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Challenges of treatment adherence by people living with HIV/AIDS in Brazil

ABSTRACT

OBJECTIVE: To analyze the difficulties related to treatment adherence by patients living with HIV/AIDS in highly active antiretroviral therapy.

METHODS: Qualitative research based on 34 interviews with patients under treatment in several outpatient services in the state of São Paulo, in 1998-1999. The group was comprised of people from different socioeconomic levels, gender, length of treatment and varied adherence levels, according to healthcare staff perception. The interviews focused on the patient's narrative about his/her disease. The content analysis classified the difficulties as follows: related to social factors and life styles, including the stigma; related to beliefs about the use of medication; and directly related to the use of medication.

RESULTS: All the interviewees reported having difficulties concerning the stigma of living with HIV/AIDS. The difficulties related to the use of medication were the most important among patients with the best adherence level. Patients with average adherence level presented all three types of difficulties.

CONCLUSIONS: Social and cultural factors are more difficult to be overcome in order to achieve treatment adherence than those related to taking medication, thus making the role played by the health sector important, supported by clear public social policies. These dimensions must be faced not only in the health sector, but also on social and political levels.

KEY WORDS: Acquired immunodeficiency syndrome, prevention & control. Acquired immunodeficiency syndrome, drug therapy. Anti-HIV agents, supply & distribution. Qualitative research. Brazil.

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INTRODUCTION

Highly active antiretroviral therapy (HAART) was introduced in the Brazilian health system in November of 1996, as part of the country's policy on free universal access to healthcare services and medications. Among the factors that compromise the success of the free universal medication distribution program is the patient adherence to antiretroviral therapy.

The phenomenon of non-adherence to treatment has been considered international, especially among people with chronic diseases.[4,20] Studies on factors associated to antiretroviral treatment (ART) in developed countries have confirmed that treatment adherence is a complex,[6] multi-causal[13] phenomenon.

To know the difficulties of people living with HIV/AIDS as regards the use of ART enables a better understanding of non-adherence to treatment in Brazilian services. Such knowledge may contribute to improve the policies geared to this group and assist healthcare professionals with dealing with these difficulties.

Aiming at assessing the first results of the adopted policy, a broad investigation on adherence to antiretroviral therapy (ART) was carried out in the state of São Paulo between the years of 1998 and 1999.[9,*] The objective of the present article was to analyze the difficulties concerning treatment adherence by the patient living with HIV/AIDS in highly active antiretroviral therapy.

METHODOLOGICAL PROCEDURES

Between 1998 and 1999, patients who were 18 years of age or older, had been in treatment for at least a month, and were attended in 27 different outpatient services in the state of São Paulo, ranging from outpatient wards at large hospitals to small *Unidades Básicas de Saúde* (Primary Healthcare Units), participated in the study. These services correspond to those that, among the ones invited to participate in the study, joined in spontaneously. A total of 103 interviews were conducted, out of which 34 were selected for analysis.

These 34 selected patients presented varied lengths of treatment and different socioeconomic characteristics. As a socioeconomic criterion, the average family income in the state of São Paulo provided by *Fundação Sistema Estadual de Análise de Dados* (SEADE – State System Foundation for Data Analysis) was used, considering as high income those whose family income was equal to or higher than R$ 800,00 per month, and as low income those whose family income was equal to or lower than R$ 350,00 per month. The level of education was referred to as high among those who had at least graduated from elementary school, and low among those who had not completed elementary school or had not had any schooling.

A semi-structured script was used for the interviews, consisting of 19 questions about the following: HIV diagnosis context, beginning of treatment, clinical status and daily life changes after the beginning of therapy. The interview also included questions concerning: ART adherence, life style, use of drugs, doctor-patient relationship and interactions with other healthcare professionals.

The interviewers were trained in preliminary tests of the instrument. The interviews, conducted in the healthcare service itself, lasted about 60 minutes and were recorded and transcribed.

Through the use of the content analysis technique,[1] the difficulties reported by the interviewees were classified as: 1) related to social factors and life styles; 2) related to negative beliefs about the use of ART; and 3) directly related to the use of medication. Next, a scale of four points was applied to these difficulties, according to the interviewee's narrative: zero for the absence of difficulty; one for little difficulty; two for moderate difficulty; and three for great difficulty. As an example, the interviewees who reported few, short-lasting side effects were given level one as the corresponding difficulty type. Those who reported a higher number of long-lasting side effects, but did not give them much importance, were classified as moderate difficulty and given level two. Those who emphasized the side effects as an important barrier to taking their medication were given level three.

