ORIGINAL ARTICLE

The profile of women with HIV/AIDS and their adherence to the antiretroviral therapy*

O PERFIL DA MULHER PORTADORA DE HIV/AIDS E SUA ADESÃO À TERAPÊUTICA ANTIRRETROVIRAL

PERFIL DE LA MUJER PORTADORA DE HIV/SIDA Y SU ADHESIÓN A LA TERAPÉUTICA ANTIRRETROVIRAL

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ABSTRACT

The objectives of this study were to characterize the sociodemographic and clinical profiles, health behaviors, beliefs and attitudes towards the disease and treatment of women with HIV/AIDS, outpatients of a university hospital located in the interior of São Paulo state, and to identify the factors that affect their adherence to antiretroviral therapy. The participants were 60 female outpatients of the referred service. The data were collected through semi-structured interviews. The women's mean age was 39.8 (standard deviation of 9.1) years; most of the women had a low education level, lived in deprived socioeconomic conditions, and were in a stable relationship. The most frequent form of infection was through a heterosexual relationship; 55% of the women had abandoned treatment, and their main reasons were the imposed therapeutic schemes, the side effects of antiretroviral drugs, coping with the disease, and the perspective of imminent death; 35% did not meet the adherence criteria, considered as taking 95% of the prescribed antiretroviral therapy.

DESCRIPTORS

HIV
Acquired Immunodeficiency Syndrome
Women
Antiretroviral therapy, highly active
Nursing care

RESUMO

Esse trabalho teve como objetivos caracterizar o perfil sociodemográfico e clínico, os comportamentos em saúde, crenças e atitudes sobre a doença e o tratamento de mulheres com HIV/AIDS atendidas no serviço ambulatorial de um hospital universitário do interior de São Paulo, bem como identificar fatores que interferem na adesão à terapêutica antirretroviral. Os sujeitos do estudo foram 60 mulheres acompanhadas no serviço. Os dados foram colhidos por meio de entrevista semiestruturada. As mulheres tinham idade média de 39,8 (desvio padrão 9,1) anos, baixa escolaridade, condições socioeconômicas insatisfatórias e mantinham relacionamento estável. A relação heterossexual foi a forma mais frequente de infecção; 55% das mulheres já abandonaram o tratamento e alegavam como principais motivos os esquemas terapêuticos impostos, os efeitos colaterais dos antirretrovirais, o enfrentamento psicológico da doença e o pesar iminente da morte; 35% delas não atingiram critérios de adesão considerando-se o uso de 95% da terapêutica antirretroviral prescrita.

DESCRITORES

HIV
Síndrome de Imunodeficiência Adquirida
Mulheres
Terapia antirretroviral de alta atividade
Cuidados de enfermagem

RESUMEN

Trabajo que objetivó caracterizar el perfil sociodemográfico y clínico, el comportamiento en salud, creencias y actitudes sobre la enfermedad y el tratamiento de mujeres con HIV/SIDA atendidas en servicio ambulatorio de hospital universitario del interior de São Paulo, así como identificar factores que interfieren en la adhesión a la terapéutica antirretroviral. Los sujetos del estudio fueron 60 mujeres atendidas en el servicio. Datos recolectados mediante entrevista semiestructurada. Las mujeres tenían un promedio etario de 39,8 (desvío estándar 9,1), baja escolaridad, condiciones socioeconómicas insatisfactorias, y mantenían relación estable. La relación heterosexual fue la forma más frecuente de infección; 55% de las mujeres ya abandonaron el tratamiento, alegando como motivos principales los esquemas terapéuticos impuestos, los efectos colaterales de los antirretrovirales, el enfrentamiento psicológico de la enfermedad y el dolor inminente de la muerte; 35% de ellas no alcanzaron criterios de adhesión, considerándose el uso del 95% de la terapéutica antirretroviral prescripta.

DESCRIPTORES

VIH
Síndrome de Inmunodeficiencia Adquirida
Terapia antirretroviral altamente activa
Mujeres
Atención de enfermería

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INTRODUCTION

The first reported cases of the global epidemics of AIDS (Acquired Immune Deficiency Syndrome) in the literature occurred in early 1981, in the United States. Two decades later, there were over 40 million AIDS patients and HIV-positive individuals, and the epidemics continues to grow, particularly in deprived countries[1].

