

LIPODYSTROPHY SYNDROME ASSOCIATED WITH ANTIRETROVIRAL THERAPY IN HIV PATIENTS: CONSIDERATIONS FOR PSYCHOSOCIAL ASPECTS

Ana Paula Morais Fernandes¹
Roberta Seron Sanches¹
Judy Mill²
Daniel Lucy³
Pedro Fredemir Palha¹
Maria Célia Barcellos Dalri¹

Fernandes APM, Sanches RS, Mill J, Lucy D, Palha PF, Dalri MCB. Lipodystrophy syndrome associated with antiretroviral therapy in HIV patients: considerations for psychosocial aspects. Rev Latino-am Enfermagem 2007 setembro-outubro; 15(5):1041-5.

Several side effects have been strongly associated with antiretroviral therapy in HIV patients. Among them, the lipodystrophy syndrome which presents alterations in body shape with central adipose hypertrophy and peripheral lipoatrophy, reported by patients as a visible marker identifying them as HIV patients. This manuscript presents an analysis of current literature regarding the psychosocial aspects of HIV patients with lipodystrophy associated with antiretroviral therapy. The results show that the alterations in body shape can be disturbing in terms of psychosocial well being, affecting quality of life and increasing the stigma associated with the disease, with consequent disturbances in social relations. This analysis provides a preliminary review of the psychosocial aspects of lipodystrophy and further studies are needed for a better understanding of this complex syndrome, which could provide new information to be used in nursing care for HIV patients affected by this problem.

DESCRIPTORS: HIV; acquired immunodeficiency syndrome; lipodystrophy; nursing

SÍNDROME DE LA LIPODISTROFIA ASOCIADO CON LA TERAPIA ANTIRETROVIRAL EN PACIENTES CON VIH: CONSIDERACIONES PARA LOS ASPECTOS PSICOSOCIALES

Varios efectos secundarios han sido fuertemente asociados con la terapia antiretroviral en pacientes con HIV. Entre ellos, el síndrome de la lipodistrofia se presenta con alteraciones en la forma del cuerpo con hipertrofia adiposa central y lipoatrofia periférica, las cuales son reportadas por pacientes como marcas visibles que los identifica como pacientes con VIH. En este manuscrito, presentamos un análisis de literatura actual con respecto a los aspectos psicosociales de pacientes con VIH presentándose con lipodistrofia asociado con la terapia antiretroviral. Los resultados demuestran que las alteraciones de la forma del cuerpo pueden ser inquietantes en lo que se refiere al bienestar psicosocial, afectando la calidad de vida y aumentando el estigma asociado con la enfermedad, con las consiguientes dificultades en las relaciones sociales. Este análisis provee un repaso preliminar de los aspectos psicosociales de la lipodistrofia; sin embargo, otros estudios son necesarios para entender mejor este complejo síndrome, proveyendo nueva información para ser utilizada en el cuidado de enfermería para pacientes con VIH que están afectados por este problema.

DESCRIPTORES: VIH; síndrome de inmunodeficiencia adquirida; lipodistrofia; enfermería

SÍNDROME DA LIPODISTROFIA ASSOCIADA COM A TERAPIA ANTI-RETROVIRAL EM PORTADORES DO HIV: CONSIDERAÇÕES PARA OS ASPECTOS PSICOSSOCIAIS

Diversos efeitos colaterais têm sido associados à terapia anti-retroviral em portadores da infecção pelo HIV, dentre esses, a síndrome da lipodistrofia apresentando hiperlipidemia e alterações na forma do corpo, com hipertrofia adiposa central e lipoatrofia periférica, relatada pelos pacientes como um visível marcador para a identificação de portadores da infecção pelo HIV. Este estudo consiste em análise da produção científica sobre aspectos psicossociais em portadores da infecção pelo HIV que apresentam lipodistrofia associada à utilização da terapia anti-retroviral. Os resultados mostram que alterações corporais podem ser suficientemente perturbadoras para o bem-estar psicossocial, afetando a qualidade de vida e aumentando o estigma da doença, ocasionando perturbações nas relações sociais. Esta revisão possibilita uma análise preliminar dos aspectos psicossociais da lipodistrofia; entretanto, outros estudos são necessários para o melhor entendimento desta complexa síndrome, trazendo novas informações a serem utilizadas no cuidado de enfermagem a portadores da infecção pelo HIV afetados por este problema.

