

ORIGINAL ARTICLE

A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals

R Power, H L Tate, S M McGill, C Taylor

Sex Transm Infect 2003;**79**:137–141

See end of article for authors' affiliations

Correspondence to:
Robert Power, Department
of Sexually Transmitted
Diseases, Royal Free and
University College Medical
School, The Mortimer
Market Centre, Mortimer
Market, London
WC1E 6AU, UK;
rpower@gum.ucl.ac.uk

Accepted for publication
19 August 2002

Objectives: To investigate the psychosocial impact of lipodystrophy on the lifestyles of HIV positive patients on highly active antiretroviral therapy (HAART).

Methods: In-depth interviews were conducted with 14 HIV positive patients on HAART at an outpatient sexually transmitted infections (STI) and HIV clinic in central London. Qualitative data from interview transcripts were analysed using grounded theory to elicit key categories and subcategories.

Results: Three main themes relating to lipodystrophy emerged: effect on the individual; impact on the social world of the individual; responses of the individual. Lipodystrophy had physical and psychological effects, ranging from bodily discomfort to low self esteem and depression. Owing to its physical manifestations it was viewed as a visible marker of HIV disease. At the level of social functioning, lipodystrophy led to problems with personal and family relationships, although having a partner was protective. Individuals reported narrowing their social world, in some cases to degrees of social isolation. Individual responses included changes in diet, increased exercise regimes, steroid use and plastic surgery (mainly collagen injections to the face). For those who had experienced serious illness related to HIV, there was a more sanguine acceptance of lipodystrophy as an unfortunate consequence of longevity and drug therapy.

Conclusions: Health professionals need to address the psychosocial implications of lipodystrophy, including the ways in which it may affect different groups and their adherence to therapy. Formative evaluations are needed to assess the potential for targeted interventions.

The primary aim of this paper is to describe some of the psychosocial and lifestyle implications of lipodystrophy as experienced by HIV positive individuals being treated with highly active antiretroviral therapy (HAART). Undoubtedly, HAART for HIV and prophylactic therapy for opportunistic infections have increased survival and wellbeing.¹ Yet, in recent years lipodystrophy has been reported in HIV infected patients taking standard therapy protease inhibitors in combination with nucleoside analogues, with a concomitant link being suggested between nucleoside reverse transcriptase inhibitors and factors related to duration of HIV-1 infection itself.^{2–5} Carr and colleagues⁶ described the syndrome of peripheral lipodystrophy (fat wasting of the face, limbs, and upper trunk), hyperlipidaemia, and insulin resistance in patients receiving potent HIV protease inhibitive therapy, noting that the prevalence and severity of lipodystrophy syndrome with long term therapy for HIV-1 infection including a protease inhibitor is unknown.⁷

Whereas most lipodystrophy research has focused on aetiology, diagnosis, and treatment, there is a growing interest and concern over its psychosocial and lifestyle implications. The small number of published studies show that lipodystrophy can have an adverse effect on the sexual behaviour and general wellbeing of HIV infected individuals.^{8–11} At the recent XIV International AIDS Conference a number of presentations on lipodystrophy highlighted issues such as impact on quality of life,¹² body image and sexual behaviour,¹³ and adherence to antiretroviral therapy.¹⁴ We wish to augment this knowledge base by presenting qualitative data from in-depth interviews conducted with HIV positive clinic patients on HAART who were experiencing lipodystrophy. For some years now these issues have been raised in the popular media, especially the gay press, as well as on the internet.^{15–17}

METHODS

Participation and recruitment

Fourteen in-depth interviews were conducted with HIV infected patients who were experiencing lipodystrophy and who were attending a large central London STI/HIV outpatient clinic. All respondents were referred by clinicians who had made a visual assessment of lipodystrophy. Commonly reported among the patients was facial atrophy (12/14); wasting of the arms (10/14), legs (10/14), or buttocks (10/14); fat deposition at the neck (2/14), abdomen (5/14), and breast (the two female respondents). The study was explained to them and an information sheet was provided. This outlined its purpose and gave details of ethical approval that had been granted by the relevant health trust. Written consent was obtained from all patients before interview. None of the patients who were referred to the research team refused to be interviewed. Interviews lasted between 45 minutes and 3 hours and took place in a variety of contexts, including the homes of the patients and offices at the clinic. Interviews were tape recorded and transcribed verbatim. They were then analysed using the tenets of grounded theory.¹⁸ In practice, this entailed a thematic analysis of the transcripts from which "categories" and "subcategories" were created. A process of constant comparison between interviews was used to consolidate dominant themes and data collection ceased when "saturation" was achieved, with themes and scenarios being repeated in successive interviews. All transcripts were analysed by at least two of the authors to ensure reliability. This allowed for discussions to be held to agree upon consensual categories and subcategories.