In Brazil, 592,914 diagnoses were made between 1980 and June of 2010, of which 385,818 referred to men and 207,080 to women. The gender ratio (male/female) has been reducing with time, shifting from 15.1:1 in 1986 to 1.5:1 in 2002, a proportion that has been maintained until today[2]. The AIDS epidemics is a serious public health issue in Brazil, and, as in other countries, it is observed that it is growing more rapidly among women than in men,[3-4] which confirms the feminization of the epidemics. In the 21st century, AIDS became one of the main causes of death of women at a fertile age, which demonstrates the magnitude of its effect on the female population[4]. Therefore, this reveals the need for better investigation on this topic, as it is a segment with specificities different from the male population, and with disadvantages regarding the prevention, control and treatment of the infection[5].

One of the referred problems regarding the prevention of sexually transmitted diseases and AIDS among women is condom use, which is a difficult negotiation between men and women, particularly in cases of stable and long term relationships. In a stable couple relationship, if women impose condom use with any purpose other than contraception, it implies risks that involve affection issues, such as breaking trust ties, cultural issues, such as the labels assigned to women that show some knowledge and initiative regarding sex, and even a risk of loosing the financial support from her partner, in case she depends on him[3]. One national study confirms the fact that women who use oral contraception consider condom use important to prevent sexually transmitted diseases only for people who do not have a stable relationship or in cases when a married man cheats on his wife. Here, they differentiate the two universes: that of the woman at *home* and that of women on the *street*[6].

On the other hand, it is possible that when women assume multiple roles – daughter, wife, mother, housewife and/or worker -, they often relegate their care with their own body and their own health to a second plan[5]. In this context, another issue is highlighted due to its relevance in this population: the adherence to the treatment of diseases such as AIDS. This aspect is a challenge for heath care professionals because of the implications that affect not only the patient but also their family and community[7].

Brazil was one of the first developing countries that guaranteed its population universal and free access to antiretroviral medication through the Unified Health System (SUS) since 1996[8]. This therapy has imposed considerable benefits to SUS clients, such as extended survival, improved quality of life, reduced morbid episodes and the frequency of hospital admissions; however, it requires perfect adherence[9]. Studies indicate that the efficacy of the treatment, expressed by the levels of viral suppression, demands that the utilization of the therapeutic regime be equal to or above 95% of the prescribed dosages. Dissatisfactory adherence may be associated with the development of viral resistance[10].

Some factors identified as limiting factors or hindrances to adherence to the medical appointment or treatment are related to characteristics of the patient, the disease and its treatment, to the patient-health team relationship, social insertion, and other factors such as their geographical distance from the health service, difficulties regarding their accessibility to the appointment (lack of physicians, large number of patients, long waiting list) and a long time interval between appointments[9].

Healthcare professionals and teams can understand the factors that hinder and facilitate adherence by obtaining the patients' description of their experiences, attitudes and beliefs regarding the disease and treatment, in order to help them understand the importance of the antiretroviral therapy and improve their adherence behavior[10]. Understanding these aspects that limit their adherence is the first step towards their management and overcoming, and, in the daily healthcare practice, the difficulties of adherence must be identified and understood case by case[10].

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Taking into consideration the emergent profile of the disease, the perspectives of a progressive increase of the female population infected with HIV/AIDS and, mainly, the importance to maintain an adequate antiretroviral treatment adherence to control its evolution, it is important to obtain information that support the planning of nursing care aiming at the optimization of adherence to these drugs.

With these purposes in view, the objectives of the present study were to characterize the sociodemographic and clinical profile, health behaviors, beliefs and attitudes about the disease and treatment of women with HIV/AIDS, patients of a specialized service at a university hospital located in the interior of São Paulo state, and identify the factors that interfere on their adherence to the antiretroviral therapy.

METHOD

Type of study: cross-sectional, descriptive study using a quantitative approach.

Field of study: developed at a university hospital in the interior of São Paulo state, in the Day Hospital Unit in HIV/AIDS and in the Unit for Clinical Research on HIV/AIDS of the class Communicable and Parasitic Diseases.

