International Scholars Journals

African Journal of AIDS and HIV Research ISSN 2326-2691 Vol. 8 (7), pp. 001-007, July, 2020. Available online at www.internationalscholarsjournals.org © International Scholars Journals

Full Length Research Paper

Esthetic self-perception of HIV/AIDS patients under antiretroviral therapy suffering from lipodystrophic syndrome and its influence on the quality of life in a city of the Brazilian northeast

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Accepted 19 April, 2020

This paper aims to evaluate the impact of lipodystrophic syndrome (LDS) on the quality of life and esthetic self-perception of people living with HIV/AIDS (PLWHA) under highly active antiretroviral therapy (HAART). This is an exploratory observational study, with quantitative and qualitative data, using world health organization quality of life instrument – HIV (WHOQOL-HIV BREF) and esthetic perception and evaluation of fat redistribution in patients with HIV/AIDS as instruments. The sample consisted of 48 PLWHA, aged between 32 and 66 years. 89.6% of PLWHA were interested in changing parts of their bodies perceived as altered or compromised by LDS, as reinforced by the fact that they "realize" (35.4%) and "feel" (35.4%) that they are differently perceived by other people. With respect to quality of life, spirituality, religion and personal beliefs obtained the highest mean (14.7) with SD = 4.0. This study suggests that HIV infection and the presence of LDS, based on the self-perception of the participants, may affect not only biomedical aspects, but psychosocial and spiritual ones as well, intervening in the quality of life of these individuals.

Key words: Lipodystrophic syndrome, quality of life, esthetic self-perception, HIV/AIDS.

INTRODUCTION

A total of 462,237 AIDS cases were recorded in Brazil from 1980 until June 2009; 21,389 in the Northern Region (4%); 64,706 in the Northeast (12%); 323,069 in the Southeast (59%); 104,671 in the South (19%); and 31,011 in the Midwest (6%). The mortality coefficient from AIDS, standardized by the Ministry of Health, through the National Bureau of STD/HIV/AIDS and Viral Hepatitis, was 6.1 per 100,000 inhabitants in 2008. Currently in Brazil, 190,000 HIV- positive patients are undergoing antiretroviral therapy (ART) and nearly 35,000 patients initiated therapy in 2008, 98.7% of whom remained in treatment 12 months after onset (Brasil, 2010).

Highly active antiretroviral therapy (HAART), introduced in Brazil in 1996, has reduced mortality and improved patient survival; moreover, since 1997, a number of metabolic and anatomical changes, described as lipodystrophy and/or lipodystrophic syndrome (LDS), have been reported. These changes began two years after the introduction of protease inhibitor (PI) drugs and were initially attributed to their toxicity. However, the introduction of PI coincided with the inclusion of nucleoside analogue reverse transcriptase inhibitors (NARTIs), and

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Abbreviations: PLWHA, People living with HIV/AIDS; **ART,** antiretroviral therapy; **LDS,** lipodystrophic syndrome; **WHOQOL- HIV *BREF*,** world health organization quality of life instrument – HIV; **HIV,** human immunodeficiency virus; **AIDS,** acquired immunodeficiency syndrome; **STD,** sexually transmitted diseases; **HAART,** highly active antiretroviral therapy; **PI,** protease inhibitor; **NARTI,** nucleoside-analogue reverse transcriptase inhibitors; **d4T,** stavudine; **ARV,** antiretroviral; **CEP-HUOL/UFRN,** Comissão de Ética em Pesquisa Hospital Onofre Lopes/ Universidade Federal do Rio Grande do Norte (Research Ethics Committee); **NRC,** national research council; **WHO,** world health organization; **SICLOM,** logistics system ARV medicines; **MW,** minimum wages; **DS,** divert standard.

and stavudine (d4T). LDS is also related to other factors such as the action of HIV proteins in the body, lifestyle and genetic characteristics (Viraben et al., 2002; Norris and Dreher, 2004; Fernandes et al., 2005; Rachid et al., 2008; Brasil, 2009).

Metabolic changes and lipid disorders support the diagnosis of hypertension, atherosclerosis and increased incidence of myocardial infarction among HIV patients under antiretroviral (ARV) treatment. Insulin resistance leads to the emergence of diabetes mellitus and, alterations in calcium metabolism, resulting in osteopenia and osteoporosis (Robinsom, 2004; Norris and Dreher, 2004; Fernandes et al., 2005; Nicholas et al., 2005).