RESULTS

The following sections summarise the main "categories" (numbered) and "subcategories" (lettered) derived from the data with illustrations being drawn from the transcribed

Table 1 Basic sample characteristics (n=14)

	Range	Mean	Mode
Sex: 12 men, 2 women			
Regular partner: 8 of 14			
Regular employment: 7 of 14			
Age (years)	28–61	42	40
Years since HIV positive diagnosis	3–17	10.8	11
Years on HAART	3–6	4.3	4

interview transcripts. Table 1 describes pertinent characteristics of the sample.

(1) The effect on the individual

(A) Awareness and physical effects

Initial awareness of lipodystrophy chiefly occurred through individuals noticing physical changes to their body shape or through comments from friends and acquaintances. Awareness also resulted from patients realising that clothes no longer fitted, or looking at old photographs of themselves and identifying differences.

The main effect for me has been an enormous abdomen, and certainly initially I lost weight in general but gained a great deal abdominal size. And I suppose this was put down to, in my mind at least, lipodystrophy. On the whole I'm left a bit freakish. I really should have braces for my underpants now as well for my trousers. (Interviewee (I) 2, male, 46 years old)

I'm so vain. I used to have a lovely bum. Now it's flat. And that's a strange one, sitting on a seat and it hurts. Because you've lost all the padding on your backside . . . You still find yourself occasionally walking past a mirror and looking in and it catches you big time. The other big one is photographs. At Christmas photos were taken and you look at a photograph of you and it's not you. (I 3, male, 36 years old)

Body shape changes were accompanied by physical effects, ranging from uneven weight gain and weight loss, reduced libido, and a perception of rapid ageing, especially in the face. More directly, fat loss to the buttocks made sitting uncomfortable.

Losing fat from your legs makes your varicose veins show much more, so it seemed really to be a blessing to society on the whole if I wasn't seen in public undressed. (I 2, male, 46 years old)

These physical effects often led to a heightened awareness and a search for knowledge about the condition, most frequently through the gay press and internet websites dedicated to this topic.

I'd seen it advertised in AIDS manuals and they had a name for it, there was a reason why I was losing weight in the face and arms. There was a name for a disease for what was actually happening. (I 9, male, 39 years old)

The changes in body shape had economic implications. Clothes no longer fitted and had to be replaced. This was a particular issue for women, where it was common for lipodystrophy to result in the top half of the body requiring a larger dress size than the bottom half.

I just put on weight. I was normally a size fourteen and then I put on weight to a size eighteen and then from there I thought I was putting on weight and I was doing exercise and then I stopped. My stomach was too big on the top part and the bottom side too small. You know you are just in

front of the mirror and you say no this is not me. It's someone else. (I 7, female, 33 years old)

(B) Psychological effects

Deleterious psychological effects were linked to lipodystrophy. For some, this meant preoccupation, depression, self-consciousness, and loss of self confidence and self esteem.

. . . very distressed about lipodystrophy . . . did not go out for months and months . . . stopped going to the gym . . . huge psychological problems . . . lost confidence socially. (I 6, male, 40 years old)

Others reported a more defiant attitude to the condition and to any negative reactions from others.

Warning for me not to go there, emotionally. Even if I don't like what's happening, it's my face, I have to live with this face. I can't let it not affect me, but I can't let it get to the point where it tortures me. (I 13, male, 61 years old)

Those with partners tended to report support and understanding, though the psychological effects of lipodystrophy could have a negative effect on intimate relationships, including problems with libido.

My partner is extremely good and the only comments he makes are affectionately teasing. He's very good about it. Fortunately he sees something in me beyond stunning body image. (I 2, male, 46 years old)

I went to a nude beach and sat down the whole time. I wouldn't stand up because I didn't have a bum. It was really boring. Without a doubt it affects my sexual confidence. I don't even consider sexual relations any more. (I 14, male, 39 years old)

(C) Indicator of HIV status

Lipodystrophy was seen as a new signifier of HIV status, especially among the homosexual community, which was deemed to be best informed about the condition. In this sense, it was perceived as the "Kaposi's sarcoma of the 21st century," as one respondent described it.

I always felt quite well but now you know, I mean I just feel like I have got AIDS stamped on my forehead. (I 8, male, 46 years old)

I am more aware of my status since this happened . . . more so than just taking the drugs. Because of lipodystrophy I look like a combination therapy user. (I 3, male, 36 years old)

Although respondents believed there to be low levels of awareness among the general public, it was considered to be only a matter of time before knowledge levels increased. This was particularly problematic for those concerned about HIV status disclosure. For those more open and confident about disclosing their HIV status, this was less of a concern.