DESCRIPTORES: HIV; síndrome de imunodeficiência adquirida; lipodistrofia; enfermagem

¹ RN, PhD, University of São Paulo at Ribeirão Preto, College of Nursing, WHO Collaborating Center for Nursing Research Development, Brazil, e-mail: anapaula@eerp.usp.br; ² RN, PhD, University of Alberta, Faculty of Nursing, Canada; ³ University of Alberta, Faculty of Nursing, Canada

INTRODUCTION

Lipodystrophy, characterized by increased serum levels of cholesterol and triglycerides, increased glycemia associated with insulin resistance, and changes in body fat distribution, is a syndrome associated with antiretroviral therapy⁽¹⁾. Symptoms of lipodystrophy include adipose tissue hypertrophy with central fat distribution, fat accumulation in the abdomen, chest and viscera, emergence of a cervical curvature called "buffalo hump", and loss of adipose tissue in the face, buttocks and upper and lower limbs⁽²⁾. Although it was first associated with the use of protease inhibitors, this syndrome has also been found among patients using reverse transcriptase inhibitors⁽³⁾. The pathogenesis of this syndrome remains largely unknown, although the effects of antiretroviral treatment on the onset of lipodystrophy have been described⁽¹⁾. In addition, it has been reported that poor compliance with antiretroviral therapy can be strongly associated with an increased risk of lipodystrophy occurrence⁽⁴⁾.

Changes in body shape can be extremely disturbing in terms of psychological welfare affecting the quality of life and enhancing the stigma of the disease^(3,5). Patients have reported lipodystrophy as a visible marker that identifies HIV status, and is perceived as "the new face of AIDS" or "the Kaposi's sarcoma of the 21st century"⁽⁶⁾. In addition, lipodystrophy causes problems in personal and family relations, which in some cases can trigger disturbances in social relations, often leading to total patient isolation. Perhaps most significantly, some patients stop taking their antiretroviral regimen in order to avoid the adverse psychosocial effects of fat wasting⁽⁵⁻⁷⁾.

The present literature review investigated the associations between the occurrence of lipodystrophy and the different parts of the body affected, the psychosocial impact of the disease, and the possible implications of lipodystrophy on the adherence to antiretroviral therapy. The objective of this review was to ultimately be able to offer information that may assist in developing and implementing future nursing interventions for AIDS patients.

METHODS

The increased emphasis on evidence-based health care requires nurses to have access to reviews

that analyze and summarize the current state of research in their areas of practice. Practitioners must be able to efficiently locate, critically appraise and appropriately apply the best available evidence in their practice settings. The identification and retrieval of relevant publications in a systematic, comprehensive and reproducible way is the initial phase in the literature review process.

Our search strategy included a computerized search of electronic databases. Among the biomedical bibliographic databases, Medline, Lilacs and CINAHL are the largest and most widely used in the world⁽⁸⁾. Therefore, this review included a review of the literature indexed in Medline (National Library of Medicine), Lilacs (Latin American and Caribbean Literature in Health Sciences) and CINAHL (Cumulative Index to Nursing & Allied Health Literature) through the Internet database updated in December 2004. The following key words were utilized for the review: HIV, AIDS, lipodystrophy, self-esteem, self-image, psychosocial impact, and nursing. The outcomes of the electronic searches were evaluated on the basis of their sensitivity and specificity. "Sensitivity" is the ability of a search to retrieve relevant articles. "Specificity" is the ability of the search to exclude irrelevant articles. The following criteria were used to select papers:

Articles dealing with:

- 1) the psychosocial aspects of HIV patients with bodily changes;
- 2) the impact of lipodystrophy on the self-esteem and self-image of affected individuals;
- 3) published in indexed journals from 1998 to 2004.

RESULTS AND DISCUSSION

Limited research has been conducted on body image in people infected with HIV. This review found ten articles dealing with the topic area in the Medline database. Eight studies were published in the following medical journals: "HIV Medicine", "AIDS Patient Care STDS", "AIDS Read", "International Journal of STD & AIDS", "Sexually Transmitted Infection", "Dermatologic Surgery", and "Clinical Infectious Disease". When the search terms "nursing", "HIV" and "lipodystrophy" were entered, two articles published in journals related to nursing were located in: "Applied Nursing Research" and the "Journal of the Association of Nurses in AIDS Care". No pertinent publications were found in the Lilacs or CINAHL databases.

The search revealed that the literature on this topic was concentrated between 2000 and 2004, reflecting the recent worldwide emergence of the syndrome. Unfortunately there was a shortage of nursing investigations regarding lipodystrophy, although the most frequently reported psychological and social effects were relevant to nursing practice. These effects included the erosion of body image and self esteem, anxiety, problems in social and sexual relations, and propensity toward demoralization and depression^(5-6,9-10). An interesting finding is that in Brazil, a country known throughout the world for its policy of universal distribution of antiretroviral medications, nurses have not published on this topic. This supports the necessity for this type of investigation.

