

# Threats to identity: lipodystrophy and identity changes in people with HIV/AIDS (PWA)

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**Abstract.** *Background and aim:* PWA today have to face new problems associated with their disease state. One of these is tied to bodily changes that are related to HAART (lipodystrophy syndrome, LDS). Applying the Identity Process Theory (Breakwell, 1986), this research aimed to study the impact that LDS body changes may have on the identity of PWA. *Method:* One hundred and eight patients (79 M and 29 F, ranging from 35 to 75 years old) at a North Italian clinic completed a questionnaire composed of scales measuring the perception of threats to the identity of PWA, physicians' and patients' assessment of LDS, time from diagnosis, disclosure and perceived social support. *Results:* Results showed that lipodystrophy changes represent a new aspect of the disease that PWA need to handle in terms of identity: the changes resulted in 'loss of the self' and constituted a particular threat to the dimension of personal identity whereby bodily changes called more into question the principles of self-esteem and distinctness. LDS, however, lead to a multiple identity threat that is aggravated by patients' perception of the severity of their bodily changes and by the perception of a lack of friendship and social support. *Conclusions:* The study highlights how complex, cyclical and dynamic are the effects that HIV status can have on the sick person: they are no longer only clinical, but also psychological and psychosocial.

**Key words:** identity process theory, threats to identity, body changes, people with HIV/AIDS (PWA), LDS

## Introduction

The lipodystrophy syndrome (LDS) is characterised by abnormal or degenerative conditions of the body's adipose tissue, together with metabolic disorders such as hyperlipidaemia and reduced insulin sensitivity. LDS is characterised in a dual mode: by sunken cheeks, thinning arms and legs (clinically defined by the term *lipoatrophy*), and by fat accumulations in the abdomen, in the jaw and in the back of the neck ('buffalo hump'). Both of these modes may simultaneously occur in one individual (1) and are both connected to the regularity, continuity and duration of employment of constituent drugs of *Highly Active Antiretroviral Therapy* (HAART). It is, in fact, the administration of the drugs themselves that involves an increase in their toxicity (2-9). Although the pathogenesis of LDS is not yet fully understood, there is

now sufficient evidence that LDS is a complication of HAART (10) that today gives people infected with HIV "the opportunity to see themselves as someone living with a chronic illness rather than someone dying from a terminal disease" (11, p. 72) and held optimistic views for their future (12).

From a psychological point of view the literature has highlighted the impact that changes related to LDS have on adherence to antiretroviral therapy (i.e. 5, 13); on the quality of life of PWA (14, 15); on their self-esteem caused by the perception of being recognisable by physical appearance as HIV-positive (16, 17) especially when changes affect the more visible parts of the body such as the face (18, 19); on social contacts, sexuality and everyday activities (20); on serious forms of psychological distress (10); and more generally on PWA physical, emotional and social well-being (21). Nevertheless, not

a specific literature interest was found about the impact that body changes related to HAART may have on the identity of PWA (22).

The majority of studies concerning identity changes in PWA were conducted prior to the introduction of HAART (23, 24, 25, among others); therefore, in the time when the majority of sick people quickly reached the terminal stage and were soon forced to face death. It is not surprising that these researches privileged the epigenetic model proposed by Erikson (26) predicting the development of identity as a succession of rigid stages. For example from that dominated by negative emotions related to the diagnosis of HIV to that of disillusionment with respect to own beliefs in terms of fighting the disease itself (27).

As is well known these models could not be more adequate to account for the changes in the identity of PWA who are now facing with a chronic disease characterized by an uncertain course, a prescribed treatment regimen, requirement for self-care, some degree of stigma, changes in roles and relationships, psychological distress, and also identity changes (11).

Because often clearly visible, bodily changes associated with HAART can trigger a disruptive break (28) in the PWA sense of identity that may result in a *loss of self* (29-31). They can cause stigmatisation (32) and discrimination (33, 34) that, in turn, influence reasons against HIV disclosure (35) that is one of the major barriers to social support from family and friends (36).

As AIDS has become a chronic disease, new theoretical models that would be able to take into account the cyclicity with which identity issues can re-emerge as a result of a change of therapy and/or with the emergence of side-effects, but also models able to detect the influence that clinical and social factors can have on determining the PWA identity restructuring processes, seem to be necessary.

Although not applied to this area of research until now the Identity Process Theory (IPT; 37) seems to meet these requirements. As is known the IPT focuses on three levels of analyses: the *structure of identity*, the *processes*, and the *principles* that guided identity's processes and changes of identity, that are *continuity*, *distinctiveness*, *self-efficacy* and *self-esteem*. It is to achieve or restore these principles that people activate

coping strategies, aimed at restoring a balanced state of their identity. Identity that is constantly shaped and modified by the multiplicity of forces acting in people's lifespan (*social context of identity*). Some of these identity changes can be expected, such as those that realize desired aspects of the self. Others may be perceived as a confirmation of identity. Others, again, are chosen or imposed, can threaten identity by questioning one or more of its principles. IPT made reference to possible forms of identity threat such as those which may arise from a state of unemployment or from atypical gender work (37) and, more recently, identity threats which may arise from being an ethnic minority (38) or from a risk perception (39). In this research IPT was used as theoretical model in order to analyse the identity restructuring processes of a group of Italian PWA suffering from LDS.

