

Correlates of perception of HIV-related lipodystrophy: the importance of fears and concerns

Eneko Sansinenea Méndez¹, Arrate Agirrezabal Prado¹, María José Fuster Ruiz de Apodaca² y Fernando Molero Alonso²

¹ Universidad del País Vasco/Euskal Herriko Unibertsitatea

² Universidad Nacional de Educación a Distancia

Autor de correspondencia: Eneko Sansinenea Méndez
E-mail: eneko.sansinenea@ehu.es

ABSTRACT

Introduction

HIV-associated lipodystrophy syndrome is a prevailing problem among people with HIV, causing them problems and stigma in social relationships.

Goals

This study was performed to research HIV related lipodystrophy correlates, especially treatment adherence variables associated to the perception of lipodystrophy, and to investigate its relationships with sex differences in people with HIV.

Methods

In a cross-sectional survey conducted with 706 people with HIV, participants described their self-perception of lipodystrophy and assessed their related fears and concerns it.

Results

Self-perception of lipoatrophy and lipohypertrophy was high in 35% and 25% of participants, respectively. In 27% of participants, fear to develop lipodystrophy highly affected adherence to treatment. Being woman, longer time since diagnosis and a lower positive affect were found good discriminating variables of high self-perception of lipodystrophy. Self-perception of lipodystrophy was higher in women than in men, and it affected worse to women.

Discussion

High lipodystrophy self-perception affected noteworthy treatment adherence. Sex differences revealed as an important factor to understand psychosocial effects of lipodystrophy on people with HIV. More research oriented to understand the aetiologic factors of lipodystrophy and its relations with gender, would provide the grounds for effective interventions designed to mitigate the stigmatic effects of lipodystrophy syndrome.

Keywords: *lipodystrophy, lipodystrophy-perception, lipodystrophy-fears and concerns, lipodystrophy-related factors*

Correlatos de la percepción de la lipodistrofia asociada al VIH: la importancia de los temores y preocupaciones

RESUMEN

Introducción

El síndrome de lipodistrofia asociado al VIH es un problema prevalente entre las personas con VIH, causando problemas y estigma en sus relaciones sociales.

Objetivos

El estudio se diseñó para conocer los determinantes de la percepción de lipodistrofia y sus correlatos, especialmente en lo que se refiere a la adhesión a los tratamientos, e investigar a su vez las relaciones de la percepción de lipodistrofia con las diferencias sexuales en personas con VIH.

Método

Se condujo un estudio transversal con 706 personas con VIH en el que describieron su percepción de lipodistrofia y evaluaron sus preocupaciones y miedos asociados (o relacionados).

Resultados

La percepción de lipoatrofia y lipodistrofia fue alta en el 35% y el 25% de los participantes respectivamente. En el 27% de los participantes, el miedo a desarrollar lipodistrofia afectó notablemente la adherencia al tratamiento. Se halló que ser mujer, un mayor tiempo transcurrido desde el diagnóstico, y un menor afecto positivo eran buenas variables discriminantes de las personas con alta percepción de lipodistrofia. La percepción de lipodistrofia fue mayor en mujeres que en hombres, y les afectó más negativamente.

Discusión

Una alta percepción de lipodistrofia afectó notablemente la adherencia al tratamiento por VIH. Por otro lado, el género se reveló como un factor importante a la hora de comprender las consecuencias psicosociales de la lipodistrofia en las personas con VIH. Una mayor investigación sobre los factores etiológicos de la lipodistrofia y su relación con el género, podría preparar las bases para intervenciones más efectivas a la hora de mitigar los efectos estigmatizantes del síndrome de lipodistrofia.