Changes in the body associated with lipodystrophy are manifested by hypertrophy of abdominal adipose tissue, intensified by the increase in visceral fat; increased breast size; gynecomastia; enlargement of the posterior neck area by the formation and accumulation of fat (buffalo hump) in men; facial lipoatrophy, predominantly in the nasolabial folds, resulting in facial wrinkling and the appearance of premature aging; and loss of fat on the buttocks, arms and legs, making the skin more elastic and emphasizing peripheral venous circulation (Kotter, 2003; Norris and Dreher, 2004; Fernandes et al., 2005; Nicholas et al., 2005). Surveys conducted in PLWHA show that coping with AIDS is an ongoing struggle involving changes in habits and behaviors, social and emotional impacts of the disease and its symptoms, uninterrupted use of medications, frequent interaction with health professionals and no hope for a cure, justifying the importance of the present study.

Studies (Fernandes et al., 2005; Malbergier, 2006; La Torre et al., 2007; Miguez-Burbano et al., 2008) underscore that psychosocial changes such as dissatisfaction with body image, mood changes caused by anxiety or unhappiness, problems with sexual relations, reduced self-esteem and increased depression, have serious repercussions on the emotional -affective health of PLWHA. Despite the benefits that antiretroviral therapy can provide, iatrogenic costs are so prohibitive that many patients eventually abandon treatment, reporting that their greatest concern was the fact that they could be identified as HIV carriers, due to the changes in their bodies. Since LDS favors disordered body fat distribution, relationships and social activities are affected by these changes, suggesting that there is a negative esthetic perception, characterized by the stigma linked to "chronic" AIDS (Power et al., 2003; Alencar, 2006; Alencar et al., 2008).

Body image can therefore be understood as a representation of subjective body image, resulting in a concept that surpasses the social and cultural spheres and comprises two specific components: perception and attitude, the latter involving affective, cognitive and behavioral issues related to the body. This is an important component in the development of the present study and further reinforced the fact that individual perception of body modifications may be independent of the perception of such changes by other individuals, or even the objective measurement of body composition using sophisticated diagnostic methods (Carter et al., 2001; Miller et al., 2003; Santos et al., 2005).

Therefore, the importance of measuring quality of life lies in the nature of the disease itself, characterized by unpredictability and multiple recurrences, and the need to assess the effect of treatment on the welfare of individuals infected with HIV. Despite treatment advances, HIV infection continues to be marked by the presence of multiple manifestations, most of them compromising the quality of life of PLWHA (Whoqol-HIV Group, 2003; Skevington et al., 2003; Remple et al., 2004; Canavarro et al., 2006). With regard to changes in body image that PLWHA face, these may strongly reflect affective-emotional problems and contradictorily, the benefits of antiretroviral therapy appear to reduce the quality of their lives.

Given that changes in body image experienced by patients with HIV/AIDS and LDS undergoing ART may interfere with quality of life, the aim of the present study is to assess the esthetic perception of these individuals and the impact on their quality of life, in order to contribute to the development of strategies that reduce these negative aspects.

METHODOLOGY

This was an exploratory observational study using quantitative and qualitative data, with the advantage of practicality (Fletcher, 2006). The study was approved by the Onofre Lopes Research Ethics Committee of the Federal University of Rio Grande do Norte (CEP-HUOL/UFRN), number 062/2006, in accordance with the ethical and methodological aspects contained in Resolution 196/96 of the National Research Council (CNP). The experiment was conducted in Natal, Rio Grande do Norte, Brazil, at a leading state medical facility. The Logistics System ARV Medicines (SICLOM), from the Ministry of Health in Brazil, was sought to estimate the sample. The drug treatment service attends 2,161 patients including: children, adults, seniors and pregnant women. According to the Human Research Ethics Committee, the sample was comprised of volunteers. The number of volunteers was not sufficient to meet the inclusion criteria of proposed research and to be indicated by some infectious disease physician present at the interview moment. The sample estimation was not able to provide a precise number of participants because of complications at the service (lack of updated medical records, employee strikes, lack of doctors, lack of drugs for distribution), and with the participants (clinical status, lack of interest, lack of time cited among others). However, during the data collection, 48 volunteers that suited the search parameters were caught.