As shown by Figure 1, our research operationalize IPT through: the identity structure (decomposed in *personal, interpersonal and social*) and the identity principles (decomposed in *continuity, distinctiveness, self-efficacy* and *self-esteem*) that guided the processes and the changes of identity. The structure and the identity principles are collocated at the centre of the *social context of identity* (PWA lifespan, Lewin, 40), whose forces can threaten identity. The PWA lifespan is divided into three dimensions: *physical*, which concerns the *diagnosed* and *perceived* disease condition; *temporal* that refers to the *clinical* course of disease and to development of therapies used to combat HIV/AIDS (*historical time*); *social*, which refers to the socio-anagraphic and psychosocial characteristics of the participants. This model is used to reach the two aims of the research:

a) to determine whether the perception of bodily changes associated with LDS threatened the identity of PWA: more specifically which contents and principles of identity were most threatened by LDS;

b) to determine whether the PWA lifespan, operationalized through the intensity and kinds of bodily changes, the *clinical* course of patients' disease and their socio-anagraphic (gender, qualification, sexual orientation) and psychosocial conditions (disclosure, social support), could predict the intensity with which a group of PWA treated with HAART and with LDS felt their identity to be threatened.

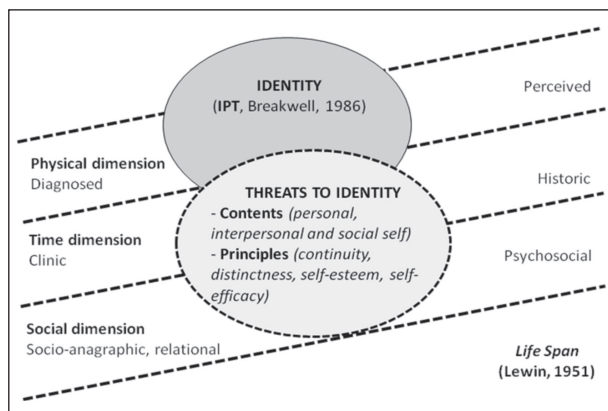


Figure 1. The Research Model.

## Methods

### Participants and procedures

118 PWA were enrolled into the study. Participants were recruited through the Metabolic Clinic of a hospital of North Italy where all of them were patients: only 17 (14.4%) were new patients, with an average of four visits to the clinic. Participants filled in a questionnaire while waiting medical staff: 68 (57.6%) for a visit and 50 (42.4%) for specific treatments.

The Hospital's Ethics Committee was informed of the research project before the study began; ethic approval was exempted for research projects not using invasive methodology. Participation in the study was voluntary and anonymous. Consent to participate was assumed on the basis of a returned questionnaire.

According to the medical evaluation, 10 (8.5%) of 118 patients did not show LDS. These cases were then excluded from the analysis.

### Measures

A questionnaire consisting of six parts was administered.

*Threats to Identity of PWA with LDS Questionnaire* (TI<sub>PWA</sub>LSD-Q). Inspired to the IPT (37) it was composed of 30 items that measured the intensity (1 = completely false for me to 6 = absolutely true for me) in which participants feel that their bodily changes threaten their identity. Each item was built to measure the *principles* of identity (continuity, distinctiveness, self-efficacy and self-esteem) that can be threatened

within three kind of *content of identity* (personal, interpersonal and social); i.e. the item "These physical changes always make me feel too different from healthy people" measures the perception of threat to the principle of distinctness concerning the personal dimension of identity; the item "If my body continues to change, my social life will deteriorate more and more" measures the perception of threat to the principle of continuity concerning the interpersonal dimension of identity. Internal consistency (Alpha) calculated on items related to the threats to the three type of identity *contents* and to the four form of the identity *principles* were good, as was that of the overall total scale (table 3).

*Physicians' Assessment and Patients' Perception of LDS*. Taken from the one proposed by Carr and Law (41), the scale was used to measure the lifespan *Physical dimension* (see Fig 1). It consists of 13 items that described bodily changes associated with LDS: i.e. accumulation of fat in the abdomen, pubic sacral region, behind the neck (6 item: *Lipodystrophy*, L) and reduction of fat: i.e. in the buttocks, legs, arms (7 item: *Lipoatrophy*, La). Both patients (*Perceived*) and physicians (*Diagnosed*) are asked to express a quantitative assessment on a four-point scale (absent, mild, moderate, severe). The internal consistency of the four indexes were good (table 1). Student *t* paired samples showed that patients overestimated both kinds of bodily changes more than their doctors did ( $t_{L,A} [(107)] = -3.42, p = 0.001$ ;  $t_L [(107)] = -7.06, p = 0.000$ ).

*Time from Diagnosis*. This was detected through the year in which patients were diagnosed with HIV (*Time dimension: Clinic*). In order to detect the *Historic Time Dimension*, the participants were divided into two groups depending on whether the year of diagnosis they indicated was before (0 = pre-HAART = 79, 74.5%) or after (1 = post-HAART = 27, 25.5%) 1996.

