Full Length Research Paper

Lipodystrophy, "social death" and treatment adherence in human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS)

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The lipodystrophy syndrome is the adverse effect to the use of the most important antiretrovirals according to the Ministry of Health of Brazil. Based on this idea, it is sought to emphasize that the lipodystrophy syndrome, as a result of acquired immune deficiency syndrome (AIDS) treatment confirms the "social death" experienced by patients and the possible interference in the process of treatment adherence. The data showed that from 48 patients (n) volunteers, 37.5% decreased their frequency to engage in social activities supported by data from the second instrument (WHOQOL-HIV BREF) regarding the facet for social isolation, in which 39.6% feel partially accepted by their friends and family, suggesting a tendency to be a "social dead". Regarding treatment adherence, 35.4% in this sample needs medicines for their daily life. It can be concluded that, despite the reduction in the social involvement of these individuals, the fact of using the medication as it was prescribed corresponds to a high percentage of people who could not live their daily lives without medication.

Key words: Lipodystrophy syndrome, social death, treatment adherence, human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS).

INTRODUCTION

After 30 years, Brazil is characterized by an epidemic of human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) stable cases, with concentration in some population subgroups in vulnerable situation. According to the latest Epidemiological Bulletin (base year 2010), there were reported [information system for notifiable diseases of AIDS cases (SINAN), YES, laboratory test control system (SISCEL), system for logistic control of drugs (SICLOM)] 608,230 accumulated AIDS cases from 1980 to June, 2011, and 397, 662 (65.4%) in males and 210, 538 (34.6%) in females (Ministry of Health Brazil, 2011a). The number of patients

receiving antiretroviral therapy in 2010 was 201, 279, according to system monitoring indicators of the national STD/AIDS (MONITORAIDS) (Souto, 2006). From the total patients in treatment, the National STD/AIDS (National Program) estimates that 49% will develop some type of lipodystrophy syndrome (LDS) (metabolic and anatomical proper usage or not of medication antiretroviral in HIV/AIDS), noting that there is support for comprehensive care provided in Ordinance No. 2.582/GM-MS of December 2, 2004 for this population (Tellini, 2006).

The LDS causes a redistribution of body fat, with peripheral fat loss and fat accumulation in the abdominal

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region, and important metabolic alterations. Facial lipoatrophy, which may affect 19% of people living with HIV/AIDS gives the person an aspect of premature aging that causes a huge impact on quality of life of the person, bringing to them the stigma of "AIDS face". These changes in body structure (lipoatrophy members, abdominal fat accumulation, hump, association of lipoatrophy with lipohypertrophy) have striking effects on the psychosocial life of HIV/AIDS carrier and they can influence the adherence to treatment (Tellini, 2006).

Study of systematic literature review indicated that the noncompliance occurs universally and their rates are comparable between the developed and developing countries. These rates range from 0.8 to 85.0% according to prescribed antiretroviral takings, which was 75.0 to 100.0% (Rocha et al., 2010). The prevalence of LDS was found between 30 and 80% of patients in treatment with associated factors such as time of use of antiretroviral, low counting of CD4+ cells and high viral load (Fernandes et al, 2005; Santos et al., 2005; Ministry of Health Brazil, 2011b). The Ministry of Health of Brazil (MS) considers SLD as one of the most important adverse effects of highly active antiretroviral therapy (HAART) due to the large value considered by the society to the "body" because it directly affects the individual's life (Ministry of Health Brazil, 2009). The bodily changes can cause a great impact in the life of a person with HIV/AIDS, since they seem to put in the physical appearance of their ideal health and then maintain secrecy about their status as HIV positive.

Body image and self-perception of the body play an important role in social relations. Thus the thought that the body image is closely related to this concern (which is the judgment they will face), to the extent that they currently do not "see" in their bodies this ideal image, and the ideal of the social environment in which they live, is strengthened. Paraphrasing the thought of Rodrigues, "the body carries in itself the mark of social life (emphasis added by the author), and expresses the concern of the whole society to consider physically, certain changes in it" (Valenca, 2003).