Non-probability sampling was used. Patients who reported agreement to participate were checked for relevance to the inclusion criteria. The procedure's sequence happened as follows: they were treated by infectious disease doctor and, according to the inclusion criteria for this study; they were directed to the interview with the researcher – who reported the research process. In the case of agreement, they participated in the survey by the administration of the instruments. The sample was composed of 48 volunteers, selected with the aid of specialists (infectious disease physicians). The inclusion criteria were: individuals with HIV/AIDS, being a volunteer, presenting with lipodystrophic syndrome (LDS), being treated with HAART, and aged between 20 and 60 years.

The study excluded those with any chronic health condition that could prevent their participation in data collection. Data were collected between September 2009 and February 2010, using two questionnaires. The first, developed by the authors to assess “Esthetic Perception of Fat Redistribution in Patients Infected with HIV/AIDS", consisted of 17 questions (6 closed, 8 open and 3 on a 5-point Likert scale), in which 1 indicates low perception and 5 high perception (with respect to the difference in appearance and frequency of social activities). It was initially applied to 14 individuals (in accordance with inclusion criteria) and underwent changes to fit the characteristics of the target population. The variables were divided into socio-demographic data, perception of changes in physical appearance after treatment with HAART, social isolation, understanding how to resolve perceived body changes and the length of time to achieve the solutions described in personal perceptions. In the absence of instrumental techniques to be used in this type of evaluation based on the population sociodemographic characteristics, it was developed an instrument with this special intention. This instrument was administered in a pilot version with 10 patients and was subsequently modified to meet the needs and specificities of the target audience. Only after that was it used for the intention purpose: the self-perception of personal body HIV/AIDS with SLD.

The second questionnaire applied was the WHOQOL-HIV BREF (Whoqol-HIV Group, 2003), composed of 31 questions covering 6 areas of human life (physical, psychological, level of independence, social relationships, environmental and spirituality) and 5 specific facets of PLWHA (symptoms of social inclusion, forgiveness and guilt, concern about the future, death and dying). The questions are scored on a 5-point scale (1, low and negative perceptions to 5, high and positive perceptions). Thus, domain and facet scores are scaled in a positive direction, higher scores denoting higher quality of life. In some aspects (pain, discomfort, negative feelings, dependence on medication, death and dying), scores are not scaled in a positive direction, which means that for these aspects, higher scores do not reflect better quality of life. Since these scores must be reversed, higher scores reflect better quality of life.The instrument mentioned is a version of the *WHOQOL-Bref*, the abbreviated form of the *WHOQOL-100*, with five extra ques-tions, HIV-specific, for people living with HIV/AIDS and accounts for 31 questions in all. The *WHOQOL-100* was developed and validated from an extensive pilot test followed by a field test in 10 centers around the world (WHOQOL-HIV Group, 2003; Zimpel et al., 2007). In Brazil, it was validated by a group and is being used for investigations about quality of life for almost two decades (Fleck, 2008).

RESULTS

The sample was composed of volunteers who met the criteria for participation in the study, which were: live with HIV/AIDS, use ARV (no time given), SLD must be present, and between 20 and 60 years old. Table 1 presents the sociodemographic distribution of the sample. The sample was composed of men and women, with an average of 43.6years. Other studies (Zimpel et al., 2007) on quality of life of HIV/AIDS patients, whose mean age was 33.9years, used the overage of 18years as inclusion criteria. When asked about education level, the vast majority studied up to the elementary or secondary school. It is noteworthy that 43.8% were single and, in terms of religion, 56.2% were catholic. With regard to income in number of monthly minimum wages (MW) (1 monthly wage ≈ U.S. $ 320.00) 36 (75.1%), the volunteers answered that they earned at least 1 MW. In summary, the sociodemographic data show a predominantly male sample, formed by young adults, with intermediate educational level, living alone in most cases, adhering to a religious sect or dogma and earning an average of slightly more than three monthly minimum wages (≈ U.S.$ 960.00).