Patients were classified in three levels: high adherence – the ones that mentioned following the exact prescription or admitted occasional failure to take the medication; intermediate adherence – the ones that reported constant failures regarding the prescribed use; and low adherence – the ones that did not take any ART medication at the moment of the interview. The difficulty found to adhere to the treatment was analyzed according to its duration as well.

All interviews were read individually by five researchers and discussed until the group reached a consensus about the classification of patients.

The ethics committee on research of *Centro de Referência em Aids do Estado de São Paulo* approved the research. All interviewees signed a free informed consent form.

ANALYSIS OF RESULTS

Among the analyzed interviewees, there were 17 men and 17 women. A total of 11 participants had low level of education and income, and 23 had intermediate level; eight had known their serologic status for one year and the others for more than one year; 16 had been in treatment with ART for less than a year and 17 for more than a year; one participant did not know how long they had been in therapy.

A total of 15 participants were classified as patients of high adherence, seven of intermediate adherence, and 12 of low adherence.

Difficulties related to social factors and life styles

The interviewees spoke of difficulties concerning the stigma, life style and personal relationships. Some mentioned the need to hide the use of medication from friends and family. Treatment adherence was influenced by leisure and work situations. The difficulties regarding the consumption of alcoholic beverages and use of drugs were considered among the social factors.

The stigma to live with HIV/AIDS was an important barrier for many interviewees, who related strong need to hide the disease, as mentioned by VE and RA:

"...only I would take them hidden from my mom, because she didn't know. So I'd hide the medicine in my friend's place, wake up, go there first thing in the morning, and take it while fasting...I'd bring with me the others I'd have to take, hide them and then go on taking them until bed time..." (female, 28 years of age, low adherence level, one year of treatment)

"...I'd have to take it hidden from others... (at work) They think it's cancer, but nobody can know this" (female, age not informed, low adherence level, length of treatment not informed – reported that she had taken medication for some months).

Even when the interviewees did not speak about hiding their medication, they described the challenges of including it in the daily routine, as mentioned by AE:

"...things got messed up, like my schedule, wherever you go, you got to bring the medicine pack, it's even upsetting to open a bunch of medicines" (male, 40 years of age, low adherence level, one year and six months of treatment)

Two women related difficulties to follow the treatment, because they have to care for another family member who has HIV/AIDS, such as VA's example:

"What really made me lose my temper was to see that my son also got very annoyed to take it... he was part of it, so I had to be a mother, an HIV carrier who had to take care of my son, who is an HIV seropositive too..." (female, 29 years of age, low adherence level, about six months of treatment).

Two men reported interruptions in the treatment due to the use of illicit drugs and/or alcohol:

"...I was getting used to them... then, I began to drink again, take drugs" (male, 28 years of age, low adherence level, one year of treatment).

"...I began to skip the medication. I said to myself, 'Well, today I'm not taking it, 'cause I'm gonna party... [drink] Come on, I was born to party..." (male, 32 years of age, intermediate adherence level, eight months of treatment).

Social drinking was frequently mentioned as a barrier to adherence. Several interviewees related interrupting the medication as they saw they were going to drink alcoholic beverages on the weekend, at parties and on public holidays. This practice was related even among the high adherence level patients, such as MR:

"I didn't take it because I drank beer... No, I didn't ask the doctor if I could..., I don't usually drink beer, ever, but New Year's Eve is a special date. Then, I'm afraid of mixing up the two and end up putting it [the medication] *aside if I know I'm gonna drink some alcoholic beverage... This is a question* [about drinking] *I haven't got answered yet"* (female, 28 years of age, high adherence level, one year and six months of treatment).

Difficulties related to negative beliefs about the use of ART

This category included opinions about medication, such as: "the medicine is what kills", "AZT is for cancer", "too much medicine is bad for health", "medicine makes you drowsy and slow", "you need to take a break from the medicine", or yet:

"My fear was to start taking AZT and, as I had already recovered, I thought it was something that would attract the disease, you know..." (male, 39 years of age, high adherence level, six months of treatment).

"Because I thought I had to take a break, had to stop for a while...even my mom thought that I had created a superpower inside me due to the medicines." (male, 42 years of age, high adherence level, two years of treatment).

Difficulties directly related to the use of medication

Side effects such as nausea, vomit, headaches and diarrhea were classified as difficulties directly related to the use of medication. Other factors directly related to the act of taking medication included the following: difficulty to dissolve or swallow it, and intolerance to the smell or taste.