The progress on reducing mortality and morbidity with the use of more potent drugs dramatically changed the natural scenery of the disease and helped enhance the quality of life of people living with HIV and AIDS (PLWHA). When there is a reduction in morbidity, there is also a decrease in the incidence of psychiatric disorders. However, a new challenge has emerged for those people living with HIV: How to re-plan the future that was not expected? It is this new reality that can generate, according to scholars, depressive and anxious states which cannot be overlooked by healthcare professionals, as they may interfere with treatment adherence, given that HIV infection may be accompanied sometimes by poverty, unstable living situations, fragmented families,

friends, and family rejection, stigma, social isolation, problems at work and other factors (Rachid and Schechter, 2008).

Currently, it is necessary to maintain informative process on antiretroviral therapy and other complementary therapies, as well as monitoring the multidisciplinary team to prevent or reduce the risk of noncompliance with treatment (Gomes et al., 2011). The treatment regimen, the profile of the bond with the assistance, social integration of the individual, the use of alcohol and drugs, the presence of co-morbidities, use of other medications, the need to support treatment for long-term, disease severity, affective intolerance (impatience, negativism, pessimism) and the patient's physical concerns regarding HIV and its treatment, as well as prejudice and anguishes, respectively related, were also cited in literature as important factors affecting the adherence to antiretroviral therapy. However, there are conflicts about the impor-tance of age, gender, family income and the expected outcome of treatment in the process of accession (Souto, 2006).

Emphasizing that perception, representations and understanding that a person has of their disease process (the meaning attributed to this process and their cognitive capacity to adapt to different situations of life, accepted as factors related to the educational level) are important components to be considered when addressing the issues of adherence to antiretroviral therapy (Souto, 2006).

Therefore, this article aims to emphasize the lipodystrophy syndrome as an adverse effect of antiretroviral therapy which confirms the "social restrictions" experienced by patients, including interfering in the process of treatment adherence.

METHODOLOGY

This exploratory study was designed as observational, with quantitative and qualitative data taking as an advantage of its feasibility (Fletcher, 2006). The study was approved by the Research Ethics Committee of the University Hospital Onofre Lopes from Federal University of Rio Grande do Norte (CEP-HUOL/UFRN), under number 062/2006, which was developed in the city of Natal, Rio Grande do Norte, Brazil in a state referral center.

The sample selection was non-probabilistic and composed of 48 people selected on the basis of medical and laboratory specialists and the infectious disease physician assistant. The following inclusion criteria were: being a person aged 20 to 60 living with HIV/AIDS, voluntary, presenting LDS, being treated with anti retroviral drug (ARV). The study excluded participants who had some chronic condition that could be an impediment factor for participation in the activities of data collection, as medical evaluation.

Data collection took place between September, 2009 and February, 2010, all participants were volunteers and asked to read and sign the statement of informed consent (SIC), according to the rules of Resolution No. 196/96 National Research Ethics Committee (NREC).

In a study on adherence to antiretroviral treatment covering the

Table 1. Descriptive analysis of socio-demographic data.

Variable	N	%
Gender		
Male	33	68.7
Female	15	31.2
Age range (years)		
32 to 42	25	52.1
43 to 53	18	37.5
54 or more	5	10.4
Level of education		
None	2	4.2
Elementary School	19	39.6
High School	19	39.6
Higher Education	8	16.6
Marital status		
Single	21	43.8
Married	9	18.8
Live as married	8	16.7
Separated	3	6.2
Divorced	3	6.2
Widower	4	8.3
Religion		
Catholic	27	56.2
Spiritist	5	10.4
Evangelical	11	23
Others	4	8.3
No answer	1	2.1
Income (MW)		
1 to 2 MW	25	52.1
3 MW or more	11	23
No answer	10	20.8
Do not work	2	4.1

MW = minimum wage;

period from 2004 to 2009, from the 1,910 related articles (national and international ones), only 176 were within the methodology standard established for the study and from these ones, only 13 studies were conducted in national territory. Regarding the type of adherence measures adopted, most of the studies used as isolated measures, the self-report (71.0%), record-dispensing pharmacy (17.1%), counting pills (6.8%), electronic device [medication event monitoring systems (MEMS)] placed on the packaging of ARV (4.0%), registry in medical records (0.6%) and serum therapy (0.6%).