Subjects: a non-probabilistic sample comprised of 60 women who met the following inclusion criteria: age equal to or above 18 years; with the clinical and cognitive conditions required to answer the questions of the study instruments; voluntary participation, signing the Free and Informed Consent Form after being informed about the study; following outpatient treatment by the health tem of the fields of study. The sample size was established according to the data collection period, i.e., May to July of 2010.

Ethical aspects: The study was authorized by the studied locations and approved by the Research Ethics Committee of the authors' institution (review number 079/2010 of March 23, 2010) in compliance with Resolution CNS/MS 196/96.

Data collection: The interviews were performed at a place that provided the necessary privacy. The women were invited to participate according to the order in which they arrived at the service. The data were collected using the following instruments: *Instrumento de Coleta de Dados – Ambulatório de Adesão ao Tratamento/aids*[7] (Data Collection Instrument – AIDS Treatment Adherence Outpatient Clinic); *Caracterização de uma população com 50 anos ou mais portadora de HIV/aids*[11] (Characterization of a population of age 50 years or older with HIV/AIDS). The authors of both instruments authorized their use in the present study.

The *Data Collection Instrument – AIDS Treatment Adherence Outpatient Clinic* consists of a semi-structured interview form that aims at measuring the adherence to antiretroviral drugs and the factors that facilitate of hinder adherence. It was originally created and validated in Brazil[7], and has been adapted and is commonly used with patients of the Day Hospital in AIDS.

The instrument *Characterization of a population of age 50 years or older with HIV/AIDS* is a form that was created and validated in Brazil with the objective to perform the sociodemographic and clinical characterization of the population of age 50 or older with HIV/AIDS; identify health behaviors, beliefs and attitudes about the disease and treatment they are undergoing[11]. It was used in this study with no need for adjustment.

Data analysis: The data were typed into a database using Excel for Windows® and analyzed using descriptive statistics, in absolute number and percentages for the categorical variables and central tendency, position and dispersion measures for numerical variables.

RESULTS

Most of the studied women were white (66.7%), in a stable relationship (46.6%) and Catholic (55%). Among all the reported religions, 65% reported being active participants. Their age ranged between 19 and 64 years, with a mean 39.8 (standard deviation of 9.1) years. Regarding children, 91.7% reported being a mother and 70% had between one and two children. In terms of education, 98.3% reported attending school, with 48.3% reporting having an incomplete primary level, with a mean 7.5 (standard deviation of 3.6) years of education. Most were unemployed or held an informal job, thus considered "*housewives*" (61.7%), followed by low-qualification occupations, such as cleaning and cooking, among others (25.3%). Most of their time was consumed with housework (74.9%), followed by work activities (25%).

Most participants (80%) reported living with two to four people, with a mean of 3.5 (standard deviation of 1.6), and 65% reported not being the bread bringer; 35% did not know their family income in minimum salaries; 51.6% reported their family income was between one and three minimum salaries. Furthermore, 75% of the women affirmed that at difficult times, they received financial help mostly from their parents and relatives (46.6%).

The women's clinical condition was assessed according to two laboratory parameters: viral load and CD4+ lymphocyte count, at two different times: in the beginning of the treatment and at the time of the interview. In the beginning of the treatment, most women had a CD4+ count lower than 200 cells/mm³ (38.7%), but with the treatment, 41.7% of the participants presented an improved CD4+ count between entre 200-500 cells/mm³. The viral load followed this characteristic, as, in the beginning of the treatment, 48.3% of the women had a viral load between 50-50.000 copies/mm³ whereas in the current count, 60% presented a viral load inferior to 50 copies/mm³. Considering this population, 76.6% had already been affected by some opportunistic HIV/AIDS-related disease, with the most frequent being pneumonia by *Pneumocystis carinii*, moniliasis, and tuberculosis (31.8%, 28.4% and 27.2%, respectively).

Regarding the staging of the disease, 50% were listed in the AIDS C3 classification[12] and 95% used antiretroviral drugs. The most commonly used antiretroviral drugs were lamivudine (52.63%), tenofovir (35.08%) and zidovudine (33.3%), and 46.7% of the participants took three to four antiretroviral drugs a day, varying between three to ten pills a day. Most participants (76.7%) reported they had to interrupt their daily activities twice a day to take all the prescribed pills.