*Disclosure (D)*. Participants were asked to indicate (Yes, No) who (partner, parents, brothers/sisters, friends, boss, work colleagues, neighbours) had knowledge of their disease. The internal consistency was acceptable. Responses on the seven items (0 = No, 1 = Yes) were summed, with a higher score indicating higher disclosure. The average score was 2.54 (1.49) showed that a medium-low number of people had knowledge of participants' disease.

**Table 1.** Mean with Range, Standard Deviation and Cronbach's Alpha of the Lifespan Variables.

Variables	N	Range	M	SD	N item	$\alpha/r$
Lipoatrophy: Medical staff assessment (LaM)	108	0-4	1.41	0.65	7	.80
Lipodystrophy: Medical staff assessment (LM)	108	0-4	0.28	0.36	6	.60
Lipoatrophy: Patients' assessment (LaP)	108	0-4	1.70	0.88	7	.89
Lipodystrophy: Patients' assessment (LP)	108	0-4	0.69	0.64	6	.73
Years from diagnosis	106	0-26	16.97	5.76	1	-
Disclosure (D)	108	0-7	2.54	1.49	7	.54
Family support (MPSS-Fa)	108	1-5	2.94	1.40	4	.92
Friends support (MPSS-Fr)	108	1-5	3.42	1.41	4	.92
Significant other support (MPSS-So)	108	1-5	3.76	1.34	4	.91

*Multidimensional Scale of Perceived Social Support* (MSPSS, 42). The scale, adapted in Italy by Prezza and Principato (43), consisted of 12 items that explore the perception of the adequacy of the support that comes from three sources: family (4 item; e.g. My family really tries to help me), friends (4 item; e.g. I have friends with whom I can share my feelings) and a particularly significant person (4 item; e.g. There is a special person who cares about my feelings). For each statement the respondents indicated if they agreed or disagreed on a five-point scale. The MSPSS subscales demonstrated very good internal consistency (Table 1). A mean score of the items for each subscale was calculated. It ranged from one to five, with higher scores corresponding to a higher perception of support received from Family, Friends and Significant Others.

*Socio-demographic characteristics.* Gender, age, condition of employment, education, sexual orientation, presence/absence of a stable dating relationship have been revealed.

#### *Sample characteristics*

A total of 108 participants was considered for the analyses. They were 79 males and 29 females<sup>1</sup>. The average age ranged from 35 to 75 ( $M = 48.54$  years,  $SD = 7.32$ ); participants had been living with HIV for 16.97 ( $DS = 5.76$ ) years on average. The sample was heterogeneous in sexual orientation, in dating status

relations, in educational qualifications, and in employment (Table 2).

#### *Data analysis*

The statistical analyses was completed in two steps corresponding to the two research aims.

In the Step 1, descriptive and correlation analyses were performed to examine the PWA perception of threats to identity caused by bodily changes. Multidimensional scaling (MDS) was then used in order to reproduce a 'cognitive map' of the threats to identity (44).

In the Step 2, a Person correlation analysis has been conducted in order to demonstrate which lifespan variables of the research model (see Figure 1) were significantly correlated with the threats to identity.

**Table 2.** Participants characteristics (N. 108)

Variables	Categories	n	%
Gender	Male	79	73.1
	Female	29	26.9
Qualification	Low	42	38.9
	Medium/High	66	61.1
Condition of employment	Had a job	77	71.3
	Did not work	31	28.7
Sexual orientation	Heterosexual	61	56.5
	Homosexual/Bisexual	47	43.5
Stable dating relationship	Yes	55	50.9
	No	53	49.1

*Note.* Percentage calculated based on valid response.

<sup>1</sup> The imbalance between males and females reflects the distribution of people referred to the clinic where the research was carried out.

**Table 3.** N. items, Cronbach's Alpha, Means, Standard Deviation and Intercorrelation between Threats to Identity of PLWA with LDS Questionnaire (TIPLWALSD-Q) Subscales.

Threat to:		N item	$\alpha$	M	SD	1	2	3	4
Identity Contents	1. Interpersonal identity	9	.87	3.49	1.20	1			
	2. Social identity	12	.89	3.22	1.08	.59**	1		
	3. Personal identity	9	.90	4.02	1.24	.67**	.59**	1	
Identity Principles	1. Continuity	10	.82	3.54	1.00	1			
	2. Distinctness	7	.63	3.52	1.07	.84**	1		
	3. Self-efficacy	5	.79	3.18	1.25	.77**	.69**	1	
	4. Self-esteem	8	.84	3.80	1.13	.86**	.82**	.71**	1
Threats to Identity Total Score		30	.94	3.54	1.00				

A hierarchical multiple linear regression analysis was then led in order to examine how and which lifespan dimensions were associated with Threats to identity after accounting for the effects of variables from the previous step. All statistical analyses were computed with SPSS version 17.0.