Palabras clave: lipodistrofia, percepción de lipodistrofia, miedos y preocupaciones de la lipodistrofia, factores relacionados con la lipodistrofia

Introduction

HIV-associated lipodystrophy is a syndrome that occurs in people with HIV who are being treated with antiretroviral medications. Lipodystrophy is characterized by the presence of an enlarged dorsocervical fat pad, circumferential expansion of the neck, breast enlargement, and abdominal visceral fat accumulation (lipohypertrophy), with peripheral fat wasting with loss of subcutaneous tissue in the face, arms, legs, and buttocks (lipoatrophy) ¹. Lipodystrophy is the most prevalent secondary effect of highly active antiretroviral therapy (HAART) ^{2,3}, but the relative contribution of the different families of drugs used in HAART to the development of lipodystrophy is unclear. There is evidence that HIV infection can also contribute to the syndrome ⁴.

Morphological changes induced by HIV-related lipodystrophy profoundly affect body image and influence health-related quality of life, producing erosion of self-esteem and confidence in relationships, decreasing the social functioning, and could compromise adherence to current antiretroviral regimens ⁵⁻⁹. Persons with HIV infection encounter both stigmatization and marginalization as a result of lipodystrophy. Facial lipoatrophy, the most stigmatizing condition of lipodystrophy for people with HIV, can cause psychological distress, lead to depression, and have dramatic effects on their self-esteem and socialization ¹⁰. On the other hand, measurement of health-related quality of life in people with lipodystrophy are complex due to a lack of consensus on the definition of lipodystrophy, a lack of appropriate methods to capture the impact of body fat changes on well-being, and the subjective perception of those changes by people who suffer it ^{8,11-12}.

Whereas most lipodystrophy research has focused on etiology, diagnosis, and treatment, there is a growing interest and concern over its psychosocial and lifestyle implications ¹³⁻¹⁵. Lipodystrophy has physical and psychological effects, ranging from bodily

discomfort to low self-esteem and depression ¹⁶. Owing to its physical manifestations it is viewed as a visible marker of HIV disease. In this sense, it is perceived as the “new face of AIDS” or “the Kaposi’s sarcoma of the 21st century” as one respondent described it ¹⁷. In addition, lipodystrophy causes problems in personal, family, and social relationships, often leading to people with HIV to isolation. Moreover, some persons with HIV could stop taking their antiretroviral regimen in order to avoid the adverse psychosocial effects of fat wasting ¹⁸.

Despite the increasing clinical interest of lipodystrophy syndrome as a significant side effect of HAART, its interference with treatment, and the repercussions of this syndrome on the well-being of people with HIV, there are still some important-questions unanswered. Understanding the psychological implications of this syndrome is essential to design interventions and health policies aimed at improving the consequences of stigmatization and discrimination associated with lipodystrophy.

This research has the following objectives: (a) to determine the degree of perceived lipodystrophy and the fears and difficulties associated with it and, (b) to analyze the determinants of the perception of lipodystrophy by people with HIV.

Methods

Participants

A non randomly selected sample of 706 people with HIV participated in the study. The target group was constituted by a population fulfilling the following criteria: confirmed diagnosis of HIV-1 infection, age between 17 and 79 years, and permanent residency in Spain.

Ethical approval and permission to conduct the research was granted by the NGOs and hospitals involved in the study. Data were collected between January and March 2010. The participants were recruited by

professional of those NGOs and hospitals during their appointments.

Measures

A questionnaire was designed, which included the following main sections: demographics (age, sex, education level, marital status, sexual behaviour); HIV-related data (transmission route, duration of infection, CD4 cell count, viral load, medical follow-up, antiretroviral treatment and adverse events); self-perception of lipoatrophy and lipohypertrophy ; treatment adherence problems related to lipodystrophy; and concerns and difficulties anticipated by the fear of developing lipodystrophy. In addition, a measure of emotional well-being was added to the questionnaire.

Self-perception of lipodystrophy

Self-perception of lipoatrophy and lipohypertrophy were assessed with the following two questions: “*To what extent would you consider that you lost fat in certain areas of the body (buttocks, arms, face, legs, etc.)?*” and “*To what extent would you consider that you accumulated fat in certain areas of your body (abdomen, neck, back, etc.)?*”. Responses were evaluated using a 10-point Likert scale, ranging from 1 (not at all) to 10 (totally). Given the good correlation of the two items ($r = .51$; $p = .000$), both items were combined in a single measure of self-perception of lipodystrophy ($M = 4.14$, $SD = .69$), in order to use it for inferential analyses.