Lipodystrophy is diagnosed subjectively, generally by the presence of lipoatrophy and/or fat accumulation on physical examination and/or patient report. In this review, three of the articles presented different definitions of lipodystrophy: 1) "poorly understood condition associated with antiretroviral therapy in HIV infection whose symptoms may include a combination of central fat accumulation, peripheral fat depletion and metabolic disorders"⁽⁵⁾; 2) "growing problem in human immunodeficiency virus-positive patients treated with highly active antiretroviral therapy"⁽⁷⁾; and 3) "unexplained trunk fat accumulation and/or fat loss in the face or extremities"⁽¹¹⁾. These different definitions suggest that lipodystrophy is still a syndrome that has not been fully clarified and defined, needing objective criteria by which to diagnose lipodystrophy. Consensus at the 1st International Workshop on Adverse Drug Reactions and Lipodystrophy in HIV was that the presence of at least one patient-reported physical change confirmed on physical examination may be useful for diagnosis, but it was agreed that this consensus was opinion based rather than evidence based⁽¹²⁾. Despite the fact that in Brazil 140,000 AIDS patients use antiretroviral treatment⁽¹³⁾ and that between 50 to 80% of AIDS patients develop lipodystrophy⁽²⁾, this review did not reveal any Brazilian studies discussing the definition of lipodystrophy.

In recent studies, lipodystrophy was observed in 34%⁽¹¹⁾ and 37.7% of German patients⁽⁷⁾, and 56% of Spanish patients⁽⁹⁾. Investigations that analyzed the onset of lipodystrophy according to the symptoms, observed an increase in abdominal girth in 32 to 60% of individuals, breast enlargement in 20%, facial lipoatrophy in 58%, loss of peripheral fat in 33 to

50%, and mixed manifestations in 8 to 86 % of patients^(9,14-15). According to the literature surveyed, the pathogeny of lipodystrophy continues to be largely unknown, although several risk factors for its occurrence have been described, including long-term HIV infection, prolonged use of protease inhibitors⁽¹⁴⁾ and a CD4 count below 200 cells/mL⁽¹¹⁾.

Several psychosocial alterations related to lipodystrophy were highlighted in the review. These included dissatisfaction with body image⁽⁵⁻⁶⁾, mood alterations demonstrated by anxiety and unhappiness⁽¹⁵⁾, problems in sexual relations⁽⁵⁾, reduction in self-esteem, and depression⁽⁵⁻⁶⁾. Furthermore, quality of life and different responses to weight change among women and men were reported. CORLESS and colleagues⁽¹⁶⁾, suggest that body image was significantly related to reduction of overall health, physical functioning and mental health in men, however no difference in quality of life was found for women

In relation to the affected region, facial lipodystrophy is noticed more often than other body changes. Therefore, patients with facial changes are more worried about stigmatization. Facial lipoatrophy was cited as an important stigmatizing factor for HIV patients, rendering them more vulnerable to the identification of seropositivity and consequently leading to decreased self-esteem and socialization⁽⁹⁻¹⁰⁾.

Alterations in body image faced by these patients have repercussions on affective and emotional health⁽¹⁷⁾. Thus, taking into consideration the benefits of antiretroviral therapy, several patients feel that the iatrogenic costs are so difficult to tolerate that they end up by abandoning treatment⁽¹⁷⁾. This behavior can be understood if we consider not only the stigmatization currently associated with HIV/AIDS, but also the pressure for a "perfect body" currently emphasized by society.

The "contamination" of body image currently associated with lipodystrophy has been documented; however, the mechanisms underlying the visible disfiguring and stigmatizing morphological changes are still unknown^(10,15,17). In addition, BLANCH and colleagues⁽⁹⁾ found that decreased sexual enjoyment and activity were observed after the development of lipodystrophy; however, there were no change in the frequency of condom use. Patients also felt less physically well and were less confident in their relationships during their experience of lipodystrophy⁽⁹⁾.

Regarding compliance to antiretroviral therapy, one study found that some patients intended to interrupt or abandon treatment as a result of body changes⁽¹⁵⁾. According to the literature, preoccupation and anxiety about the future and the possibility of occurrence of lipodystrophy, with its metabolic and morphologic complications, are frequent. However, patients who experienced complications of HIV infection and were near death considered lipodystrophy as a manageable price to be paid in exchange for longevity⁽⁶⁾. Inadequate adherence to treatment is a major, if not the most important, factor associated with treatment failure. Insufficient plasma levels of the medications and partial suppression of viral replication are ideal conditions for the development of viral resistance, with the possible emergence of drug-resistant viral strains⁽⁵⁾.

CONCLUSION

Lipodystrophy syndrome is a significant side effect of antiretroviral treatment, not only due to its increased prevalence, but also due to its interference with treatment. This is due to the metabolic and morphologic alterations that contribute to the reduction in adherence to treatment and with the reduced quality of life in individuals affected by the syndrome.