## Results

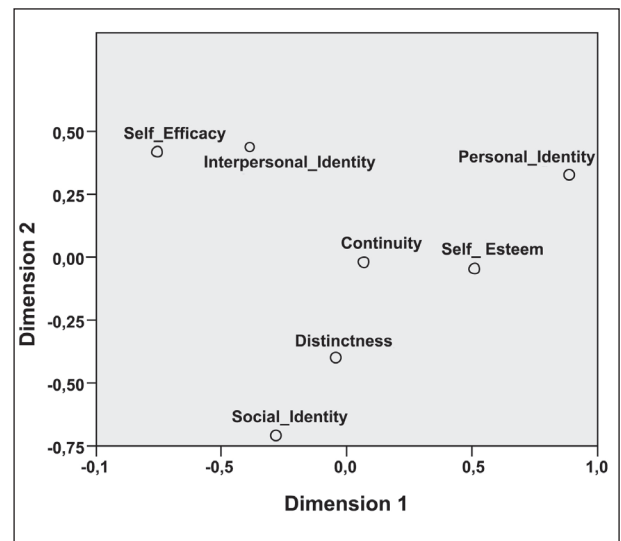
### *Perception of threats to identity caused by LDS.*

Descriptive and zero-order correlations were performed to examine the PWA perception of threats to identity (Table 3).

With regard to the identity contents, participants reported a fairly low level of threats to their Social identity, a medium level to their Interpersonal identity and a higher level to their Personal identity. Only this last score was, in fact, above the theoretical median of the scale (3.5). With regard to the identity principles, participants reported a low level of threats to the Self-efficacy, a medium level to Continuity and Distinctness, and a higher level to the Self-esteem identity principle. In this case, only threat to the Self-efficacy were below the theoretical median of the scale (3.5). Identity content and the identity principle subscales were highly and positively correlated.

Multidimensional scaling (MDS) was then Conduced (44). In order to allow a representation able 'to specify whether the proximities are similarity or dissimilarity measures' (45, p. 1619) we applied the

PROXSCAL method. A plot of Kruskal's stress values by number of dimensions suggested that a two-dimensional MDS solution provided an adequate fit, explaining 99.6% of the matrix variance with a stress value of 0.008. A plot of this solution revealed three kinds of threat configurations (Figure 2): (1) threats to Interpersonal identity which appeared primarily to undermine the Self-efficacy principle; (2) threats to Social identity that questioned more than anything else the distinctness principle; (3) threats to Personal identity that questioned especially the feelings of Continuity and Self-esteem.



**Figure 2.** MDS Mapping (PROXSCAL) of Seven Threats to Identity Subscales using Euclidean Distance.

*Lifespan variables on perception of threats to identity.*

Person correlation analysis has been conducted after one participant was excluded from the analysis because of responses far from the mean of a set of items, Mahalanobis > 39.25, DF = 16,  $p > 0.001$  (46). All categorical variables were transformed into dummy variables (Table 4).

It is interesting to note that the more serious the physician's assessment of the accumulation of fat in the patient's body (*Lipodystrophy, LM*) was, the less PWA perceived that bodily changes threatened their identity. Conversely, the patient's assessment of a more serious reduction of fat in their body (*Lipoatrophy, LaP*) threatened their identity more. No other physical indicators were

**Table 4.** Intercorrelations among Lifespan Variables and Threats to Identity Scores (N. 107)

Lifespan	Threats to identity dimensions and principles								
Dimensions	Variables	Interpersonal Identity	Social Identity	Personal Identity	Continuity	Distinctness	Self-Efficacy	Self-Esteem	Threats to Identity: total score
Diagnosed Physical	Lipoatrophy: Medical staff assessment (LaM)	.10	-.17	-.04	-.12	-.08	.11	-.06	-.05
	Lipodystrophy: Medical staff assessment (LM)	-.26**	-.22*	-.15	-.22*	-.19	-.24*	-.25*	-.25*
Perceived Physical	Lipoatrophy: Patients' assessment (LaP)	.32**	.09	.35***	.26**	.16	.32**	.30**	.28**
	Lipodystrophy: Patients' assessment (LP)	.02	.01	.19	.10	.06	.04	.08	.08
Clinic Time	Years from diagnosis	.02	-.13	.09	-.01	-.07	-.04	.04	-.02
Historical Time	Historical time of diagnosis	-.05	.11	-.07	-.04	.05	.01	.00	.00
Socio-, Anagraphic Relational	Gender (1 = Female)	.16	.19	.23*	.20*	.24*	.10	.26**	.22*
	Age	-.15	-.18	-.19 <sup>05</sup>	-.17	-.20*	-.14	-.22*	-.20*
	Qualification (1 = medium/high)	-.09	-.08	-.02	-.08	-.03	-.06	-.09	-.07
	Condition of employment (1 = had a job)	-.06	-.04	-.12	-.06	-.10	-.06	-.09	-.08
	Sexual orientation (1 = heterosexual)	-.06	-.10	-.06	-.06	-.12	.01	-.13	-.09
	Stable dating relationship (1 = yes)	.09	.03	.01	.05	.08	.01	.04	.05
Psychosocial	Disclosure (D)	.02	-.07	-.05	-.04	-.07	.03	-.07	-.05
	Family support (MPSS-Fa)	.04	-.18	-.22*	-.20*	-.13	-.01	-.15	-.15
	Friends support (MPSS-Fr)	-.20*	-.28**	-.21*	-.27**	-.30**	-.16	-.24*	-.27**
	Significant other support (MPSS-So)	-.13	-.21*	-.20*	-.18	-.10	-.25**	-.24*	-.21*

$r^* < 0.01$  \*\* < 0.01 \*\*\* < 0.001

significantly related to the threats to identity. With some exceptions, threats to identity were higher in Females and decreased with Age. No other socio-anagraphic and relational lifespan variables were significantly related to the threats to identity. With regard to the psychosocial variables of participants' lifespan, MSPSS subscales and first of all MSPSS-fr were highly and negatively correlated with most measures of threats to identity: the greater the perceived social support the less intense were the threats to identity that participants reported. With some exceptions, the correlations showed that lifespan variables were associated to all seven  $TI_{PWA}LS-Q$  subscales with the same intensity and in the same direction. For this reason, in the subsequent analysis we chose to consider only the Threats to Identity Total Score.