Adherence difficulties and fears associated with the lipodystrophy syndrome

Lipodystrophy-related adherence difficulties were assessed with the question “*To what extent would you consider that fear to develop lipodystrophy affects adherence to antiretroviral treatment?*” Responses were

evaluated also using a 10-point Likert scale, ranging from 1 (not at all) to 10 (totally).

Concerns and difficulties anticipated by the fear of developing lipodystrophy were evaluated using three questions “*To what extent are you concerned for the possibility to develop the lipodystrophy syndrome in the future?*”, “*If you are taking antiretroviral treatment, to what extent have you considered to stop medication for the fear to develop the lipodystrophy syndrome?*”, and “*If you are not taking antiretroviral medication, to what extent the lipodystrophy syndrome is a reason to doubt or to refuse treatment?*”; these items were evaluated using a 5-point Likert scale, ranging from 1 (not at all concerned or not probable) to 5 (extremely concerned or very probable).

Affective dimensions

Also, it was measured the affectivity of the participants using a Spanish validated version of the Positive and Negative Affect Schedule (PANAS) ¹⁹. This questionnaire has 20 items and it measures two dimensions, Positive and Negative Affect on a 5-point Likert scale (1= very slightly or not at all, 5= extremely). The internal consistency in this study of both dimensions was high (Cronbach's $\alpha = .93$ and Cronbach's $\alpha = .91$ for Positive and Negative Affect respectively).

Procedure

The questionnaire was anonymous and self-administered. The process to complete it took approximately 20 minutes. The people in charge of each NGO or of the diverse health professionals at the participating hospitals gave the appropriate instructions before administering the questionnaire, obtained participants' informed consent, and stayed with the participants while they completed the questionnaires in order to address any doubts that might arise. The survey was conducted in accordance with the principles of the Helsinki Declaration and its amendments.

Data analysis

Firstly, exploratory analysis was performed to detect missing, atypical, or extreme data, as well as to ensure that the statistical assumptions of multivariate analysis techniques were met. We did not observe a consistent, unique, and detectable pattern of missing data and there were few for most of the items. Thus, no imputation was performed for the missing values.

According to the objectives of the study, analysis of data includes both descriptive and inferential techniques. To assess factors associated with self-perception of lipodystrophy, a stepwise discriminant analysis was performed. Independent variables included socio-structural, health care-related and psychological well-being-related variables, whereas self-perception of lipodystrophy was the dependent variable. In order to be used in the discriminant analysis, this variable was dichotomized by the middle theoretical point of the scale. Thus, there were two categories for this variable: absence or low lipodystrophy self-perception (scores ≤ 5) and presence of lipodystrophy self-perception (scores ≥ 6). Finally, in order to analyze sex differences in relation to lipodystrophy, it was used the Student's independent *t* test.

Results

Sociodemographic and HIV related data of the 706 people with HIV-1 infection included in the study are shown in Table 1. Most participants were men, heterosexual and single who had mainly acquired HIV infection through unprotected sexual relations. Clinical data show an acceptable immunological status and virological control of the participants.

Self-perception of lipodystrophy and associated fears and difficulties

Self perception of lipodystrophy and lipohypertrophy percentages are presented in Figure 1. In order to be more clearly understood, both variables were divided in tertiles. As it can be seen, an important part of the sample showed considerable self-perception of lipodystrophy, taking into account the percentages of participants that reported in the second and third tertiles (almost a half of the sample in the lipodystrophy column and more than a third in the lipohypertrophy column, taking both categories together).