In these studies it was observed that the main methods used for measuring adherence were subjective measures based on self-reporting by respondents (61.5%); objective measures, based on pharmacy dispensing record (7.7%); devices electronic packaging placed on ARVs (5.9%) and combination of methods (23.1%) (Rocha et al., 2010). For the study, there was a need to structure an instrument that could measure the idea of self-image that these patients have about themselves and morphological changes (LDS). Crossing this information with an instrument previously validated and widely publicized (WHOQOL-HIV BREF) sought to verify the relationship with adherence to treatment or not.

The instruments used were "self-perception in aesthetics of fat redistribution in people infected with HIV/AIDS", developed by the authors for the referred research. Due to lack of instrumental techniques to be used in this type of evaluation based on socio-demographic characteristics of the target population, this instrument was developed with this special intention. Only after the pilot and the necessary changes that the instrument was available to verify the self-perception of people with HIV/AIDS and LDS. The instrument consists of 17 questions, closed with 6, 8 and 3 open in Likert scale of 5 points: where 1 indicates low perceptions and 5, high perceptions (telling about the difference in appearance and frequency of social activities).

Initially, the pilot was given as 14 participants suffering changes to meet the specifics of the target audience. The variables were divided into socio-demographic data, perception of changes in physical appearance after beginning ARV treatment, social isolation, understanding how it could resolve the noticed bodily changes and the amount of time to achieve the solutions listed in the personal perception.

The second questionnaire was the WHOQOL-HIV BREF, the World Health Organization (WHO) (WHOQOL-HIV Group, 2003), using an instrument based conceptually justified, excluding an assessment based solely on criteria associated with clinical components of HIV infection and enhancing also the psychosocial dimensions markedly essential in the lives of infected patients. This instrument consists of 31 questions covering 6 domains of life (physical, psychological, level of independence, social relationships, environment and spirituality) and 5 specific facets of PLHA (symptom, social inclusion, forgiveness and guilt, concern about the future, death and dying). The questions are scored on a 5-point scale (1, negative perceptions and low to 5 high and positive perceptions). Thus, the scores of the domains and facets are arranged in a positive direction, and higher scores denote better quality of life. In some dimensions (pain, discomfort, negative feelings, dependence on medication, death and dying), the scores are not arranged in a positive direction, which means that for these facets, higher scores do not denote better quality of life, these scores need to be reversed so that higher scores reflect better quality of life.

RESULTS

The data in Table 1 show the distribution by sex of 68.7% men and 31.2% women, and from these ones, 52.1% were aged 32 to 42 years, 37.5% between 43 and 53 years and 10.4% between 54 and 66 years, with an average of 43.6 years; studies whose mean age of subjects was 33.9 years old with inclusion criteria, the age should be above 18 years to take part in the research. In summary, these data represent a predominantly male sample formed by young adults with a certain

Table 2. History living with AIDS and antiretroviral treatment time.

Variable	N	%
Time PVHA (years)		
1 to 9	17	35.4
10 to 15	25	52.1
16 to 20 or more	6	12.5
Time TARV (years)		
1 to 9	23	47.9
10 to 15	23	47.9
16 or more	1	2.1
No answer	1	2.1

Table 3. Frequency of Involvement in social activities.

Variable	N	%
I	18	37.5
NJF and F	6	12.5
F	11	23.0
F and NVF	4	8.3
VF	9	18.7

I = Infrequent; NJF = not just frequent; F = frequent; NVF = not very frequent; VF = very frequent.

a certain educational level, alone in most cases; they have involvement with any religious sect or dogma and live with a little more than three minimum wage on average.