Considering the 60 interviewed women, 41.7% currently presented some opportunistic HIV/AIDS-related disease, and 58.3% presented other diseases. The main opportunistic diseases were neurotoxoplasmosis (15.2%),

followed by pulmonary tuberculosis and neurotuberculosis (8.5%) and, among the other illnesses, the most common were hormonal (23.3%) and cardiovascular (15%) disorders.

It was observed that 75% of women referred having treated opportunistic diseases, whereas the proportion of women with this information on their medical record was 76%. The current opportunistic diseases were reported by 23.3%, while their medical records indicated that 41.7% were undergoing treatment for some opportunistic disease.

Regarding their life habits, the majority reported not drinking alcohol (78.3%), smoking (73.3%) or using drugs (98.3%). In terms of sexual activity, 66.7% reported being active and all were heterosexual. Among the sexually active women, 61.7% reported having a steady partner, in a relationship of 10.4 years (standard deviation of 7.1), and 48.3% lived in the same house. Only one (1.7%) reported being in more than one relationship, and 61.7% reported having protected sex, with condom use being unanimous. Among those who had protected sex, 16.7% reported facing difficulties, which main concern was that the partner complained about using the protection.

Regarding their sex life before the diagnosis, 13.3% reported maintaining sexual relationships with more than one person and 85% did not use protection. The main appointed reasons were their trust in the partner, associated with a disregard concerning the need for protection (83.5%) and a lack of knowledge about the virus and the disease (15.1%).

In terms of their beliefs and attitudes towards the disease and treatment, 51.7% of the participants reported their life routine changed because of their HIV/AIDS treatment and 31.7% considered their treatment difficult to follow. Although they considered the prescribed treatment regime difficult, considering the number of drugs, their forms and times, 65% denied needing help with the medication, and were able to remember all the details of the treatment.

When asked about how long that had been aware of their diagnosis, the answers ranged from less than one year to 20 years, with a mean of 9.4 (standard deviation 4.3) years. The main way they learned about their diagnosis were the blood tests, performed after having sex with a person infected with HIV (28.3%) or during hospital stay due to health complications (25%). They started treatment over nine years ago according to 45% of the participants, and 88.3% reported they improved from the health complications after starting the treatment.

The main means of infection, according to the women, was through intercourse (90%), and 5% acquired by vertical transmission. Most (75%) referred experiencing previous complications due to HIV/AIDS and a similar percentage (76%) denied the presence of any current complications related to the virus.

The side effects of the antiretroviral therapy were reported by 55%, and the main complaints were gastrointestinal symptoms (46.7%) and discomfort associated with feeling weak (25%).

An expressive proportion (55%) claimed having abandoned the treatment at some time mostly because of depression and the expectation of imminent death (20.2%), the adverse reactions (18.4%) and the reports of not tolerating the treatment, associated with their forgetting to take the pills at the correct times (15.2%). All participants experienced a worsened health condition after they abandoned the treatment. The occurrence of an opportunistic disease (26.7%) and their concern of making their children orphans and not watching them grow (20.1%) were reported as the main reasons for their returning to treatment. Also regarding the abandonment of the treatment, 35% report they did so only once, but according to their medical records, in 15% of the cases there was disagreement between their statement and the record of the number of times they abandoned the treatment, which was usually twice as many.

The information provided by the healthcare team was considered sufficiently clear to 98.3% of the participants.

It is highlighted that, among the participants, 35% did not achieve adherence, considered as a 95% intake of the prescribed antiretroviral medication, on the three days before the interview.

DISCUSSION

The AIDS epidemic in Brazil is currently characterized by the heterosexualization, feminization, young age, low education level, and pauperization of the disease [13]. In this study, the sociodemographic profile of women with HIV/AIDS follows the evolution of the characteristics of the Brazilian population affected by the disease. According to the 2010 Epidemiological Bulletin of the Ministry of Health[2] the incidence rate of reported AIDS cases on the national disease surveillance database (SINAN) was greater in the age group between 30 and 39 years, which agrees with the mean age found in the present study (39.8 years). Regarding maternity, 91.7% reported being a mother and 70% had between one and two children, which is similar to the findings of a study performed with women living with HIV/AIDS in São Paulo, which identified a mean of 1.8 children[14].