"...sometimes I find it difficult, when it comes to diluting it, because it's like this, the time comes, wherever you are... For example, I'm here, if I have to take the medicine, I got to put it right here and go drink some water... It was this medicine that got on my nerves. Then, I did something I shouldn't have done, I threw it in the garbage..." (male, 30 years of age, high adherence level, one year of treatment).

"So, this medicine thing, I got to the point where I couldn't even look at it, and it goes in the fridge. I just couldn't, it's six pills per dose" (female, 30 years of age, intermediate adherence level, one year and six months of treatment).

There were reports about the difficulties concerning therapeutic regimes and certain confusion about the intervals between doses:

"I'd forget... Then, at night I'd not take it because I hadn't taken it in the morning (...) because this medication should be taken every 12 hours. So, I had taken at 8 in the morning, then, I'd be in doubt if I should take it at 8 at night." (female, 28 years of age, high adherence level, one year and six months of treatment).

"Then, you say, 'It's been an hour, but then, if I take it, it's close to the next dose.' So, I don't take it." (male, 34 years of age, high adherence level, four years of treatment).

Adherence and length of treatment

The difficulties described were analyzed according to their intensity and frequency, and related to the time of treatment: beginning or current.

The Table shows the frequency and intensity level at which the patients mentioned the barriers, so that three difficulty categories were classified, and divided into past and present. The time reference was defined by the interviewee himself/herself.

The difficulties occurred more frequently/intensely in the first stage of the ART. Six people out of the 34 interviewees related not having had any difficulties in the beginning of the treatment.

The patients classified with high adherence level described difficulties directly related to the use of medication more frequently, compared to other difficulty categories. Low adherence patients mentioned difficulties of all categories with similar frequency.

The story of adherents is one of overcoming difficulties, of changing behaviors and life styles, as described by LS and GE:

"In the beginning it was hard to get it right, that cocktail thing, the time thing, even the prejudice. I was a bit of prejudicial myself. Now, it's all right. Nowadays, I take it as if it were normal" (male, 40 years of age, high adherence level, one year and eight months of treatment).

"... it's not that I don't notice that I'm taking medication any longer... The routine of my habit of taking medication is beginning to pass unnoticed... It's not so aggressive anymore" (female, 32 years of age, high adherence level, one year and four months of treatment).

For those who continued to have problems, the difficulties that were the hardest to overcome are related to the stigma of the disease:

"... if I leave it in my bedroom, and my brother is locked in there with his girlfriend, which happened a while ago, how do I get the medicine?... I know, you could ask me, 'Isn't it better if your brother knows?' If I tell them, they may take it badly and make things worse..." (male, 30 years of age, high adherence level, one year of treatment).

FINAL CONSIDERATIONS

All participants said they wanted to adhere to the treatment. However, even the patients with the highest adherence level had their moments of non-adherence, usually in the beginning of the treatment.

In the present study it was possible to capture the subjectivity regarding what "the beginning of the treatment" is to the patients, when the disease manifests itself and is incorporated to the routine. This represents challenges such as the diagnosis confidentiality, the adaptation to the regime requirements, and the difficulties with side effects of medication, among other things. The understanding of treatment adherence as a dynamic phenomenon[17] and the introduction of ART as a crucial moment in the history of the patient were important factors among the interviewees, corroborating other studies.[13,19]

The use of alcohol is considered a factor associated to the lack of adherence to the treatment of chronic diseases in general,[3,5] currently representing a challenge to people who live with HIV/AIDS.[15,17,*]

In Brazil, it is common sense that drinking and medication cannot go together. This opinion may have helped people, even the ones with high adherence level, to stop taking the medication in order to drink, even if socially. Laws et al[6] also reported on patients who suspend the medication (medicine holiday) to drink, as found in the present study. Data from this study confirm other studies that point to[7,9,17,*] a very chaotic life style by some drug users as a determining factor in non-adherence, and not the use of drugs per se. Ware et al[18] discuss about the interference of drugs in treatments, but conclude that this does not occur in all situations or in all cases. Illicit drugs frequently constitute a taboo, creating a kind of "pact of silence" between healthcare professionals (who do not investigate their use) and patients (who do not reveal their use). The stereotypes associated to drug users stop them from being seen in their singularity, preventing healthcare professionals from assisting them with specific difficulties.[18]

The opinion and negative attitudes related to the medication appeared in other studies as well, as "too much medicine is bad for health"[10] or that it is not good to take medication for long periods of time.[6,7,14,17]

The difficulties found in the beginning of the treatment require more interaction between healthcare professionals and patients. Factors linked to the medication can be overcome, for instance, by adapting the treatment times or change of medicines. This is also one of the conclusions that Vervoort et al[17] came to in their

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* Nemes MIB, organizador. Aderência ao tratamento por anti-retrovirais em serviços públicos no Estado de São Paulo. Brasília: Ministério da Saúde, 2000.