Regarding the history of living with HIV/AIDS (Table 2), 52.1% were between 10 to 15 years of diagnosis, with an average of 10.5 years. As for the "use of antiretrovirals", part of the respondents (47.9%) were between 1 to 9 years usage and the rest (47.9%) were between 10 to 15 years, then the average decreased to 8.5 years, which may indicate that the patients started antiretroviral therapy soon after the diagnosis of HIV/AIDS and that this may have been caused by delayed diagnosis. However, it is interesting to note that half of the patients, 50%, had only 1 to 3 hospitalizations and half this period, 50% of hospitalizations has never suffered after initiation of treatment, therefore the average admission which suffered after diagnosis of HIV (0.93) is considered low, and this may be related to treatment efficacy.

In this article, however, we will give emphasis to the data that are related to variables, LDS, which deals with the decrease in the frequency with which people engage themselves in social activities and for interference with the adherence to treatment somehow. For this, it was made a revision of the two instruments mentioned above, so that the data were taken of only variables mentioning social isolation and treatment adherence and also recalling that all participants have some kind of LDS since this data was an inclusion criterion for the study participants.

The instrument that deals with the "self-perception in aesthetics of fat redistribution in people infected with HIV/AIDS" in item 14 refers specifically to "frequency" with which the person engages in social activities, making a comparison between before and after developed AIDS. In this item, from a Likert scale, participants were asked to choose between: Infrequent (I), and Not Just Frequent and Frequent (NJF and F), Frequent (F), and Not Very

Frequent and Frequent (F and NVF) and Very Frequent (VF), whose results are shown in Table 3, noting that the frequency with which the volunteers engage in social activities is seemingly minor, represented by the percentage of volunteers (37.5%) who reported they have reduced their social activity when compared with their life before and after the disease AIDS. The WHOQOL-HIV BREF has six domains as described in Table 4. Among its facets were defined five which are considered specific for people living with HIV/AIDS. These are: symptoms of PLWHA, social inclusion, forgiveness and guilt, worries about the future, death and dying.

The domain IV of the WHOQOL-HIV BREF that deals with social relations could corroborate the findings of the body self-perception instrument with regard to the idea of social isolation. Its facets are personal relationships, social support, sexual activity and social inclusion. In this case, we used only social inclusion facet, as this is considered by scholars (WHOQOL-HIV Group, 2003) specific for people living with HIV/AIDS. The values are distributed in a Likert scale ranging from none to total, where values of 1 to 5 are distributed as follows: 1 none, 2 little, 3 average, 4 very much, 5 completely. The results are reported in Table 5.

The data show that 39.6% of participants feel partially (average) accepted by the people who know them, which may mean certain fear of social exposure or who might have lived situations of prejudice that suggest certain reservations about living with people in the social mean. With regard to treatment adherence, the WHOQOL-HIV BREF presents data that were arranged in a Likert scale, which is about how a person needed some medical treatment for their daily life, on a scale that goes from nothing to extremely, whose values are defined as follows: 1 would be nothing, 2 little, 3 more or less, 4 quite and 5 extremely. From Table 6 it is observed that most of the studied group (35.4%) believes that they need medical treatment for their daily life.

DISCUSSION

The respondents "note" themselves different (35.4%)

Table 4. Domains and facets of the WHOQOL-HIV.

Domain	Facets
Domain (I): Physical	Pain and discomfort Energy and fatigue Sleep and rest **Symptoms of PVHAs***
Domain (II): Psychological	Positive feelings Cognition (thinking, learning, memory and concentration) Self-esteem Body (body image and appearance) Negative feelings
Domain (III): Level of independence	Mobility ADL (activities of daily life) Dependency on drugs or treatments Ability to work
Domain (IV): Social Relations	Personal relationships Social support Sexual activity **Social inclusion**
Domain (V): Environment	Physical security Dwelling Finances Care (access and quality of health and social care) Information (acquire new information/learning new skills) Leisure 22 physical environment (pollution/noise/traffic/climate) 23 transport
Domain (VI): Spirituality/religion/personal beliefs	SRPB (spirituality/religion/personal beliefs) **Forgiveness and guilt** **Concerns about the future** **Death and dying**

Overall quality of life and general health perception. *Facets that are highlighted in bold are specific to people living with HIV/AIDS, and as such they were added to the original WHOQOL.
Source: Zimpel and Fleck (2007).