You spot it yourself, your boyfriend, your friends, strangers. Because it follows certain lines. And so therefore I think I'm more aware of it. But general Joe Public? I doubt it, no. They realise that you look ill. People come up to you and say, "have you been ill?" (I 3, male, 36 years old)

(2) Impact on the social world of the individual

(A) Social functioning

The psychological and body image effects of lipodystrophy had an impact on social functioning. Most respondents reported narrowing their social worlds, even to the extent of shunning a social life.

I don't know if I can bring myself to go to the beach . . . I'm not worried about people thinking I might be HIV positive or have lipodystrophy, I'm just worried that I look horrible. (I 1, male 48 years old)

Especially if it is somewhere where I am going to meet a lot of people that I have not met before it would definitely stop me going to places and stop me going out. (I 6, male, 40 years old)

Yes it has completely changed because I can't go out. Whatever dress I put on I do not look good in it because here I am too huge in the top half and down here I do not have any. (I 7, female, 33 years old)

This narrowing of social life was especially noted in relation to homosexual men's attendance at popular gay venues, where body image was often perceived to be at a premium and where the manifestations of lipodystrophy were construed as a marker of HIV status. It was also seen as a barrier to new and casual sexual relationships, because of low self confidence and low self esteem, as well as resulting from reduced libido.

I look like a cube . . . I feel in a neurosis about it . . . sometimes I catch people staring at my face . . . As a gay man, feeling that you are attractive is a very important thing . . . if there is any such thing as the gay culture that is what it is around. (I 13, male, 61 years old)

It's my self image and how other people look at me. Public image I suppose. I'd rather be attractive than unattractive, and yes it (lipodystrophy) does affect my self confidence on that level. (I 5, male, 47 years old)

(B) Reaction of others

Although friends noticed and commented on the condition, those knowledgeable about HIV disease and its consequences were likely to be accepting and understanding, whereas those with limited knowledge were less so.

What with losing so much weight. I am having a lot of panics. If I'm with people who don't know, and not everyone knows I'm HIV positive, you just start making up little white lies, just trying to cover up, but it goes on so long people start to say "What's happened, you look awful?" (I 10, male, 28 years old)

I was a bit depressed I thought "oh it does show, people do notice." (I 4, male, 59 years old)

As noted above, a supportive partner was likely to have a protective effect on the individual.

He (partner) always says it's okay, you look alright. We've been together two and a half years. It's nice of him to say that I look alright, but to me I don't look alright. (I 10, male, 28 years old)

Reactions from strangers were liable to have a negative effect, such as casual remarks about change in weight and body shape. The women interviewed were especially sensitive in this area, particularly when casual comments were made about their body shape changes, which some mistook as early indicators of pregnancy.

Friends ask: "oh, are you pregnant?" (I 11, female, 30 years old)

One man felt he had been overlooked for promotion at work because of his appearance and plummeting self confidence. Responses from family members were varied and depended to some extent upon their previous attitudes towards HIV infection. Some noticed body shape changes and discussed these with the interviewee, others said nothing.

I try and fatten up if I'm going to go and see my mother because she worries. The last time I went over, I only heard this afterwards, that she sat up all night worrying with my elder sister about what was wrong with me. (I 9, male, 39 years old)

Many of these reactions led to isolation and poor social functioning of respondents. On the other hand, some were more sanguine about the effects and manifestations of lipo-

dystrophy and continued to live a full social life despite the reactions of others.

Oh yes, the pluses definitely outweigh the minuses. I wouldn't want to be a walking skeleton though. (I 9, male, 46 years old)

(3) Response of the individual

(A) Personal experience

For those who had been very ill before going on HAART or who had been through several treatment regimens, lipodystrophy was more likely to be accepted and seen as an unfortunate by-product of HIV disease and concomitant treatment.

I've been living with this thing for fifteen years, so well I am just grateful every day that I am still alive and I know without these pills I certainly probably would be dead, so it's striking the balance. (I 8, male, 41 years old)

These individuals seemed less likely to want to change treatment and/or take breaks from their current treatment regimens, though all had thought about this as an option.

I have thought of taking one of these drug holidays . . . but I know what it was like before I started taking these tablets. I was constantly sick . . . It was very depressing . . . The question is should you stop and risk getting sick again? (I 10, male, 59 years old)

I'd rather be alive and out there, rather than being lying half dead in hospital because I was so vain I stopped taking the drugs. (I 3, male, 36 years old)

For some the decision around medication and HAART was complicated by external issues, such as parental responsibilities.