Hierarchical Multiple Linear Regression analysis was then leaded. Only lifespan variables which were significant at  $p < 0.05$  from bivariate results were included in the multivariate model. To check for the presence of multicollinearity, the variation inflation factor (*VIF*) statistic was first examined across the predictor variables. The highest *VIF* statistic was 1.32, suggesting that multicollinearity was not present (47). All assumptions about the residual error were satisfied [ $M_{ZRESID} = 0.00$ ;  $SD_{ZRESID} = 0.00$ ;  $t$  Durbin-Watson = 1.69; Autocorrelation = 0.00].

The first step of this analysis contained Physicians' Assessment of the Lipodystrophy (*LM*) that negatively predicted the Threats to Identity Total Score (Table 5). The physicians' assessment effect tended to decrease in the second steps of analysis. The second step added Patients' Assessment of Lipoatrophy (*LaP*) which positive effect decreased when Gender and Age were entered into the regression equation, and increased in the last steps. Gender had only a moderate and non-significant ( $p > 0.05$ ) effect in step 3 in which the adjusted  $R^2$  did not increase significantly. Gender and Age had no influence in steps 4, when Social Support from Friends, Family and Significant other were introduced into the analysis. In this last step only the friends support reduced the perception of PWA identity threats: The model explained the 19% of variance and showed that, after all, patients' perception of the seriousness of the reduction of fat in their body, together with the social support that they could derive from their friends, were the lifespan variables that affected their perception of threats to identity more.

## Discussion

For a person with HIV or AIDS implies, today, dealing with the effects of the new antiretroviral

**Table 5.** Hierarchical Multiple Regression Analyses of Lifespan Dimensions as Predictors of Threats to Identity Total Score (N. 107)

Lifespan Dimensions	Diagnosed Physical		Perceived Physical		Socio-Anagraphic		Psychosocial	
	$\beta$	t	$\beta$	t	$\beta$	t	$\beta$	t
Lipodystrophy: Medical staff assessment (LM)	-.25	-2.59*	-.18	-1.89 <sup>06</sup>	-.16	-1.53	-.16	-1.55
Lipoatrophy: Patients' assessment (LaP)			.23	2.43*	.19	1.92 <sup>06</sup>	.24	2.50*
Sex (1 = female)					.17	1.75 <sup>08</sup>	.13	1.45
Age					-.08	-.81	-.06	-.60
Friends' support							-.24	-2.53*
Family support							-.09	-.93
Significant other support							-.09	-.90
$R^2$	.05		.09		.11		.19	
$\Delta R^2$	.06*		.05*		.03		.10**	
F	(1.105) = 6.70*		(2.104) = 6.46**		(4.102) = 4.32**		(7.99) = 4.58***	

Note. Only those variables significant at  $p < 0.05$  from bivariate results were included in the multivariate model.

$p < 0.05^*$ ;  $p < 0.01^{**}$ ;  $p < 0.001^{***}$ .

therapies (2, 3, 6, 7, 9) and in particular with the body changes associated to LDS. Starting from the assumption that for PWA the manifestation of bodily changes could elicit a new discontinuity in their biographies (28) and, consequently, a further restructuring of their identity (29-31), the present research wanted to analyse the perception that a group of HIV+ patients who have developed lipodystrophy reported about whether and how these changes were experienced as forms of threat to their identity. To do this, it was chosen to apply the IPT (37-39) as a model more suitable than staged models to capture the processes of re-structuring of identity that such physical threats can generate.

If the HIV diagnosis is a disruptive moment breaking the sense of identity of people who are affected (29), the results of this study have shown that lipodystrophy changes result in 'loss of the self' that are more evident for some identity aspects than others. Only rarely participants did admit that their bodily changes could threaten their relational identity or harm their social position. It is reasonable to assume that being sick for many years, these patients may have already faced problems of identity such as those related to the presentation of themselves and their disease to others and those associated with the need to cope with the social stigma that, inevitably, is associated with their disease status (10, 32-34). The perception of threats to feelings of distinctness, efficacy, but especially of continuity and self-esteem, became indeed much more intense when applied to personal identity, which is the most individual and intimate part of identity, not shared or reflected outside; what in Erikson (26) conceptualisation represents the Ego Identity notion.