The increase in the proportion of AIDS cases among people with a lower education level has been referred to as pauperization, considering, within this context, education as a marker of their socioeconomic condition[15]. In the present study, it was highlighted that most women had an incomplete primary education and were unemployed, most were *housewives* or held low qualification jobs, which agrees with other studies[15-16]. A low education level can imply harms to adherence, which also implies they

may face difficulties to understand the treatment due to their limited ability to interpret the information provided by the health team and in recognizing the importance to follow the treatment correctly. Having a job and fair socioeconomic conditions are essential to maintain treatment adherence for women with HIV/AIDS. The socioeconomic dimensions affect the living with HIV/AIDS because the medications require eating quality foods, attending medical appointments take time, and they need financial resources for transportation, extra medication and to support the household[17].

In addition to their level of education and occupation, income is also among the important indicators to measure the health-related socioeconomic level. Over half the studied population referred having a mean family income of between one and three minimum salaries, and 75% reported that when needed, their parents and relatives provided financial support [13].

Most women reported they were in a stable relationship (46.6%), in agreement with other studies with women with HIV/AIDS[14-15]. Most participants had an active sex and affective life and, among them, 61.7% reported that their partners use condoms. However, those who had protected sex revealed the need for a daily negotiation with the partner, which disliked using the condom. These women's report shows their vulnerable position to HIV infection, as they face difficulties to negotiate condom use, discuss about loyalty, and also abandon the relationships they considered that put them at risk for infection. The infection situation resembles the female condition, in terms of their submission and dependence on their partners and love as the elements forming the feminine identity, thus avoiding any preventive actions[15]. The main cause of infection, in this study, was intercourse, similar to other study findings[15-18]. Heterosexual relationships is the form of transmission that has most contributed with the feminization of the epidemic in Brazil[15]. Preventive behaviors, despite the subjects' awareness, are usually not followed (individual vulnerability). Gender and income differences interfere in their acquisition of information and also affect their decision-making process regarding the prevention of AIDS (social vulnerability). Make and female roles that are culturally established have a strong effect on the individuals' decisions regarding the prevention of HIV/AIDS (cultural vulnerability)[18].

When subjects refer to their lives before being diagnosed with HIV/AIDS, most of them reveled they had unprotected sex, because they had a steady partner in which they trusted and, therefore, were not concerned about the need to use protection. The reports suggest that these women are not well informed about the forms of protection, because they understand that not using condoms may represent their trust in their partner and the certainty that, at least on their behalf, they are in a monogamous relationship and fully compromised to their relationship. For these women, their diagnosis was a big surprise, mainly because many got AIDS from their steady partner, when they believed their relationships stood on the strong security of trusting and believing one another.

A study on the infection between couples[19] found that most female participants associated the trust to a form of relating with their partner, which somehow made them feel safe regarding the risks of becoming infected by HIV. The condom has hence been seen as a way of avoiding an undesired pregnancy and its use was abandoned when the trust tie was established between the couple. It is believed that when the relationship is established, the bodies become one and risks disappear, and partners are safe and trustworthy people[19].

In this study it is observed that the women apparently do not have behaviors compatible with those referred to as risk behaviors to acquiring HIV/AIDS, which are associated with prostitution, promiscuity, and extramarital relationships [18]. Most of them referred not drinking alcohol, smoking or using drugs, and reported being in a stable relationship, i.e., they oppose the profile considered to be at risk for the women in the social imaginary in Brazil[3]. As other authors have evidenced, these women's perception of risk is rather small, considering that the conjugal image expressed the culture in which they are inserted regarding their roles and hierarchy in the affective-sexual relationship. This could explain their restriction regarding the adoption of preventive behaviors, which makes them vulnerable to HIV infection[18]. For these women who did not identify themselves with the risk group, AIDS would continue being *other people's disease*[20]. For them it is like there are two types of AIDS: the other's AIDS and common people's AIDS. The former is seen as having been acquired voluntarily, as a result of irresponsible behavior. The latter is considered involuntary, a consequence of male nature and their social role, that of a wife.