I have to stay well for my kids, not taking medication is not an option. (I 11, female, 30 years old)

Indeed, some could see positive outcomes of lipodystrophy, such as increased levels of energy from improved diet and additional regular exercise. One even spoke of the positive benefits of early retirement that came as a result of his condition.

I just watch what I eat, but then again on the other side, it's made me eat, eat fatty stuff. It's pushed me towards joining a gym, which I need to do anyway, and I'm taking steroids which helps things along. (I 9, male, 39 years old)

(B) Practical response

Some had made no major changes in their lives as a result of lipodystrophy. Others had taken positive steps to ameliorate the condition, including eating more, joining a gym, taking steroids, and seeking plastic surgery (especially collagen injections in the cheeks of the face).

He (plastic surgeon) is going to fill the dips in the cheeks, which will help to reduce the lines, because my cheeks have gone down so much it's suddenly become very, very prominent. So that's what we're going to do. (I 3, male, 36 years old)

Others, convinced of the link between lipodystrophy and HAART, reported having taken breaks from drug therapy or trying new combinations of drugs. Less direct measures entailed joining a support group or buying new clothes to disguise the changes in body shape. A common response was to seek referral for additional psychological or dietary help.

My doctor referred me to see the psychologist and the dietitian. One for the head, one for the body. It's helped. (I 14, male, 39 years old)

(C) Relationship with doctor

Respondents reported an initial reluctance to speak with their doctor regarding actual or potential concerns about lipodystrophy, as it was perceived as trivial and wasting the doctor's

time. However, there was a general feeling that patients' concerns were listened to and that the doctors took them seriously, though it was sometimes felt there was not enough time in a routine consultation to address these issues and concerns.

I know someone whose doctor was virtually dismissive, you know this isn't an issue that we need to deal with, you've been through a lot of illness, you're lucky to be here really, you're on this combination therapy—you can't expect everything to be all right, you're just going to have to put up with it. But now, now there's a lot of people presenting with it and a lot of people are experiencing a lot of problems psychologically, and physically people are looking quite different. I think this is being taken seriously and that is validated for me that I am allowed to be worried about it and I don't feel it's me being neurotic. It's something important. (I 6, male, 59 years old)

All 14 respondents answered affirmatively to a general question about the need for more psychosocial support for those concerned about lipodystrophy.

The future

Worry and concern about the future was common, especially relating to uncertainty and fear about the longer term prognosis and development of lipodystrophy.

And of course with combination therapy coming along the whole ball game's changed. It's very odd, especially after so many years of not planning for the future. And other things to think about, like lipodystrophy. Resistance. Odd twists to it. Which sort of, I don't know, stirred things up a little more. Ignorance was bliss. (I 3, male, 36 years old)

More of a negative impact if I didn't take medication. I probably wouldn't be here . . . (Lipodystrophy) is a side effect or byproduct of being on combination therapy . . . one that I don't have any control over. I have a concern if it will affect my mobility. (I 12, male, 52 years old)

Anxiety was heightened by the perception that little is currently understood about the condition and that the metabolic complications have been linked to cardiovascular and other potentially serious medical conditions.

I am concerned that it gets worse. I don't even want to stay this way. I want to get a little better. (I 10, male, 28 years old)

On the other hand, those who had many years' experience of the complications of HIV disease, and especially those who had been close to death, were not unduly concerned about the future. Ultimately, and with all the caveats outlined above, a counterbalancing view was that the complications resulting from lipodystrophy were an acceptable, albeit undesirable, price to pay for longevity.

The side effects, I suppose are quite small, when you consider that I could be dead. (I 1, male, 48 years old)

In the middle of a tragedy you have to be able to laugh . . . Fat loss aside, terrible feelings aside, the greater thing is I want to stay alive and people will have to take me as I am. (I 13, male, 61 years old)