Table 5. Idea of social inclusion.

Variable	N	%
None	0	0
Little	7	14.6
Average	19	39.6
Very much	9	18.7
Completely	12	25
No answer	1	2.1

Table 6. Idea of treatment adherence. "*How much do you need medical treatment for your daily life*".

Variable	N	%
Nothing	8	16.6
Little	8	16.6
More or less	12	25
Quite	17	35.4
Extremely	3	6.2

compared to before and after the disease AIDS, which is confirmed when they "feel" they are viewed differently (35.4%) by individuals, which underscores the tendency to social isolation because the "frequency" of engaging in social activities seems to decrease (37.5%). This study (Silva and Alchieri, 2011) suggests that in evaluating the body self-perception of people living with HIV/AIDS on ARV use (even without specifying usage time and/or class or generation of drugs, and who have SLD), there may be direct interference in the ability to interact, and often the person engages in social activities. This makes them isolate themselves (social death) so that this does not denounce their status as HIV positive (forced disclosure of diagnosis).

The fear of loss of social identity, prejudice and stigma brings to people the need to hide HIV infection, thus maintaining the secret lies in the center of the representations from the carrier. Being "illegal" becomes often necessary to maintain social interactions possible, and not talking about the situation to friends and family is a way of removal of the stigmatizing condition. The secret needs to be kept for fear of social death and the need to be accepted and loved. Therefore, the underground would be the only way to survive in the face of difficulties (Freitas et al., 2010).

When comparing the data obtained in social inclusion tool "self-perception in aesthetics of fat redistribution in people infected with HIV/AIDS", defined as the frequency of these people engaged in social activities, with the data obtained in the WHOQOL-HIV BREF, defined on the basis of how these people felt completely accepted by others (Table 5), it is observed that there is not much difference because the first instrument to decision making in getting involved in social activities became infrequent (37.5%) with the passage of time since the second instrument volunteers felt "average" (39.6%) accepted by others, which could suggest the fear of being exposed for not disclosing their HIV status and fear of been treated with prejudice.

In a study (Gomes et al., 2011) performed in a reference service from Rio de Janeiro with 30 seropositive patients, fear of being noted by society as seropositive was found in the speech of the participants, as follows:

"People choose to conceal HIV-positive serology, considering that HIV has, in its metaphorical history, moral and reprehensible judgment that interferes in the private lives. (...) In general, the negative depiction socially elaborated, referring to those who are living with HIV/AIDS, is reinforced by the language and metaphors used to talk and think about HIV and AIDS. This process increases the fear and, above all, the isolation of those affected ones. Nevertheless, the stigma is extended to family and friends. (...) As a consequence, the study subjects tended to guard or to exclude themselves from society after the discovery of diagnostic. (...)"

Comparing with the data obtained, it is verified that in a (also small) sample of just 48 people, the frequency with which patients decreased social interaction or involvement in social activities was considerable, 37.5% in the first instrument (self-perception) and 39.6% in the second instrument (WHOQOL-HIV BREF), noting that the second instrument refers to "be socially accepted-social inclusion". However, this data could only be confirmed with a larger study which can relate to the SLD aspect of social inclusion.

Regarding adherence to treatment, 35.4% of patients are aware that improvement or maintenance of general health is closely linked to proper use of medication, as well as the fulfillment of the goals proposed for treatment by the multidisciplinary team (WHOQOL-HIV BREF). But fears regarding the metabolic transformations and body (SLD) that may occur as a result of prolonged use of medication is evident when 35.4% of patients feel and notice that others see them differently when compared with before and after the disease AIDS.

Actually, could the data be interpreted as compliance with treatment for this group? Must it take into consideration the time of use of antiretrovirals, 8.5 years on average? In other words, the fact that the research group has already on the average 10.5 years of life carrying the disease HIV/AIDS, and have already gone through some sufferings related to the problems arisen from this experience, could strengthen the thought that even though the idea that antiretroviral drugs can produce certain changes in the body and a person's body, SLD is important to keep the use of drugs and receive the support of the multidisciplinary team as part of treatment for HIV/AIDS.

