one for death; two for assistance by physicians of other institutions; a homeless patient for assistance by another health center, another one for no count of viral load; and yet another one was transferred to another unit. The loss of ten subjects during the interview was due to refusal. Nine possible participants, who the professionals had contacted by phone, were impossible to find when the study actually began.

Among patients analyzed, there were 15 men and 13 women. The predominant age bracket included individuals between 20 and 49 years of age, representing 78,57%. Among the total, 92,86% were of a middle school educational level. Because of a lack of reliable records related to employment and income, it was not possible to identify the profession or the occupation of two of the subjects.

The health policy advocates that a partition per territory, through which patients access services within their respective programmatic areas, is not possible of

enforcement in what refers to HIV/Aids. The patient in need of ART can refer to another primary care unit to obtain the necessary drug therapy yet not to the specialized services[1]. Furthermore, matters related to prejudice and to fear of identification can be responsible for the migration towards other services.

Table 1 shows data on comorbidity or on worsening factors that may interfere in the adherence process.

Table 1. Distribution of patients in Arvt according to comorbidity or worsening factor at the CSEGSF, as per demographic data (N=28). Period: 2014-2015

Variables	Number of patients	%
Use of illegal drugs		
Yes	08	28,56%
No	20	71,42%
Used cocaine	03	10,71
Use of alcohol		
Yes	19	67,85%
No	08	28,57%
No record	01	3,57%
Undergoing mental health treatment		
Yes – psychiatry and /or psychology	04	14,28%
No record	23	85,72%
Depression diagnosis		
No	25	89,28%
Diagnosis when interrogated by nurse	01	3,57%
Yes	02	7,15%

Source: CSEGSF hard copy medical records.

CSEGSF- Germano Sinval Faria School Health Center; ART- Antiretroviral Therapy.

It is verified that 71.42% of patients deny making use of illegal substances, 28,56% declare such use and 10,71% report having used cocaine but being currently in abstinence. Regarding alcohol consumption, 67,85% of subjects report uses, a mark quite close to what the literature describes3.

In a large number of medical records, -89.28%, no mental health occurrence could be found, probably revealing not only patients not manifesting depression but also suggesting there could be insufficient diagnosis of mental disturbances16.

The research revealed that 50% of the subjects had an HIV diagnosis and initiated ART in 2014, whereas the other half, whose diagnosis came prior to 2014, probably began ARV treatment because of the implementation of Treatment as Prevention (TasP).

Since the advent of the combined Antiretroviral Treatment (ART), HIV infection has been regarded as a chronic disease. Therefore, once the ARV treatment begins there can be no more interruption due to the viral replication risk[5]. As the time of medication usage increases up until the end of a

lifetime, fatigue becomes a common and expected consequence resulting from daily use, complexity of schemes, different restrictions and social and even physical changes related to treatment. For that reason, an early adoption of ART is possibly a factor that may hinder adherence[14].

On the other hand, a new presentation of the antiretroviral therapy, reducing the scheme to a single tablet, helps in the extended use of ARVs and acts as an adherence facilitator.

Table 2 shows the outcomes of adherence according to those three criteria. Self-reporting will be discussed in the interview session.

Table 2. Distribution of patients at the CSEGSF, according to the adherence criteria defined by the study: Siclom (N = 28), Viral Load (N = 28) and Interviews (N = 18). Período 2014-2015

Adherence	Siclom %		Viral Load %		Interview%	
	n	%				
Yes	17	60,74 %	20	71,42 %	10	55,55 %
No	11	39,26 %	08	28,58 %	08	44,45 %
Total	28	100 %	28	100 %	18	100 %

Source: Siclom, hard copy records and interviews.

CSEGSF- Germano Sinval Faria School Health Center; Siclon- System for Logistical Control of Medication.

It was verified that, according to the dispensation of drugs standard, 60.74% of patients were considered adherent. The monitoring of ARV dispensation is important for the identification of patients with irregular removal of such drugs from the pharmacy[9], even though, as in other adherence methods, it might bring accuracy problems[8]. Interpreting data on ARV dispensation suggests nothing else but adherence or non-adherence, given that being in possession of the medication is no assurance that it will be ingested regularly or ingested according to the prescription[6,8,9].

According to viral load count, 71.42% of patients were adherent.

Viral load count is not ideal for gauging adherence, considering that several factors can influence such measurement, and 96% of patients remaining in treatment and receiving ARVs have non-traceable HIV levels in their bloodstream[7].