Regarding the characterization of the patients' clinical condition, in the beginning of the treatment, 48.3% had a viral load between 50 and 50.000 copies/mm³ and 38.7%, a TCD4+ lower than 200 cells/mm³. It is known that the number of TCD4+ lymphocytes in the peripheral blood is currently considered the main marker of immunologic harm caused by HIV and it is an important indicator of the progression to AIDS. These women, consequently, were at a high risk to developing opportunistic infections. The diseases that define AIDS[12] include conditions indicative of severe immunosuppression, particularly of cellular immunity, in addition to a TCD4+ lymphocyte count below 200 cells/mm3, regardless of the presence of symptoms. Most participants (76.6%) have experienced at least one HIV/AIDS-related health complication, represented by an opportunistic disease. The diagnosis of the most common opportunistic infections and clinical manifestations among the patients are in agreement with a study in which the observed distribution was pneumonia by *Pneumocystis carinii* (31.8%), moniliasis (28.4%) and tuberculosis (27.2%)[21].

In the present study, it was observed that using the antiretroviral treatment was necessary for nearly all participants (95%). The increased survival of individuals with HIV/AIDS, as well as the reduced incidence of opportunistic diseases have been widely demonstrated with the use of antiretroviral drugs, which consists of an important positive result of these medications. Despite the great benefit generated by this treatment, and its recognition by individuals with HIV, there are yet many difficulties to be solved. One of them is the adherence to the drug treatment[22].

By analyzing the participants' beliefs and attitudes towards the disease and treatment, 51.7% claimed their life routine changed because of their HIV/AIDS treatment, which is in agreement with another study[20] in which women reported losses and predominantly negative changes (loss of joy, feeling odd, fear, social isolation due to prejudice, the routine of medical appointments and frequent exams) after they received their diagnosis.

Another fact that draws attention in the present study is that 31.7% of the participants considered their treatment hard to follow, pointing at the number of prescribed medications, and their form and time of intake as the main causes. It is known that the prescribed therapeutic regime is associated to non-adherence even when the medication is provided by the health service. This is one of the main factors that affect the treatment with antiretroviral drugs, because the therapeutic regimes are usually complicated and require a lot of effort from the clients, who need to adjust their foods, times and daily rhythm to comply with the treatment[22].

The considerable advancement in antiretroviral drugs was a conquest for HIV/AIDS patients, but one of the main hindrances for the adherence to treatments with these drugs are their frequent side effects. Those effects were reported by 55% of the present study participants, as observed in other studies[16,21-22]. It is highlighted that many participants were able to associate each side effect to a given antiretroviral drug and revealed they quit taking it when they felt worse when taking them. Their main complaints were gastrointestinal symptoms (nausea, vomiting, diarrhea), followed by discomfort associated to a sensation of weakness, which are also the main symptoms presented in literature.

Treatment abandonment deserves special attention, as 55% of the women reported having interrupted the treatment at some time. The related causes for this attitude were mainly depression and their expectation of imminent death, followed by the adverse reactions associated to the antiretroviral drugs. The perspective of imminent death is one of the main aspects for their non-adherence. Although they deal with the collateral effects and prejudice, discouragement also emerges in view of the perspective that the treatment is still unable to cure them and can only extend their life[22]. The women's reports show their fragility and powerlessness towards the disease that, in spite of all the current scientific knowledge remains incurable. The meaning created in the lives of these women appears to be filled with hopelessness, fear, and thoughts that limit their future life projects, as they consider it worthless to deal with the physical and social burdens imposed by the disease, considering that they will not achieve definitive cure[22].

The reports focus on the fact of having to take the medication for the rest of their lives in order to survive, hence considered the greatest mediators of their lives.

Regarding the abandonment, many pointed out the fact that *they could not tolerate the treatment*, associated to their forgetting to take the pills on the correct times. As in another study[21] the main reason reported for treatment failure was forgetting to take the medication. Considering that forgetfulness can represent a form of rejection, it is emphasized that it is necessary to seek mechanisms to help patients engage in the treatment.

As expected, all the participants who abandoned the treatment experienced a worsened overall health condition, according to their reports, because of an opportunistic disease, as well as the support from their partner and children, the women went back to the treatment. The conviction on the positive effects of the treatment appears to lead subjects to believe that the only way to continue to live. Although there are factors that hinder adherence, other encourage people to comply[22]. On of those factors, considered important for adherence, is the support and acceptance from close ones. Isolation due to the resistance to accept their own situation or the fact that there is much prejudice in the social environment, in addition to the lack of support and the absence of someone to exchange experiences make adherence more difficult[20].