Related to the fears and difficulties associated with lipodystrophy, results show that 27.3% of the par-

GRAPH 1. LIPOATROPHY AND LIPOHIPERTROPHY PERCENTAGES IN THE SAMPLE

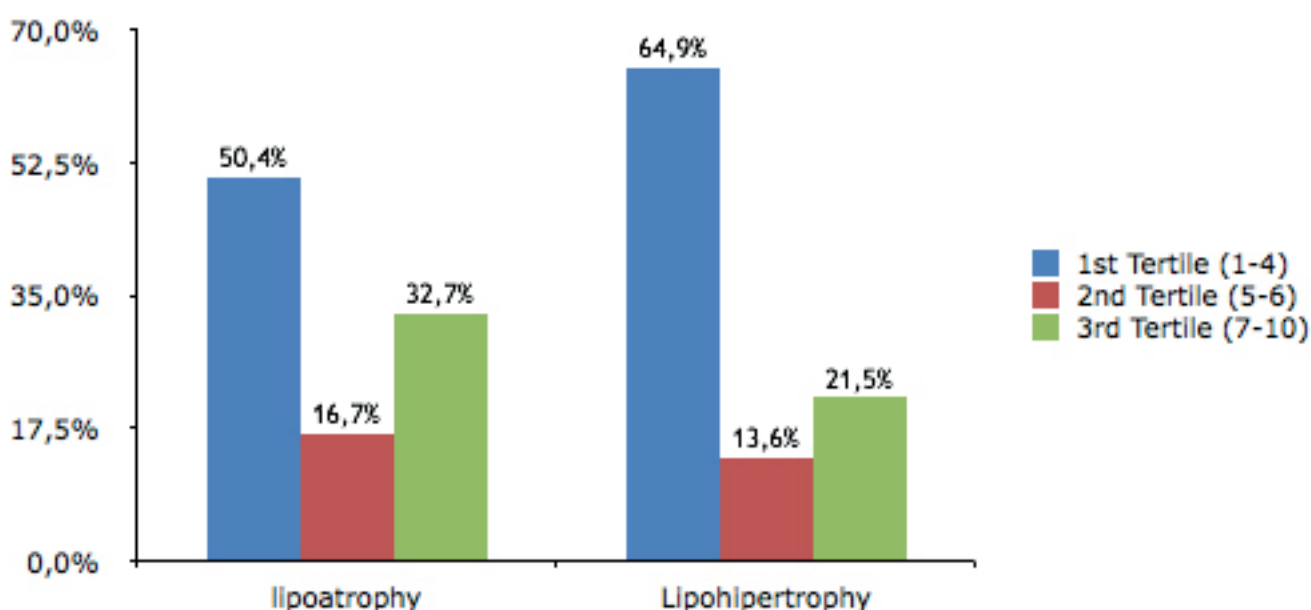


TABLE I . SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF THE 706 PARTICIPANTS INCLUDED IN THE STUDY

| | Data |
|--|-------------------|
| Gender | |
| Males | 70.8 |
| Females | 28.2 |
| Transsexual | 1.0 |
| Age, years, mean (\pm SD) | 43.1 \pm 7.6 |
| Education level | |
| No studies | 4.8 |
| Primary education | 41.1 |
| Secondary education | 35.3 |
| University degree | 18.4 |
| Other | 0.4 |
| Marital status | |
| Married/living with a partner | 31.1 |
| Divorced/separated | 17.2 |
| Single | 45.4 |
| Widowed | 6.2 |
| Sexual behavior | |
| Heterosexual | 61.2 |
| Homosexual | 26.7 |
| Bisexual | 6.8 |
| No answer | 5.3 |
| Transmission route | |
| Unprotected sexual relation | 51.7 |
| Sharing of injecting materials | 27.8 |
| Transfusion | 1.3 |
| Unknown (various concomitant practices) | 17.8 |
| Other | 1.5 |
| Duration of infection, years, mean (\pm SD) | 13.7 \pm 7.9 |
| CD4 cell count, cells/mm ³ , mean (\pm SD) | 521.3 \pm 313.3 |
| Undetectable plasma viral load | 84.2 |

Data in percentages unless otherwise stated.