The present review revealed a scarcity of studies dealing with the lipodystrophy psychosocial

outcomes. The repercussions of this syndrome on the well being of HIV patients, frequently neglected despite the large number of affected patients, were highlighted. Additionally, the review highlighted many issues that are relevant for nurses in the care and treatment of AIDS patients. Understanding the impact of this syndrome, including the clinical and psychological implications, is essential for the planning of nursing care for AIDS patients. Thus, caring for people with AIDS calls upon a range of physical, psychological, social, and spiritual interventions that, in the absence of a cure, can make a palpable difference for patients⁽¹⁸⁾.

Health care providers, researchers, and policy makers are inundated with unmanageable amounts of information. They require literature reviews to efficiently integrate existing information and provide data for rational decision-making. Although this bibliographic review permitted an important summary of the psychosocial aspects of lipodystrophy due to antiretroviral therapy, further studies are needed for a better understanding of this complex syndrome, providing new information to be used in nursing care of HIV patients affected by this problem.

ACKNOWLEDGEMENTS

This research was supported by CNPq and FAPESP (Fernandes, APM: 04/08388-9)

REFERENCE

1. Viraben R, Aquilina C. Indinavir-associated lipodystrophy. *AIDS* 1998; 16:37-9.
2. Carr A, Samaras K, Chisholm DJ, Cooper DA. Abnormal fat distribution and use of protease inhibitors. *Lancet* 1998; 351:1736.
3. Kotler DP. HIV lipodystrophy etiology and pathogenesis. Body composition and metabolic alterations: etiology and pathogenesis. *AIDS Read* 2003; 13:5-9.
4. Amassari A, Antinori A, Cozzi-Lepri A, Trotta MP, Nasti G, Ridolfo AL et al. Relationship between HAART adherence and adipose tissue alterations. *Journal of Acquired Immune Deficiency Syndromes* 2002; 31:140-4.
5. Collins E, Wagner C, Walmsley S. Psychosocial impact of the lipodystrophy syndrome in HIV infection. *AIDS Read* 2000; 10: 546-50.
6. Power R, Tate HL, McGill SM, Taylor C. A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals. *Sexually Transmitted Infections* 2003; 79:137-41.

7. Oette M, Juretzko P, Kroidl A, Sagir A, Wettstein M, Siegrist J et al. Lipodystrophy syndrome and self-assessment of well-being and physical appearance in HIV-positive patients. *AIDS Patient Care and STDs* 2002; 16:413-7.
8. Jenuwine ES, Floyd JA. Comparison of Medical Subject Headings and text-word searches in MEDLINE to retrieve studies on sleep in healthy individuals. *J Med Libr Assoc* 2004; 92:349-53.
9. Blanch J, Rousaud A, Martinez E, De Lazzari E, Peri JM, Milinkovic A, et al. Impact of lipodystrophy on the quality of life of HIV-1-infected patients. *Journal of Acquired Immune Deficiency Syndromes* 2002; 31:404-7.
10. James J, Carruthers A, Carruthers J. HIV-associated lipoatrophy. *Dermatologic Surgery* 2002; 28:979-86.
11. Mauss S, Corzillius M, Wolf E, Schwenk A, Adam A, Jaeger H et al. Risk factors for the HIV-associated lipodystrophy syndrome in a closed cohort of patient after 3 years of antiretroviral treatment. *HIV Medicine* 2002; 3:49-55.
12. Carr A. HIV lipodystrophy: risk factors, pathogenesis, diagnosis and management. *AIDS* 2003; 17: 141-8.

13. Healthy Minister (BR). Available from: <http://www.aids.gov.br/final/tratamento/politicas/medicamentos.htm>. Access in 21 January 2005.
14. Dreezen C, Schrooten W, de Mey I, Goebel FD, Dedes N, Florence E et al. Self-reported signs of lipodystrophy by persons living with HIV infection. *International Journal of STD & AIDS* 2002; 13: 393-8.
15. Paton NI, Earnest A, Ng YM, Karim F, Abouhab J. Lipodystrophy in a cohort of human immunodeficiency virus-infected Asian patient: prevalence, associated factors, and psychological impact. *Clinical Infectious Diseases* 2002; 35: 1244-9.
16. Corless IB, Nicholas PK, McGibbon CA, Wilson C. Weight change, body image, and quality of life in HIV disease: A pilot study. *Applied Nursing Research* 2004; 17: 292-296.
17. Tate H, George R. The effect of weight loss on body image in HIV positive gay men. *AIDS Care* 2001; 13: 163-9.
18. Galvao MTG, Paiva SS, Sawada NO, Pagliuca LMF. Analysis of proxemic communication with HIV/AIDS patients. *Rev. Latino-am Enfermagem* 2006 July-August, 14(4):491-6.