The women's concern regarding their children and the desire to watch them grow was an important factor among those reported as important for their adherence to the antiretroviral treatment. As observed by other authors, [17] the women reported finding their strength on maternity. Women often stop worrying about their own death and start worrying about the effect of their death on their children, as they know they depend on her to survive and thus feel obligated to protect them against the prejudice they may eventually suffer because of the view that still persists in society regarding the stereotypes associated to AIDS.

Finally, by asking the women about how much medication they took every day over the three days before the interview and the subsequent comparison to the medical records containing the medical prescriptions of the antiretroviral medications, it was observed that 35% of the participants did not achieve a satisfactory adherence, which is a minimal 95% intake of the prescribed medications, i.e., levels near the ideal to suppress the viral replication and contain the multiplication of strains resistant

to antiretroviral drugs. This finding is in agreement with that of another study[21] in which 34% of the participants reported levels below the 95% of adherence to the antiretroviral treatment.

CONCLUSION

The present study, performed with women with HIV/AIDS following treatment at an outpatient service of a university hospital in the interior of São Paulo state, found results that showed that the subjects were young women (mean of 39.8 years), in a stable relationship and with children; with a low education level and unemployed, or performed low-qualification occupations; most were in the stage AIDS C3 and used antiretroviral drugs; were sexually active, but not all of them had protected sex; the main form or transmission was by heterosexual intercourse; for most participants, their life routine changed because of the HIV/AIDS treatment, which they consider difficult to follow; half of them abandoned the treatment at least once, mainly due to depression and their expectation of imminent death, adverse reactions to the antiretroviral drugs and reports of not tolerating the treatment; abandonment caused a worsened health condition and the occurrence of an opportunistic disease encouraged them to return to the treatment; nearly all participants reported that the information offered by the health team were sufficient for their understanding, however 35% did not achieve adherence, evaluated by the intake of 95% of the prescribed antiretroviral treatment, on the three days before the interview.

It is highlighted, in this study, that the women are being infected with the virus within their conjugal relationships and, therefore, there is a need for campaigns and orientations aimed at couples in a stable relationship, which should take into consideration the values involved in the adoption of prevention measures.

Treatment adherence was observed as something that is achieved on a day to day basis and it appears that effective adherence is only achieved after women truly recognize their need for the treatment and their condition as a person with HIV/AIDS. Furthermore, this study emphasized the importance that women assign to their desire to take care of their children and watch them grow, point to this factor as a relevant reason to maintain treatment adherence. This aspect deserves further investigation in future studies.

Another factor that should be highlighted is that most women felt well informed regarding the explanations they received from the healthcare professionals at the services were the study took place, which reveals the importance of the support from the professionals involves. In this context, emphasis is given to the nurses' role in the multiprofessional team, considering that this professional provides direct care to people with AIDS and must always be careful to provide appropriate orientations and investigate the main factors associated with their non-adherence. It is essential to explain the procedures using simple and objective language aiming to find, with the patients, more tolerable ways to use the antiretroviral treatment regimes and to avoid they forget taking the medications. It is key to help them understand that AIDS is considered a chronic disease and that only with the help from this treatment they can have a quality live. However, nurses must be alert to the factors involved in each patient's particular adherence to treatment and trey to rescue the support from the women's family, as they feel more prepared to deal with all the discrimination of the disease if they are supported by relatives and friends. Therefore, it is believed that it would be possible to achieve a more effective adherence.

REFERENCES

1. Ribeiro AF, Madalasso G, Veras MASM, Guerra MAT, Lemos RRG. Epidemiologia – HIV. In: Veronesi RF, editor. Tratado de infectologia. 3ª ed. São Paulo: Atheneu; 2005. p. 118-27.

2. Brasil. Ministério da Saúde; Departamento de DST, AIDS e Hepatites Virais. Dados epidemiológicos de DST, HIV/aids. Boletim Epidemiológico Aids [Internet]. 2010 dez. [citado 2011 abr. 20]. Disponível em: http://www.aids.gov.br/publicacao/boletim-epidemiologico-2010

3. Santos NJS, Buchalla CM, Fillipe EV, Bugamelli L, Garcia S, Paiva V. Mulheres HIV positivas, reprodução e sexualidade. Rev Saúde Pública. 2002;36(4 Supl):12-23.