Participants on antiretroviral treatment recognized that fear to develop lipodystrophy highly affected compliance with treatment. The probability to stop antire-

troviral medication or to doubt to take it was between “somewhat probable”, and “very probable” in 19.4% and 33% of the participants, respectively. Finally, a

total of 58.9% of participants were between “somewhat concerned” and “extremely concerned” for the possibility to develop lipodystrophy.

Determinants of the perception of lipodystrophy in participants: results of the discriminant analysis

The discriminant analysis identified a significant function that explained 100% of the variability of the model, Wilkis lambda (λ) = .86, $\chi^2(3, N = 248) = 35.2, p < .001$. According to results of this function, variables that allowed the classification of subjects with the presence of self-perception of lipodystrophy were female sex, longer duration of infection and lower positive affect. Standardized coefficients of the discrimi-

nant function are shown in Table 2. Seventy-two percent of participants were correctly classified.

Sex differences and lipodystrophy

The results of analysis by sex showed differences in several of the variables studied (Table 3).

Firstly, we found, there were statistically significant differences between men and women in the mean values of self-perception of lipodystrophy. Secondly, results show more difficulties and fears in women. So, difficulties in treatment adherence were significantly higher in women than in men. Women also expressed more thoughts of leaving antiretroviral treatment and more doubts for starting treatment. Furthermore, women showed significantly higher values for the fear to

TABLE 2. DISCRIMINANT ANALYSIS FOR THE IDENTIFICATION OF VARIABLES ASSOCIATED WITH THE DEGREE OF SELF-PERCEIVED LIPODYSTROPHY

| Predictors | Standardized coefficients | Wilkis lambda | F statistics and level of significance |
|-----------------------|---------------------------|---------------|--|
| Gender | .352 | .963 | F = 9.43; p = .002 |
| Duration of infection | .602 | .941 | F = 15.41; p = .000 |
| Positive affect | -.641 | .931 | F = 18.11; p = .000 |

TABLE 3. DIFFERENCES BETWEEN MEN AND WOMEN IN SELF-PERCEIVED LIPODYSTROPHY, ASSOCIATED DIFFICULTIES AND PSYCHOSOCIAL WELL-BEING

| Variable | Men | | Women | | t (fd) | p | CI 95% | Cohen's d |
|-------------------------------|------|------|-------|------|-----------|-------|----------------|-----------|
| | M | SD | M | SD | | | | |
| Perceived lipodystrophy | 3.88 | 2.52 | 4.70 | 2.97 | -3.6(667) | <.001 | [- 1.27, -.37] | -.30 |
| Adherence difficulties | 3.44 | 3.07 | 4.31 | 3.29 | -3.2(650) | .001 | [- 1.40, -.34] | -.27 |
| Thoughts of stop treatment | 1.58 | .98 | 2.05 | 1.35 | -3.5(360) | <.001 | [- .72, -.21] | -.43 |
| Doubts to start treatment | 1.98 | 1.2 | 2.45 | 1.34 | -2.3(229) | .018 | [- .85, -.08] | -.38 |
| Fear to develop lipodystrophy | 2.91 | 1.32 | 3.26 | 1.36 | -2.3(412) | .021 | [- .64, -.05] | -.26 |
| Positive affect | 2.55 | .85 | 2.33 | .87 | 3(676) | .002 | [-.08, .36] | .25 |
| Negative affect | 2.16 | .81 | 2.35 | .89 | -2.7(676) | .007 | [- .33, -.05] | -.22 |

develop lipodystrophy in the future. Finally, positive and negative affect were for slightly lower than the theoretical mean of the scale ($M = 2.23$, $SD = .86$ and $M = 2.48$, $SD = .84$, respectively), and we found women showed lower positive affect and higher negative affect.