In the study in Rio de Janeiro service (Gomes et al., 2011), the above exposed becomes evident:

"(...) Respondents demonstrated that to understand the importance of the correct use of HAART, however, there are several factors that influence the inappropriate use of these medications, leading often to treatment dropout (emphasis added by the author). It was identified that one of the reasons that lead to such behavior is related to the side effects of these drugs, especially the change of body image (emphasis added by the author) that can characterize people with HIV as 'AIDS infected' because of lipodystrophy."

The core message about the treatment is that "AIDS equals death", and the drugs included in the daily life ensure survival and a way to resume normalness of their lives, even if it is "difficult". The report below expresses a strikingly affirmative statement.

"It was hard to get used to these medicines, because I struggled and had sickness. But it goes along, goes along, until you get used to them and after you do it, you have to take them properly, at the right time, so reactions can't come up, right? The result is great, because the medicines are pretty good and if you take them properly, the result is awesome. The medication must be taken otherwise you don't have a satisfactory return that doctors want (Freitas et al., 2010)".

The discovery of HIV infection, in most cases translates into solitude, closure, mistrust, secrets, lies and disappointment, even within the family. These aspects of wear, suffering and social exclusion point to difficulties in treatment adherence and emphasize the need for greater investment in health services understanding of AIDS as an event beyond the clinic, requiring the formulation of strategies for integration and intersectoral cooperation in monitoring people living with HIV/AIDS, to promote health and improve the quality of their lives. It is worth noting that social support from family, friends, and even multidisciplinary team are crucial for coping and overcoming the disease, especially regarding treatment adherence (Freitas et al., 2010; Gomes et al., 2011).

Conclusions

The initial proposal of this article was to emphasize the lipodystrophy syndrome as an adverse effect of antiretroviral therapy which confirms the "social death" experienced by patients, which can affect the process of adherence to treatment, being considered one of the most important adverse events due to prolonged use of HAART, because at first sight when they see themselves suffering with the bodily changes, it causes a conflict between preserving life (taking medication) and pre-serving body image (just when you stop taking that ARV associated to changes). With the data, we can see that there is a relationship between the presence of SLD and social isolation due to the difficulty to deal with inquiries from relatives and friends as the changes in their body image, which is the possibility of denouncing the diagnosis until later. While it can occur also in difficulty with treatment adherence before these changes, however the study corroborates other theorists who note that over time (over two years of treatment) and according to clinical complications which occur, patients tend to use medication properly, even if it costs them their social interaction.

It is observed that there is a relationship between the presence of SLD and occurrence of social isolation, however the phenomenon of adherence (or not) to treatment seems to be extremely related, considering that, even with severe state, SLD patients use drugs and

bodily changes seem to be taken as the "price to pay for longevity".

ABBREVIATIONS

AIDS, Acquired immune deficiency syndrome; **HIV,** human immunodeficiency virus; **SINAN,** national notifiable diseases system; **SIM,** mortality information system; **SISCEL,** laboratory testing control system for the national lymphocyte count TCD_4^+/CD_8^+ and viral load network; **SICLOM,** logistical medication control system; **MonitorAIDS,** indicator monitoring system for the national STD/AIDS program; **PN-DST/AIDS,** national STD and AIDS program; **MO,** minister's office; **MH,** ministry of health; **LDS,** lipodystrophy syndrome; **HAART,** highly active antiretroviral therapy; **PLWHA,** people living with HIV and AIDS; **REC,** research ethics committee; **HUOL,** Onofre Lopes University Hospital; **UFRN,** Federal University of Rio Grande do Norte; **ARV,** antiretroviral; **WHO,** World Health Organization; **MW,** minimum wage; **WHOQOL-HIV BREF,** World Health Organization Quality of Life-HIV bref, **SIC,** statement of informed consent; **NREC,** National Research Ethics Committee.

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