Results of this study are then in line with researches that have shown how the body is a fundamental dimension of self-definition for PWA (23), but also confirm that not always and not for all subjects bodily changes associated with the LDS call into question the overall structure of identity. In this sense, the results confirm that the sequential models utilized before the introduction of HAART are no longer able to take the paths of the identity restructuring processes of patients submitted to new HIV treatments. IPT (37) seems us a more suitable model to study identity threats related with LDS changes. This model has allowed us to show that the all types of identity threats are highly and significantly correlated:

so, we can reasonably assume a possible effect of multiple threats to identity. Nevertheless, some principles resulted more threatened with reference to specific identity contents. This was clearly shown by the results of the MDS; the feelings of not being able to do things that PWA would have liked to do, such as having lasting romantic relationships (self-efficacy), were seen to threaten more the patients' interpersonal dimension of identity than the others, whereas the concern about being stigmatised because of their condition (distinctness) was what most threatened their social identity.

Finally, using IPT model allowed us to analyse the effects of the *context of identity*. The results have confirmed, above all, the importance of the type and severity of bodily changes (17), especially those perceived by patients than those assessed by the doctors (14, 15). It was also noted that, in the eyes of patients, was lipoatrophy and not lipodystrophy more associated with the perception of threats to identity. Supporting those within the clinical context who have long argued for the importance of considering the perceptions and evaluations of patients (20), these results suggest also the importance of body's cultural representations. Being thin, in fact, appears to be a marker of people identity as HIV patient more than being fat.

In contrast with the importance that the literature has attributed to the temporal dimension (23), mainly in order to determine the stage of the disease (27) and of the identity disruption (23-25, 28), our results have not shown significant trends. It is possible to assume that the situation of our participants was very different from that of patients of researches conducted before the introduction of HAART. In the actual era (11) it seems more reasonable to assume a cyclic path for the re-actualisation of the identity questions, no longer marked by clinical or historical times of disease, but rather by the emergence or re-emergence of problems, such as those associated with the effects of therapies that introduce new discontinuity in patients (48, 49).

Was instead the possibility of counting on the support, first of all of a friend that, according to the literature (36, 51, 52), seemed to play an important role in reducing feelings of identity threat resulting from the perception of the relevant changes that the body has undergone.

Unlike the findings described in the literature, neither having a job nor disclosure was associated with



the participants' perception of identity threats (23, 49). As indicated by several authors (50) work would allow PWA to maintain high self-esteem and good social relationships, and make them feel self-sufficient and in control of their own lives. Even in this case is probably the advanced age of the sample to explain these results. Nevertheless, it is important to note that in the case of patients like those considered here the possibility of returning to work may have been perceived by some as a further threat to their identity, linked mainly to the need to 'reveal' their status to others. Fear of the consequences of stigma can perhaps also explain why disclosure did not emerge as a variable that offset the perceived threat of identity, as found in the literature (23, 48, 49).

The current study has several limitations. First, cause-effect conclusion about the impact of lifespan variables on perception of identity threats cannot be based upon the study's findings due to its cross-sectional design. Second, because of privacy, it wasn't possible to collect data about patients clinical condition, such as CD4 level, comorbidity, compliance, severity of other side effects.

Despite these limitations, the study raised some very topical issues from a clinical point of view, especially the problems with which psychologists working in this field will increasingly be confronted. Moreover, unlike the literature, which largely dates back to a pre-HAART era, it highlights how complex, cyclical and dynamic are the effects that HIV status can have on the sick person: they are no longer only clinical, but also psychological and psychosocial.

## Acknowledgements

The authors thank prof. Glynis Marie *Breakwell* for her suggestions and Maria De Paola for her help in collecting and storing data.