As for the third adherence standard, which is self-reporting, 55.55% of the interviewed subjects informed having made correct use of the ARVs.

As per official data[3], the average rate of non-adherence is of 34.5%. However, there can either be large variability among values found or, depending on the type of measurement and on how to define adherence, confirmation of results.

The established percentage of adherence varies in accordance to the adherence metrics definition to be applied, be it self-reporting through interviewing, daily record, tablet count, medical record registry, pharmacy dispensation, electronic device, or a combination of methods, besides the study design itself[3,7,9]. The other important means for evaluating adherence is depression itself.

The analysis of the BDI instrument considered significant a depression whose results were above 21 points, corresponding to 22.23% of the subjects (*table 3*), which is quite close to the results of the systematic review and of the metanalysis[17,18].

Table 3. Distribution of patients in Arvt according to result of the instrument for tracing depression symptoms in patients who began ArvT in 2014 at CSEGSF (n=18). Period: 2014-2015

Subject		BDI II
N	%	
11	61,11%	Absence of symptoms
3	16,66%	Light to moderate symptoms
4	22,23%	Severe symptoms

Source: BDI II.

BDI II- Beck II Depression Inventory; CSEGSF- Germano Sinval Faria School Health Center; ART- Antiretroviral Treatment.

Data shown suggest a 22.23% prevalence of depression among the interviewed subjects[12,15,16].

The study revealed that only 5.55% of the interviewed subjects with a high depression score acknowledged a relation between depression and ARV ingestion.

My world was gone... at that moment, I could no longer consider myself someone normal. Everything was gone, leaving me with no surface where to stand on. ... I cannot work any longer... all I do is cry... if I knew that if I stopped on this very day I would die tomorrow, I would have already stopped. Medication was also the hardest part of my life... it is the only moment when I remember I have the HIV. Most of the time I try not to think that I have the HIV... There would be times when... I would take it on one day and not want to take it on the other day. (P11).

Patients adhering to treatment stop taking the medication as prescribed at some moment and, in spite of having experienced the discovery of HIV as something difficult to accept, eventually manage to rebuild their life by adapting to the new situation. However, non-adhering patients can only think about the deeply disturbing moment of discovering they have the disease. In that sense, it is possible that the 22% rate of depression prevalence indicates a group more prone to abandon treatment. As for the 55%, they continue to experience the disease as

something deeply disturbing and this seems to be predominant among patients incapable to adhere[19].

The interviews made possible the acknowledgement of categories leading to an understanding of the experience of living with HIV/Aids and of the adherence to treatment based on psychosocial aspects that actively interfere in the process. Such categories are the discovery by the HIV bearer of his condition, the impact this has on his life, the experience with the antiretroviral therapy, and the protection network.

Discovering one bears HIV/Aids

The moment of receiving the diagnosis is critical considering the severity of the disease and how there can be an impairment prognosis, and it can unfold in ways important to the life of the individual, to his treatment and consequently to his adherence habits.

The care taken when communicating the diagnosis, and the interaction with the health professional, are critical at that moment, given that the emergence of helplessness feelings might affect the way patients use the message they receive from the professionals so as to define their life projects[3].

Among 18 patients, only four of them received the contagion news from the CSEGSF professionals. Three of them became aware of their condition through the positive testing of their spouses. One came to know

because of laboratory examination. All of them remain asymptomatic. The other 14 received the information from professionals of other health services, seven of which remained asymptomatic.

Surprisingly, for some receiving the diagnosis did not cause any unrest neither any significant impact: "*It was normal... I already knew it*" (P13).

The majority of the subjects demonstrated ambivalence between life and death when becoming aware that they were bearing the HIV/Aids. The anguish felt at that moment seems to relate to the possibility of death, partially because of the persistent understanding that Aids kills, partially because an important change will have to take place in order to live with the disease in an effective manner and with quality of life.

Five patients reported having found reasons to move on with life and look for treatment, showing resilience in spite of the pain felt when receiving the diagnosis:

A milestone was the moment when I had to review my concepts, when I had to reorganize matters, when I also had to reconsider my life goals, but nothing to the extent of shaking my structure. (P19).

A patient described how devastating receiving the HIV diagnosis was to him:

When I became aware that I had the HIV, it was shocking... I began to cry, I felt there was no ground underneath me. I have this feeling to this day when I remember it. I arrived at work and I said, 'Boy, I am going to die. I am... I don't know what I will do with my life'. (P6).