When asked about how long they have been living with HIV/AIDS, 52.1% were diagnosed from an average of 10. 5 years (between 10 to 15 years ago). With regard to the "use of antiretrovirals (ARV)”, part of the respondents (47.9%) had used them from 1 to 9 years and the same percentage (47.9%) from 10 to 15 years, the overall mean was 8.5 years, indicating that some patients started antiretroviral therapy shortly after HIV/AIDS diagnosis and that this may have been caused by delayed diagnosis. However, it is interesting to note that half of the group had only 1 to 3 hospitalizations in this period and the other half (50%) were never hospitalized after beginning treatment. Thus, the mean hospitalization rate after HIV diagnosis of 0.93 is considered low, possibly due to treatment efficacy.

When asked “how is your health?", 35.4% responded that it was neither bad nor good, 25% considered it good, 37.5% reported it being very good, and only 2.1% did not respond. With respect to considering themselves “currently ill”, the vast majority (81.3%) said "no", 16.6% said “yes” and 2.1% did not respond, corroborating similar findings (Canavarro et al., 2008). Research conducted in the State of Rondônia with 20 participants obtained similar data, both in relation to considering themselves currently ill and their general health status (Nascimento, 2006).

The results were confirmed by evaluating responses from the WHOQOL-HIV questionnaire. Table 2 shows the mean and standard deviation values of the domains: physical; psychological; independence level; social relations; environment; and spirituality religion personal beliefs.

The highest mean (14.7) and SD (4.0) was observed in the spirituality/religion/personal beliefs domain (linked to forgiveness and guilt/concerns about the future/death and dying). Unlike other areas, HIV infection may affect quality of life beyond biomedical aspects, which means that psychosocial and spiritual issues should also be considered (Canavarro et al., 2008; Giovelli, 2009).

With regard to assessment of esthetic perception, based on the disordered redistribution of body fat, most respondents (89.6%) showed interest in changing some body parts perceived as altered or compromised by manifestations of the syndrome. Among the most mentioned are: the face, lower limbs (legs, buttocks, hips), trunk (abdomen) and upper limbs (arms, breasts, shoulders).This corroborates other studies (Santos et al., 2005; Mutimura et al., 2007; Mello et al., 2008) previously described. These perceived changes were placed in hierarchical order, as shown in Table 3.

These data are reinforced when respondents "perceive themselves" differently (35.4%) before and after AIDS,

Table 1. Descriptive analysis of the data sociodemographics.

Variable	N	%
Sex		
Masculine	33	68.7
Feminine	15	31.2
Age group		
32 to 42 years	25	52.1
43 to 53 years	18	37.5
54 or +	5	10.4
Schooling		
None	2	4.2
1º Degree	19	39.6
2º Degree	19	39.6
3º Degree	8	16.6
Married status		
Unmarried	21	43.8
Married	9	18.8
Survives how married	8	16.7
Separately	3	6.2
Divorce	3	6.2
Widower	4	8.3
Religion		
Catholic	27	56.2
Spiritualist	5	10.4
Evangelica	11	23
Other one	4	8.3
No answer	1	2.1
Income (MW)		
1 to 2 MW	25	52.1
3 MW or +	11	23
No answer	10	20.8
Do not work	2	4.1

which is confirmed when they "feel" they are seen differently (35.4%) by other people. This shows the tendency toward social isolation, since the "frequency" of engaging in social activities seems to decrease (37.5%). The present study suggests that in evaluating body self-perception of HIV/AIDS patients undergoing ART (even without specifying for how long and/or class or generation of drugs), and who suffer from LDS, there may be direct interference from social interaction and frequency in which a person engages in social activities. Individuals isolate themselves in order to hide their HIV positivity (forced disclosure of diagnosis), resulting in reduced quality of life.

The assessment of quality of life in PLWHA shows that body self-perception, related to the fields of spirituality / religion / personal beliefs (linked to forgiveness and guilt, concerns about the future, death and dying), may affect individuals psychosocially and spiritually. It may be either a negative aspect, which relates to isolation, difficulty with personal care and social interaction or a positive aspect, which deals with the reorganization of life in terms of internal well-being and harmony with the world around them.