## References

1. Guaraldi G, Orlando G, Squillace N, De Santis G, Pedone A, Spaggiari A, De Fazio D, Vandelli M, De Paola M, Bertucelli C, Aldrovandi C, Nardini G, Beghetto B, Borghi V, Bertolotti M, Bagni B, Grazia Amorico M, Roverato A, Esposito R. Multidisciplinary approach to the treatment of metabolic and morphologic alterations of HIV-related lipodystrophy. *HIV Clin Trials*. 2006; 3: 97-106. [HTC](#)
2. Ammassari A, Murri R, Pezzotti P, Trotta MP, Ravasio L, De Longis P, Lo Caputo S, Narciso P, Pauluzzi S, Carosi G, Nappa S, Piano P, Izzo CM, Lichtner M, Rezza G, Monforte A, Ippolito G, d'Arminio Moroni M, Wu AW, Antinori A; AdICONA Study Group. Self-reported symptoms and medication side effect influence adherence to highly active antiretroviral therapy in persons with HIV infection. *J Acquir Immune Defic Syndr*. 2001; 28: 445-449.
3. Ammassari A, Antinori A, Cozzi-Lepri A, Trotta MP, Nasti G, Ridolfo AL, Mazzotta F, Wu AW, d'Arminio Monforte A, Galli M; AdICoNA Study Group. LipICoNA Study Group. Relationship between HAART adherence and adipose tissue alteration. *J Acquir Immune Defic Syndr*. 2002; 31/suppl3: 140-144.
4. Carr A, Cooper D A. Adverse effect of antiretroviral therapy. *Lancet*. 2000; 56: 1423-1430.
5. Collins EG, Burgoyne RW, Wagner CA, Abbey SE, Alman MH, Nur ML, Wamsley SL. Lipodystrophy severity does not contribute to HAART nonadherence. *AIDS Behav*. 2006; 10(3): 273-277.
6. Duran S, Spire B, Raffi F, Walter V, Bouhour D, Yornot V, Cailleton V, Lepout C, Moatti GP. Self-reported symptoms after initiation of a protease inhibitor in HIV infected patients and their impact on adherence to HAART. *HIV Clin Trials*. 2001; 10: 38-45.
7. Guaraldi G, Murri R, Orlando G, Orlandi E, Sterrantino G, Borderi M, Grosso C, Cattelan AM, Nardini G, Beghetto B, Antinori A, Esposito R, Wu AW. Morphologic alterations in HIV infected people with lipodystrophy are associated with good adherence to HAART. *HIV Clin Trials*. 2003; 4: 99-106.
8. Omrani AS, Pillay D. Multi-drug resistant HIV-1. *J Infection*. 200; 41: 5-11.
9. Paton NI, Earnest A, Ng YM, Karm F, Alboulhab J. Lipodystrophy in a cohort of human immunodeficiency virus infected Asian patients: prevalence associated factors and psychological impact. *Clin Infect Dis*. 2002; 35: 1244-1249.
10. Oette M, Juretzko P, Kroidl A, Sagir A, Wetsyein M, Siegrist G, Haussinger D. Lipodystrophy syndrome and self-assessment of well-being and physical appearance in HIV positive patients. *AIDS Patient Care ST*. 2002; 16: 413-417.
11. Siegel K, Lekas HM. AIDS as a chronic illness: psychosocial implications. *AIDS*. 2002; 16(4): 69 - 76.
12. Bogart LM, Catz SL, Kelly JA, Gray-Bernhardt ML, Hartmann BR, Otto-Salaj LL, Hackl KL, Bloom FR. Psychosocial issues in the era of new AIDS treatments from the perspective of persons living with HIV. *J Health Psychol*. 2000; 5(4): 500-516.
13. Corless IB, Kirksey KM, Kempainen J, Nicholas PK, McGibbon C, Davis SM, Donal S. Lipodystrophy-associated symptoms and medication adherence in HIV/AIDS. *AIDS Patient Care ST*. 2005; 19(9): 557-586.
14. Huang JS, Lee D, Becera K, Santos R, Barber ED, Matheus