Results found by older studies regarding reactions to the diagnosis are similar, in spite of how significantly the treatment expectation and survival rates for people with HIV/Aids have improved[3].

Emotional shock, concern with health condition, anxiety related to the appearance of symptoms, anguish, fear of dying, fear of being left alone by relatives and friends, anger, shame and guilt were among the reactions found[3].

Cardoso and Arruda[19] state that this moment of discovery is associated to death, yet it requires a new life condition, a one better adapted to the new situation.

Patients described finding in their children a reason to live and to engage in ART: "*I had this desire to kill myself, but then I thought about my children... I was desperate... But I knew I didn't want to die ...*" (P20).

Ayres[20] addresses care as a philosophical construct, a category to describe philosophical understanding and practical attitude, considering the meaning that health actions acquire in the several situations whenever there is a claim for therapeutic action and for interaction between one or more subjects aiming at finding relief to pain or some kind of well-being. Ultimately, taking care of others is taking care of oneself, and this is what is what becomes clear when the concern with his children leads to P20 taking care of himself.

A few subjects described the impact when receiving the diagnosis: "*I got nervous at the moment. It had never occurred to me that I would have to bear something so serious*" (P2).

Yet others experienced not only the impact of receiving the diagnosis but a feeling of discomfort that would not leave and could lead to depression: "*I am not normal any longer as I have limitations. I am not any longer a person who can do certain types of things*" (P11).

The concept of recovery seems to be important for the understanding of what these patients describe about the difficulty to find solutions to the discomfort that receiving the HIV diagnosis causes.

Recovery is defined as a process, a daily challenge and a return of hope, of personal confidence, of social participation and of a sense of having control over one's life that ends up taking place. It is not at all a matter of returning to the stage prior to the disease.

On the contrary, it is about finding personal strength yet having the disease as a baseline, and finding new solutions to the adversities[21].

When receiving the diagnosis, it is inevitable that the interviewed subjects raise the question on the means of transmission and to have them mostly falling into the category of sexual HIV transmission.

In Brazil, 96.4% of registered cases among women, in 2012, derived from heterosexual intercourse with HIV infected partners. Among men, 36.8 % of cases resulted from heterosexual intercourse, 50.4% from homosexual intercourse and 9% from bisexual intercourse. The remainder of cases relate to blood and vertical transmission[2].

Among the interviewed subjects, 33% clearly stated that they had caught the disease from having sex with someone with whom they had an intimate relationship, like husband, wife, companion or sweetheart. Besides discovering that they had a severe and chronic disease, these people had to deal, against their will, with breaking of trust.

> Boy, it was him (the companion) who brought it to me. I am positive about it as I had intercourse with no one else. On the only occasion when we were apart, we both had relations of our own during that period... but I am totally certain that I played it safe. (P6).

A patient described having been contaminated by her boyfriend, who kept it secret until he fell ill and was taken to the hospital: "*I became aware that he had it. Later on, when I went to test myself, I found out I had it*" (P7).

For a few patients, it is not worth to investigate the form of transmission:

> You see, I am both interested and not interested... As far as I see, when you decide to investigate, when you look back to investigate, you hurt much more. So it makes more sense to treat than to look back. We cannot treat what is gone. (P1).

Becoming aware of an HIV positive status because of sexual transmission also leads to feelings of anger and betrayal: "*The way it was passed on to me was somehow coward*" (P10).

The concepts of fidelity, stability, regular partner relation and monogamy provide a feeling of safety to those who put them into practice, which can lead to letting go of condoms during intercourse, but can also be partially responsible for a more devastating impact when receiving the diagnosis.

There were those who described failure in using the condom: "*the condom ended up being torn when I was with my ex-boyfriend*" (P19).

The refusal to believe in the diagnosis and the absence of reaction seem to relate more to denial of the disease than to unawareness of the HIV:

> I tried not to lose it... I kept a serious face while looking at the doctor... I remember placing my hand over the paper and saying: 'I don't have that... I am determining it in the name of Jesus [...] In the name of Jesus, I don't have this disease'. (P15).

Impact over life

There are cases in which the diagnosis becomes a propeller for changes considered positive, relating to valuing oneself and life, to being optimistic and hopeful[3]. Living with the HIV can lead to a sense of sensitivity and solidarity. The concept of resilience relates to understanding the diagnosis yet allowing it to make room for change and for new opportunities in life[21].

The first identified impact relates to a positive change in life:

> I understand not everything is bad. It was beneficial in the sense of allowing me to take a better look at myself as a human being and even physically speaking. Taking better care of my health, so to say. (P19).