Discussion

The main objectives of this study were to assess self-perception of lipodystrophy and its relationships with associated factors. Results have shown that the perception of lipodystrophy is extensive among people with HIV in Spain and that there is a negative association between lipodystrophy perception and their emotional well-being. There is also a clear difference against women on the perceptions around lipodystrophy's potential consequences for participants' well-being.

Firstly, results of the descriptive analysis have shown a wide perception of both lipoatrophy and lipohypertrophy, although lipoatrophy was self-perceived in a greater extent. The percentages found in the case of lipoatrophy are consistent with data of some cohort studies, in which prevalence between 28% and 49% has been reported ²⁰⁻²¹.

In the sample researched in this study the perception of lipoatrophy was higher than perception of lipohypertrophy. In agreement with that, it also has been found that there was a greater perception of lipoatrophy (46.8%) than that of lipohypertrophy (28.7%), and in a cross-sectional study carried out in Spain, 56% of 150 interviewed patients fulfilled clinical criteria for lipodystrophy ^{13,22}.

Lipodystrophy was regarded as an important obstacle to compliance with antiretroviral treatment. Interestingly, fears and difficulties also affected people who did not perceived that they had developed some manifestations of the syndrome. Thus, anxiety is present in more than half of participants because they

have expressed a high fear of developing the lipodystrophy syndrome in the future. Moreover, threats to health in this group of people is evident, since one fifth of them have thought about leaving the treatment for fear of developing lipodystrophy and one third of those who have not started antiretroviral therapy hesitate to do so for fear related to changes in body image. These findings are in agreement with other studies in which self-reported lipodystrophy has been associated with adherence failure ²³⁻²⁴.

Results of the present study have also shown the profile of people with a high self-perception of lipodystrophy. This profile is related to a longer duration of HIV infection, lower positive affectivity and female sex. In relation to the duration of HIV infection, other studies have not found the influence of this variable on perception of lipodystrophy ²⁵. However, an association between the presence of symptoms and AIDS diagnosis was observed ²⁶. Although in our study AIDS diagnosis was not measured, a longer duration of HIV infection may be related with more symptoms of the disease and also with a higher exposure to antiretroviral drugs, including those that have shown to be more frequently associated with lipodystrophy in the past.

Regarding to negative affect, HIV infection is associated with many stressors that may result in negative affect ²⁶⁻²⁷. It should be noted that study subjects showed a low level of positive affectivity, reflecting low levels of enthusiasm, activity, energy, or confidence. The lipodystrophy syndrome or the fear of developing it closely relates with negative affect for people with HIV. Some studies have shown that lipodystrophy might have a negative influence on the different aspects of psychological well-being, such as self-esteem, depression or anxiety ^{10, 22}.

With regard to the finding that being a woman was a variable with discriminant validity for a high self-perception of lipodystrophy, it should be also taken into account that social aesthetic values related to physi-

cal appearance have a greater impact on women, so that lipodystrophy may affect to a greater extent and intensity to women with HIV than men ²⁹.

Results have also shown that female sex was not only related to a high self-perception of lipodystrophy, but also that women expressed more fears and difficulties related to the syndrome. In this respect, women as compared with men expressed more fear to develop lipodystrophy, more difficulties in treatment adherence and were more reluctant to initiate antiretroviral therapy. The fact that women with HIV are more vulnerable to the effects of lipodystrophy syndrome ²⁹ and have more distress than men has been documented in different studies ³⁰⁻³².

Results of the present study indicate that lipodystrophy is becoming an important aspect of well-being of people HIV nowadays, and there is a need to address this problem. Based in the results of this study, women with HIV should be focus of specific attention and support in regard of lipodystrophy, and both men and women should be asked about the presence of lipodystrophy symptoms, that we know could be in the basis of leaving antiretroviral treatment. The aetiology of lipodystrophy syndrome is unclear, ranging from factors related from lymphocytes to life style ²⁵. How all these factors relate to gender is still mostly unknown. More research in lipodystrophy aetiologic factors related to gender is needed, in order to prevent stigma and assist suitably the needs of people with HIV.

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