- WC. Body image in men with HIV. *AIDS Patient Care ST*. 2006; 20(10): 668-677.
15. Reynolds NR, Neidig JL, Wu AW, Gifford AL, Holmes WC. Balancing disfigurement and fear of disease progression: patient perception of HIV body fat redistribution. *Aids Care*. 2006; 18(7): 633-673.
  16. Mauss S, Corzillius M, Wolf E, Schwenk A, Adam A, Jaeger H, Knechten H, Goelz J, Goetzenich A; DAGNA Lipantiretroviral therapy study group. Risk factor for the HIV-associated lipodystrophy syndrome in a closed cohort of patients after 3 years of antiretroviral treatment. *HIV Med*. 2002; 3: 49-55.
  17. Blanch J, Rousaud A, Martinez E, De Lazzari E, Milinkovic A, Peri JM, Blanco JL, Jaen J, Navarro V, Massana G, Gatell JM. Factors associated with severe impact of lipodystrophy on the quality of life of patients infected with HIV-1. *Clin Infect Dis*. 2004; 38(10): 1464-1470.
  18. Persson A. Facing HIV: Body shape change and the (in) visibility of illness. *Medical Anthropology*. 2005; 24(3): 237-264.
  19. Nilsson SL, Gardner M, Karlsson M, Bratt G, Walther R. Perception of facial lipohypotrophy social isolation/stigma and psychological distress. 2006 August; Paper presented at the 16th International Conference on AIDS Toronto Canada.
  20. Guaraldi G, Orlando G, Murri R, Vandelli M, De Paola M, Beghetto B, Nardini G, Ciaffi S, Vichi F, Esposito, Wu AW. Quality of life and body image in the assessment of psychological impact of lipodystrophy: validation of the Italian version of assessment of body change and distress questionnaire. *Qual Life Res*. 2006; 15: 173-178.
  21. Halkitis PN, Shrem MT, Zade DD, Wilton L. The Physical Emotional and Interpersonal Impact of HAART: Exploring the Realities of HIV Seropositive Individuals on Combination Therapy. *J Health Psychol*. 2005; 10(3): 345-358.
  22. Secchiaroli G, Mancini T, De Paola M. Implicazioni psicologiche della Sindrome da Lipodistrofia come effetto collaterale di terapie antiretrovirali in persone portatrici di infezioni HIV/AIDS Una rassegna critica della letteratura. *Psicologia della Salute*. 2009; 3: 87-112.
  23. Merriam SB, Courtenay BC, Reeves PM. Ego development in the face of death: how being HIV-positive affects movement through Erikson's adult stages of development. *J Adult Dev*. 1997; 4: 221-235.
  24. Tewksbury R, McGaughey D. Identities and identity transformations among persons with HIV disease. *FFP: Journal Of Gay Lesbian and Bisexual Identity*. 1998; 3: 213-232.
  25. Thomas MR. The Eriksonian model as a framework for the psychosocial assessment of the HIV positive individual (CDROM). Abstract from: ProQuest File Dissertation Abstract Item: 9516193; 1994.
  26. Erikson EH. *Identity youth and crisis*. New York NY: Mor-ton; 1968.
  27. Griffin KW, Rabkin JG. Perceived control over illness realistic acceptance and psychological adjustment in people with AIDS. *J Soc Clin Psychol*. 1998; 17(4): 407-424.
  28. Bury M. Chronic illness as biographical disruption. *Sociol Health Ill*. 1982; 4: 176-182.
  29. Charmaz K. *Good days, bad days. The self in chronic illness and time. Identity dilemmas of chronically ill men*. 1997; New Brunswick, New Jersey: Rutgers University Press.
  30. Kralik D. The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *J Adv Nurs*. 2002; 39: 146-154.
  31. Ridson A, Eccleston C, Crombez G, McCracken L. How can we learn to live with pain? A Q-methodological analysis of the diverse understandings of acceptance of chronic pain. *Soc Sci Med*. 2003; 56: 375 - 386.
  32. Herek GM, Capitanio JP, Widaman KF. Stigma social risk and health policy: public attitudes toward HIV surveillance policies and the social construction of illness. *Health Psychol*. 2003; 22: 533-540.
  33. Varas-Diaz N, Toro-Alfonso J, Serrano-Garcia I. My body my stigma: body interpretations in a sample of people living with HIV/AIDS in Puerto Rico. *Qual Rep*. 2005; 10(1): 122-142.
  34. Cao X, Sullivan S, Xu JE, Wu Z. Understanding HIV related stigma and discrimination in a "blameless" population. *Aids Educ Prev*. 2006; 18(6): 518-528.
  35. Derlega VJ, Winstead BA, Greene K, Serovich J, Elwood WN. Perceived HIV-related Stigma and HIV Disclosure to Relationship Partners after Finding Out about the Seropositive Diagnosis. *J Health Psychol*. 2002; 7(4): 415-432.
  36. Schrimshaw EW, Siegel K. Perceived Barriers to Social Support from Family and Friends among Older Adults with HIV/AIDS. *J Health Psychol*. 2003; 8(6): 738-752.
  37. Breakwell GM. *Coping with threatened identities*. London: Methuen; 1986.
  38. Timotijevic L, Breakwell GM. Migration and threat to identity. *J Community Appl Soc*. 2000; 10: 335-372.
  39. Breakwell GM. *The psychology of risk* Cambridge: Cambridge University Press; 2007.
  40. Lewin K. *Field theory in social science: selected papers* New York NY: Harper & Row; 1951.
  41. Carr A, Law M. An objective lipodystrophy severity grading scale derived from the lipodystrophy case definition score. *J Acquir Immune Defic Syndr*. 2003; 33: 571-576.
  42. Zimet GL, Dahlem NV, Zimet SG, Farley GK. The Multi-dimensional Scale of Perceived Social Support. *J Pers Asses*. 1988; 52: 30-41.
  43. Prezza M, Principato MC. La rete sociale e il sostegno sociale. In M Prezza, M Santinello (Eds) *Conoscere la comunità* (pp193-233) Bologna: Il Mulino; 2002.
  44. Nosofsky RM. Attention similarity and the identification-categorization relationship. *J Ex Psychol Gen*. 1986; 115: 39-61.
  45. Leydesdorff L, Vaughan L. Co-occurrence matrices and their applications in information science: Extending ACA to the Web environment. *J Am Soc Inf Sci Technol*. 2006; 57: 1616-1628.
  46. Tabachnick BG, Fidell LS. *Using multivariate statistics* (4th ed) Needham Heights MA: Allyn & Bacon; 2001.
  47. Myers RH. *Classical and modern regression with applications* Boston MA: PWS-Kent Publishing Co; 1990.

48. Baumgartner LM. The incorporation of HIV/AIDS into identity over time: transformational tales continued. *Adult Edu Quart.* 2007; 17: 919-931.
49. Courtenay BC, Merriam SB, Reeves PM, Baumgartner LM. Perspective transformation over time: a two-year follow-up study of HIV-positive adults. *Adult Edu Quart.* 2000; 50: 102-119.
50. Timmons JC, Fesko SL. The impact meaning and challenges of work: perspectives of individuals with HIV/AIDS. *Health Soc Work.* 2004; 29(2): 137-145.
51. Foà C, Copelli P, Cornelli MC, De Vincenzi F, Fanfoni R, Ghirardi L, Prandi R, Artioli G, Mancini T. Meeting the needs of cancer patients: identifying patients', relatives' and professionals' representations. *Acta bio-medica: Atenei Parmensis.* 2014; 85 (Suppl. 3, Health Professional Issue I-2014): 41-50.
52. La Sala R, Foà C, Artioli G, Mancini T, Sarli L. Therapeutic adherence and health outcomes in acute coronary syndrome (SCA) patient: the role of nursing. *Acta bio-medica: Atenei Parmensis.* 2014; (85 / Suppl. 3, Health Professional Issue I-2014): 14-27.

Accepted: 9 February 2015

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