4. Santos NJS, Tayra A, Silva SR, Buchalla CM, Laurenti R. A aids no Estado de São Paulo: as mudanças no perfil da epidemia e perspectivas da vigilância epidemiológica. Rev Bras Epidemiol. 2002;5(2):286-310.

5. Takahashi RF, Shima H, Souza M. Mulher e Aids: perfil de uma população infectada e reflexões sobre suas implicações sociais. Rev Latino Am Enferm. 1998;6(5):59-65.

6. Giacomozzi AI, Camargo BV. Eu confio no meu marido: estudo da representação social de mulheres com parceiro fixo sobre prevenção da Aids. Psicol Teor Prat. 2004; 6(1):31-44.

7. Colombrini MRC, Dela Coleta MF, Lopes MHBM. Fatores de risco para a não adesão ao tratamento com terapia antiretroviral altamente eficaz. Rev Esc Enferm USP. 2008;42(3):490-5.

8. Dourado I, Veras MASM, Barreira D, Brito AM de. Tendências da epidemia de Aids no Brasil após a terapia antirretroviral. Rev Saúde Pública. 2006;40 Supl:9-17.

9. Gir E, Vaichulonis CG, Oliveira MD. Adesão à terapêutica antirretroviral por indivíduos assistidos em uma instituição no interior paulista. Rev Latino Am Enferm. 2005;13(5):634-41.

10. Brasil. Ministério da Saúde; Secretaria de Vigilância em Saúde. Programa Nacional de DST e Aids. Manual de adesão ao tratamento para pessoas vivendo com HIV e aids. Brasília; 2008.

11. Lima TC, Gallani MCBJ, Freitas MIP. Validação do conteúdo de instrumento para caracterizar pessoas maiores de 50 anos portadoras Virus da Imunodeficência Humana/ Síndrome da Imunodeficiência Adquirida. Acta Paul Enferm. 2012;25(1):4-10.

12. Centers for Disease Control and Prevention (CDC). Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults. MMWR [Internet]. 1992 [acesso em 2010 Out 10]; 41(RR-17): [aprox. 17p.]. Disponível em: http://www.cdc.gov/mmwr/preview/mmwrhtml/00018871.htm

13. Andreolli A. As pessoas que vivem com HIV/Aids: uma revisão da literatura científica [monografia]. Porto Alegre: Universidade Federal do Rio Grande do Sul; 2008.

14. Paiva V, Latorre MR, Gravato N, Lacerda R. Sexualidade de mulheres vivendo com HIV/AIDS em São Paulo. Cad Saúde Pública. 2002;18(6):1609-20.

15. Gabriel R, Barbosa DA, Vianna LAC. Perfil epidemiológico dos clientes com HIV/AIDS da Unidade Ambulatorial de Hospital Escola de grande porte-município de São Paulo. Rev Latino Am Enferm. 2005;13(4):509-13.

16. Lignani Junior L, Greco DB, Carneiro M. Avaliação da aderência aos antirretrovirais em pacientes com infecção pelo HIV/Aids. Rev Saúde Pública. 2001;35(6):495-501.

17. Costa DAM, Zago MMF, Medeiros M. Experiência da adesão ao tratamento entre mulheres com Vírus da Imunodeficiência Humana/Síndrome da Imunodeficiência Adquirida. Acta Paul Enferm. 2009;22(5):631-7.

18. Maia C, Guilhem D, Freitas D. Vulnerabilidade ao HIV/Aids de pessoas heterossexuais casadas ou em união estável. Rev Saúde Pública. 2008;42(2):242-8.

19. Oltramari LC, Otto LS. Conjugalidade e Aids: um estudo sobre infecção entre casais. Psicol Soc. 2006;18(3):55-61.

20. Cardoso G, Arruda A. As representações sociais da soropositividade entre as mulheres e a adesão ao tratamento. Cad Saúde Coletiva. 2003;11(2):183-99.

21. Carvalho CV, Duarte DB, Merchán-Hamann E, Bicudo E, Laguardia J. Determinantes da aderência à terapia antirretroviral combinada em Brasília, Distrito Federal, Brasil, 1999-2000. Cad Saúde Pública. 2003;19(2):593-604.

22. Teixeira MG, Silva GA. A representação do portador do vírus da imunodeficiência humana sobre o tratamento com os antirretrovirais. Rev Esc Enferm USP. 2008; 42(4):729-36.

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