The resilient capacity to approach the disease and the treatment and to deal with the means of contagion and their consequences is decisive for adherence to treatment and for protecting against depression.

Another impact made evident relates to relationship break-ups and to fear of having a new relationship, which involves not only affection aspects as well as sexual ones.

The saddest part is that I broke up with my ex and now I don't find it possible to have a relationship with someone else, neither will it be possible to live together with someone... I can't tell how the person will react ... (P6).

Another person described the interruption of sex life:

A life project was destroyed... I stopped having sexual intercourse... I don't feel I am in my right to destroy someone else's life...I raise a wall when it comes to this ...I wanted to have a child of mine, to live a normal life. (P10).

This feeling of 'being blocked' from love and sex relationships after diagnosis is very common, even more so when it is understood that the means of contagion was sexual[3].

It was observed that psychological aspects or experiences related to sadness, depression or anxiety were significant. The findings regarding depression show that it might not relate directly to the HIV diagnosis, but rather to its consequences, not necessarily having an impact on the ingestion of medication:

I became a very frail person, an impatient one, and everything would become a reason to complain. After everything I went through in my relationship and with my family, I locked myself up and ran out of patience to listen. (P12).

A subject described quite precisely the relation between HIV and depression, most of all regarding relationships, as if it were not possible anymore to trust people:

I don't feel like living any longer. I don't feel like getting involved with anyone. What was passed on to me is something I don't want to pass on to anyone. Not even to my worst enemy. (P24).

There were accounts of depression of a more severe kind, where there was a willingness to die: *"I wanted to die... I got so depressed that I would not feel hungry neither thirsty"* (P20).

An important aspect is fear of the social stigma coming along with the disease, which modifies and restrains the lives of the ones involved and prevails in this study given its major impact:

It will be hard for me to find a regular job. No one accepts me anymore. There is even a girl who won't give me a chance to date her any longer, because I have this disease. (P23).

The majority of the interviewed subjects keep the diagnosis to themselves due to this stigma. They either do not share it or share it only with those closest to them:

I told it to my son and to my boyfriend. (P11).

... I lack strength to tell it to my mother... I am afraid of disappointing her. (P24).

I am afraid of people looking at me differently... (P14).

The fear of having revealed their HIV status led to the search of other health services: *"I didn't want to be treated here, I wanted to be treated somewhere else... there are many people who are cruel to us, who are prejudiced"* (P16).

According to Carvalho and Paes[21], the stigma and prejudice that remain associated to HIV and Aids contribute to the suffering experienced when receiving those diagnoses and are a reason for keeping the news secret. Sharing or not information and feelings related to diagnosis, treatment and prognosis is a decision that has an influence on family and social relations, on the adherence to treatment and on self-care[22], as shown by Cardoso and Arruda[19].

Pachankis[21] discusses the differences

between visible and invisible stigma and states that invisible stigma is cause of stress as it requires decision making on to whom to disclose, being this a source of anticipation anxiety related to the possibility of being discovered, isolated and excluded. *"I didn't want to come here as I was ashamed of what society could say, not because of myself but because of my children"* (P20).

Patients in the study corroborate the findings of Gomes et al.[23] given that they seem to have more fear of the social consequences of their condition than of the condition itself and the possibility of it getting worse. There is deep fear of 'social death', of rejection, resulting in dual suffering due to social implications overlapping physical ones.

Experience with the antiretroviral

The experience regarding the adverse effects of the ARVs was no different among those who were asymptomatic, and joined the ART only because of the change in the MH protocol, and the other patients.

> In the first two weeks, when I started taking the medication, I felt quite a lot of nausea, but went on. (P1).

> The medication was also the hardest part of my life because of its effects... it seemed like I was walking on thin ice. I would always get dizzy, I would twist my tongue and wouldn't feel well, my body would feel different... a sensation of discomfort. (P11).

There were accounts of people who did not feel the adverse effects: *"The treatment itself was not bad... I didn't experience any discomfort, didn't feel sick..."* (P12).

The beginning of treatment is the hardest period for adherence due to the inclusion of the drugs and their side effects into the daily routine[24], and because it mobilizes a field of representation related to being HIV positive[19].

In spite of the strong reactions caused by

such drugs, the disappearance of symptoms in a few months is expected, with the system eventually adapting itself to the substances: *"I felt awful, but I was aware that I was going through an adaptation period"* (P19).