DISCUSSION

According to the Ministry of Health, there was a 50% reduction in AIDS-related mortality, and a 12-fold increase in survival, from 5 months to nearly 5 years. New therapies have changed not only the therapeutic field and the lives of these individuals, but also society's attitudes toward the disease. Moreover, public policies have been implemented to meet these new specificities (Reis, 2008).

The WHOQOL-HIV BREF deals with issues related to individual health conditions, as in a study (Zimpel et al., 2007) where the subject’s health condition was considered an important factor in understanding overall quality of life. There are also studies (Corless et al., 2004; Herzlich, 2004; Scliar, 2007) that highlight the importance of evaluating weight gain or loss during the course of AIDS, since this can be seen by patients as a measure of improved or deteriorated health. The concept of health is not the same for all individuals. It is related to time, place, social class, individual values and religious, philosophical and scientific concepts. When their weight is higher and closer to its ideal level, patients tend to have better quality of life indexes.

In a survey (Turato, 2003; Souza, 2008) on perception, viewpoints, perspectives, life experiences, and analogies of a sample group of 12 PLWHA, in which the length of time since AIDS diagnosis was between 2 and 14 years, two discourse categories describing the trajectory of the disease emerged: loss and reorganization of life. The first describes the following stressful events, perceived as phases of the disease: loss of immortality, loss of identity, loss of health, early symptoms, change in medication, changes in clinical status, onset of opportunistic infections, variation in viral load and CD4 and loss of hope. The second category shows the need for support and motivation to face the chronicity of the disease, with support coming from religion, family and health professionals. Despite the small sample size, the data obtained in the present study, with mean length of time since AIDS diagnosis of 10.5 years, corroborate other findings related to spirituality, religion and personal beliefs, in the search for a new meaning of life.

In a study (Rai et al., 2010) with 90 individuals (30 asymptomatic, 30 symptomatic and 30 with AIDS) conducted in India, it was observed that the quality of life

Table 2. Analysis quality of life for the powers of the *WHOQOL-HIV Bref.*

	Physicist	Psychological	Level independence	Social relations	Environment	Spiritualty religion personal beliefs
Average±DS	(13.7±2.7)	13.7±3.1	14.2±2.9	14.2±3.2	13.3±2.4	14.7±4.0

Table 3. Percent of participant's esthetic perception of study.

Area defined as important	First place	Second place	Third place
Face	15	3.5	1.7
Lower limbs	10	6.2	5.3
Trunk	11	14	7.1
Upper limbs	1.8	4.5	5.3

of people infected with HIV was significantly related to the clinical stages of HIV infection. More care and attention was required for physical, psychological, level of independence, involvement, social and spiritual relationship domains.

Another study (Nascimento, 2006) found that the spiritual dimension of life is broader than that of the religious aspect and that there is a distinction between religion and spirituality, where the former is adherence to beliefs and practices relating to a religious institution and the latter a relationship established with a superior being that the individual has faith in. Thus, people tend to ascribe to God the cause and resolution of health problems, appealing to this imaginary force as a cognitive, emotional or behavioral resource to help them cope with the disease and achieve resilience.

Several studies (Carter et al., 2001; Hadigan et al., 2001; Chen et al., 2002; Galli et al., 2002; Heath et al., 2002; Kotter, 2003; Corless et al., 2004; Fernandes et al., 2005; Jacobson et al., 2005; Mello et al., 2008) have investigated lipodystrophic syndrome (LDS) since 1997. The interest of the scientific community in quality of life increased after PLWHA gained access to life-extending drugs, underscoring the need to establish long-term goals. Thus, studies that deal with perception and the impact of body and metabolic changes associated to LDS are essential, since these changes may interfere with treatment continuity and the quality of life of these individuals (Corless et al., 2004; Santos et al., 2005; Mutimura et al., 2007).