Table. Difficulties* reported in the beginning of and in the current use of antiretroviral therapy. São Paulo, 1998/1999.

User	Factors related to medication		Factors related to life style		Negative beliefs	
	Past	Present	Past	Present	Past	Present
Low adherence level						
AE	3	NA	2	NA	3	3
CO	1	NA	2	NA	0	0
CR	1	NA	3	NA	2	2
CS	3	NA	0	NA	3	3
CA	3	NA	0	NA	2	NI
MA	1	NA	0	NA	2	2
NN	2	NA	0	0	0	0
RA	0	NA	3	NA	2	2
RE	3	NA	1	NA	0	0
VE	0	NA	3	NA	0	0
VR	2	NA	3	NA	0	0
VA	3	NA	2	NA	0	0
Intermediate adherence level						
AD	3	1	3	2	0	1
JE	3	3	0	1	0	0
PO	3	0	3	2	0	1
RO	2	0	3	1	0	0
SE	3	2	0	0	1	1
VL	1	0	3	3	0	0
WN	3	1	1	1	2	1
High adherence level						
AC	0	0	0	0	2	0
AL	NI	1	0	0	1	1
AS	NA**	1	0	0	0	0
AM	3	0	0	0	0	0
AR	1	0	0	0	1	0
CE	1	0	1	0	0	0
ER	3	0	3	2	1	0
FO	3	2	0	0	0	1
GE	3	1	0	0	0	0
LA	3	1	0	0	0	0
LO	1	0	2	2	0	0
LS	0	0	1	0	1	0
MV	2	0	0	0	0	0
MC	3	1	2	0	0	0
MR	3	0	0	0	0	0

* The intensity and frequency criteria were based on reports by interviewees.
** The patient was in the beginning of the treatment and, as a result, the difficulties refer to the present moment only.
NA: does not apply (did not have difficulties at present, because the interviewee does not take medication any more)
NI: not informed

literature review. These authors emphasized the care one must have when explaining about the side effects of the treatment and the measures to be taken when these occur, keeping in mind that the medications are toxic and that the ambivalence of their action must be discussed.

Furthermore, professionals in healthcare services have an important role to clarify misunderstandings and point out that postponing the time to take the medication, for example, is better than omitting the dose. Patients make the decision of skipping the dose and do not bring this matter to the medical consultation as a question. Barford

et al,[2] while researching the communication between doctors and patients during consultations in San Francisco and Copenhagen, concluded that this communication is frequently superficial and unskillful.

There are few qualitative studies on adherence to ART in developing countries. However, the results from the present study were similar to the ones found in qualitative studies carried out in developed countries,[6,10,13] pointing to difficulties that are common to all patients.

The Brazilian policy on universal access to ART has reached good results, such as the decrease in morbidity and mortality and the reduction in the number of hospitalizations and costs of treatment.[14,16] The treatment adherence rates obtained in Brazilian studies have been comparable to those found in wealthy countries.[11] For the continuance and development of this success, high adherence rates must be kept all over the country. For this to happen, apart from guaranteeing access to treatment, it is necessary to improve the quality of care and also invest in policies that reduce social and cultural problems that affect patients living with HIV/AIDS.

The narratives presented in the present study refer to experiences with the ART in the first years of free access. It is possible that the challenges to adhere may have changed. Effects from prolonged use of medication, such as lipodystrophy,[8,12] are known at present.

Furthermore, pharmacological development has reduced the difficulties regarding the use of medication, such as side effects and the number of daily pills. The negative opinion about therapy may have changed as well, given the better promotion of treatment benefits.

As a conclusion, difficulties related to side effects, in spite of their importance, are insufficient to explain treatment non-adherence. On the other hand, as regards difficulties related to social factors, such as stigma, it appears to be more difficult to find technical solutions, as they are part of broader social dynamics. However, healthcare professionals can help patients deal with such factors in their personal lives, especially in the beginning of the treatment, when these seem to be more crucial. Despite the undeniable importance of the health sector in this aspect, this sector must be supported by public policies on the social and political levels, as well as by actions from the organized society, aiming at reducing discrimination and prejudice.

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