Several patients reported improvement regarding adverse effects, especially in the second year of treatment, which coincides not only with the time of ingestion of ARVs by the subjects but also with a change in the display of the drugs: *"In the beginning of the second year it already felt much better"* (P6).

The understanding of treatment continuation had to do with attending medical consultations, taking the prescribed tests and taking the ARVs: *"If you follow it, you will be alright. I did what the doctors told me, and it was alright. I'm keeping on, I can't stop"* (P16).

Two subjects considered abandoning the treatment. Four of them actually did abandon ART, yet only one subject linked the interruption of the ARV treatment to feelings related to depression.

> I was actually taking the medication as I should, but then I came across hard times. So I thought, if I really caught this thing, I might as well wait for my time to come. (P20).

All others denied even having thought about interrupting.

The improvement because of ART seems to have been acknowledged by the patients:

> I soon noticed the change brought to my body by the medication, I felt the difference... I don't feel tired like before. So it got better. I can feel the taste of food, I am eating better... (P23).

Part of the population of this study started the ARV therapy only because of the change in the HIV/Aids treatment protocol established by the MH, and was in good general condition, with no symptoms. That would be a reason why a few individuals did not acknowledge improvement through the medication treatment.

Protection network

In general, the intimate protection network provided the necessary social support in the form of spouses, friends, mother, father and companions. However, even within this familiar network, patients chose to whom they should disclose: "*I told it only to my companion*" (P19).

The presence of relatives and friends can be decisive for maintaining treatment as it helps in the daily routines, including those related to basic health care and the following up of the medication schedule[22]: "*My current husband supports me to the point that he reminds me that it is time to take the medicine. He asks me if I have already taken it*" (P15).

Emotional support can be decisive both for the acceptance of treatment and for protecting from the risk of suicide. At the very moment of receiving the diagnosis, support from family or from someone playing that role seems to be important;

The friend with whom I shared the diagnosis gave me a hug; he was the person who helped me when I most needed it, through his moral support. Had it been not for him being with me on the day I picked up the test result, I wouldn't be here any longer, because I would have thrown myself in front of a car coming fast as soon as I saw the result was positive. (P6).

Social support, especially when provided by the family, is related to a reduction in psychological pain, in frequency of psychiatric symptoms, in rates of anxiety and depression and is connected to better quality of life as well[10].

Patients go through a process of accepting the diagnosis, which influences how they will engage in the treatment and has an effect on the way family and social network can understand what is going on and position themselves accordingly.

There are certainly aspects beyond rationality at play in the treatment and in how to adhere to it, with a range of interference beyond PLHA.

Faith and belief provide a fundamental kind of social support[25]: "*If not for God, I think I would have killed myself*" (P14).

Religion contributes to building an understanding of the world and of life by means not only of its cosmology but also of its daily practices, therefore playing an important role in terms of providing social suppport[25] and corroborating the findings of this research:

I am evangelical; I have God in my life. When anguish comes, I pray to the Lord. At the time of despair, I bend my knees and begin to pray to the Lord, because only He is for me. (P24).

Social support has a positive influence on the health status of people as it can be understood as an agent making possible better control over life. Therefore, it strongly helps in the confrontation of adversities and in sharing experiences based on exchange and mutual care, given that it benefits both the one receiving as well as the one providing support[23,24].

Conclusions

The combination of the three adherence standards established by the study, in spite of the variations amongst them, showed that 38.88% of the interviewed subjects were considered adherent. The viral load threshold reached by almost all patients is a sign of therapeutic success.

It is still a challenge to identify adequate and effective manners to measure adherence. In that sense, it is important to do more research and with a larger number of patients, especially by means of the yet timid utilization of the viral load standard, if one wants to test a good method to adhere to ART.

The duration of the study might have influenced the non-verification of depression as a variable with impact on treatment. Even if 22.24% of patients were found to be depressed, they seem to have adhered to ART. However, one must treat depression symptoms in order

to avoid any worsening of the psychological condition to the extent of it affecting the quality of life of those individuals and the ingestion of antiretroviral medication.

It is essential that public healthcare service professionals pay attention to the aspects shown and that the health centers have available a multi-professional team. Training professionals is important for them to know the disease, the stigma, the treatment and the hindrances to adherence, even in the sense of

stimulating the development of a network to protect and support patients and their relatives.

Collaborators

Maria Fernanda Cruz Coutinho and Gisele O´Dwyer were responsible for conception, planning, analysis and data interpretation.

Vera Frossard was responsible for the final version of the manuscript. ∎

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