One study (Collins et al., 2000) aimed to understand the effects of lipodystrophy on self-esteem, body image, relationships, and quality of life of AIDS patients (33 volunteers) and evaluate whether the health professionals caring for them met their expectations. Based on the perception of the participants, the study suggested that lipodystrophic syndrome may have a negative effect on social and psychological aspects, interfering in the quality of their lives. Even though the authors did not quantify these factors, the following themes were evident in the respondents' discourse: changes in body image and self -esteem, problems with social and sexual relations, loss of control, anxiety related to revealing their condition and propensity for demoralization and depression. Although the negative aspect of lipodystrophy was clearly evident in some studies, others showed a positive tendency toward finding strategies to minimize the damage caused by body changes, as seen in the following quote: "*I thought I would not want to live with this; but now, it does not make much of a difference*" (Collins et al., 2000: 550). This emphasizes that the relationship between changes and reduced self-esteem is directly linked to cultural issues, where physical appearance is of a great importance for a "good" social life.

Another study (Mutimura et al., 2007) aimed to evaluate the quality of life of HIV- positive individuals undergoing HAART treatment experiencing problems of fat redistribution. Out of a sample of 100 HIV-positive patients, aged between 21 and 50 years, 50 who were suffering from fat redistribution and 50 who were not treated with HAART. They observed that patients on HAART suffering from fat redistribution had longer treatment time, unlike those under HAART with no body fat redistribution. This suggests that even if there was no difference between the groups regarding perceived quality of life, the group that presented with body changes experienced more psychological and social discrimination, social isolation, shame of appearing in public and fear of disclosing their condition than those who had no body alterations.

A qualitative study (Teixeira and Silva, 2008) aimed to understand the social representations of HIV/AIDS carriers on drug therapy and to analyze the relationship between this perception and motivation to adhere to treatment. The sample consisted of 9 patients hospitalized for infectious diseases. It was found that patients were full of hope early in the treatment, as if it would solve all their problems, but there were negative aspects underlying the benefits of the medication (side effects, compromised social life, financial difficulties and discrimination) that are difficult to overcome, demonstrating the need to develop effective coping strategies. This means that these aspects could favor the reorganization of life and improve the resilience of individuals afflicted by HIV/AIDS.

The results suggest that social support (family, friends, and health professionals) is essential to face the many difficulties caused by the disease until patients manage to cope with their new reality. In this sample it was evident that “not currently considering oneself ill”, may suggest an arduous but ongoing rebuilding process.

In a study (Giovelli, 2009) conducted on the psychosocial aspects of PLWHA, focusing on symptoms of depression, social support and quality of life, 63 people with HIV undergoing ARV treatment were interviewed, using a cross-sectional descriptive correlation design. There was no significant association between biological markers, depression symptoms, socio-demographic data, social support, quality of life and degree of compliance. However, it was evident that social support, religiosity / spirituality / personal beliefs contribute to protecting health, strengthening the resilience process. Self-care was encouraged and stimulated by social support.

Conclusion

The descriptive indicators contained in the reports on body image issues, collected through the Esthetic Perception and Evaluation of Fat Redistribution in HIV/AIDS patients questionnaire, show predominant perception of compromised esthetics. This is related to the face, lower limbs (legs, buttocks), trunk (abdomen and thorax) and upper limbs (arms, shoulders) in terms of functional movements and activities, without evidence of significant differences for gender, age, and other socio-demographic characteristics. It is important to emphasize that "perceiving one-self differently" and "being perceived differently" directly interfere in the frequency study participants engaged in social activities. This suggests that these factors may reduce quality of life due to the possibility of revealing their condition, as discussed throughout the text.

With regard to quality of life (*WOQOL-HIV BREF*), these data corroborate the findings of the esthetic self-perception instrument, in that, despite the small sample size, the highest mean was found in the spirituality / religion / personal beliefs domain, since it is connected to forgiveness and guilt, as well as concerns about the future, death and dying, indicating that being an HIV/AIDS carrier goes beyond biomedical aspects, to include psychosocial and spiritual issues in this phase of life and stage of the disease.

It should be underscored that most participants did not consider themselves ill. This may show the need to understand the concept of health and illness for HIV/AIDS patients as a favorable factor for the construction of support strategies to achieve bio psychosocial well-being. We noted that subjects had difficulty understanding the stage of HIV that they were in, although this was not the focus of the *WOQOL-HIV BREF*. The present study reinforces the importance of actions that promote social support from family, friends, health professionals and religion, among others, to ensure encouragement and motivation for self-care. This need was clearly demonstrated when participants reported not considering themselves ill, suggesting that inner strength was found during the process of strengthening (resilience) and reorganizing their lives.

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