DISCUSSION

The psychosocial and lifestyle impacts of lipodystrophy reflect concerns raised more generally in studies of body shape change and body image. These range from preoccupation with the body (body cathexis) and behavioural elements (avoidance of situations where the body's perceived inadequacies are highlighted), to comfort, competence, predictability (or lack of it), as well as appearance.¹⁹ Lipodystrophy can negatively impact on body shape and functioning, raising issues of illness and mortality, and can have a detrimental effect on

relationships with others, not least because of fears about unwanted disclosure of HIV status.^{20, 21} Although it may be perceived as an unfortunate complication of HIV disease, our data confirm the recent studies referred to in the introduction which show lipodystrophy can cause physical and psychological discomfort, leading to reduced self esteem and self confidence, resulting in poor social functioning and social isolation. This stated, it should be noted that our sample was derived from those attending a large metropolitan HIV/STI clinic and we need to conduct similar qualitative, as well as complementary quantitative, studies among other groups from other settings. None the less, our data indicate the need for healthcare professionals to address these issues, be they related to diet, body image, HIV status disclosure, drug therapy adherence, or other issues. We need to work towards as clear a case definition as is possible in order to refer relevant patients to specialist help.²² A number of lipodystrophy clinics have already been established at existing HIV services, providing a range of services including psychological support, and advice on lifestyle issues such as diet and exercise. In this context we need to consider the place of patient involvement in antiretroviral treatment decisions.²³

Although our sample was clinic based, there is a suggestion from the data of the need to assess and respond to the differing experiences and needs of varying groups. For example, it is likely that responses to the needs of homosexual men and heterosexual women will diverge along certain lines and that the cultural imperatives of ethnic minorities around issues such as HIV status disclosure might need particular attention in light of lipodystrophy. To this end we need to conduct formative evaluations to assess and explore the potential for targeted interventions, including education and awareness raising programmes.

Authors' affiliations

R Power, Royal Free and University College Medical School, London, UK
H L Tate, Camden and Islington Community NHS Trust, London, UK
S M McGill, HIV Sexual Health Psychology Services, Camden and Islington Mental Health NHS Trust, London, UK
C Taylor, Royal Free and University College Medical School, London, UK

REFERENCES

- 1 **Palella F**, Dalaney K, Moorman A, et al. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *N Engl J Med* 1998;**338**:853–60.
- 2 **Qaqish R**, Fisher E, Rubkin J, et al. HIV associated lipodystrophy syndrome. *Pharmacotherapy* 2000;**20**:13–22.
- 3 **Van der Valk M**, Gisolf E, Reiss P, et al. Increased risk of lipodystrophy when nucleoside analogue reverse transcriptase inhibitors are included with protease inhibitors in the treatment of HIV-1 infection. *AIDS* 2001;**15**:847–55.
- 4 **Roche R**, Poizat-Martin I, Yazidi C, et al. Effects of antiretroviral drug combinations on the differentiation of adipocytes. *AIDS* 2002;**16**:13–20
- 5 **Madge S**, Kinloch-de-Loeos S, Mercey D, et al. Lipodystrophy in patients naive to HIV protease inhibitors. *AIDS* 1999;**13**:735–7.
- 6 **Carr A**, Samaras K, Burton S, et al. A Syndrome of peripheral lipodystrophy, hyperlipidaemia and insulin resistance in patients receiving HIV protease inhibitors. *AIDS* 1998;**12**:51–8.
- 7 **Carr A**, Samaras K, Thorisdottir A, et al. Diagnosis, prediction, and natural course of HIV-1-Protease-inhibitor-associated lipodystrophy, hyperlipidaemia, and diabetes mellitus: a cohort study. *Lancet* 1999;**353**:2093–9.
- 8 **Duckers NHTM**, Stolte IG, Albrecht N, et al. The impact of experiencing lipodystrophy on the sexual behaviour and well-being among HIV-infected homosexual men. *AIDS* 2001;**15**:812–13.
- 9 **Schrooten W**, Coleblunders R, Youle M, et al. Sexual dysfunction associated with protease inhibitor containing highly active antiretroviral treatment. *AIDS* 2001;**15**:1019–23.
- 10 **Martinez E**, Garcia-viejo MA, Blanch L, et al. Lipodystrophy syndrome in patients with HIV infection: quality of life issues. *Drug Safety* 2001;**24**:157–66.
- 11 **Collins E**, Wagner C, Walmsley S. Psychosocial impact of the lipodystrophy syndrome in HIV infection. *AIDS Read* 2000;**10**:546–50.
- 12 **Orlando G**, Guaraldi G, Murri R, et al. Does lipodystrophy affect quality of life? AIDS 2002 Barcelona XIV International AIDS Conference. Abstract code: ThPeB7340.
- 13 **Bello M**, Changes in sexual behaviour due to body image in people living with HIV: a pilot study. AIDS 2002 Barcelona XIV International AIDS Conference. Abstract code: ThPeB7337.

- 14 **Kendall T**, Perez-Vasquez H, Luna. Side effects and adherence to antiretrovirals by HIV-positive Mexican women. AIDS 2002 Barcelona XIV International AIDS Conference. Abstract code:WePeF6679.
- 15 **Stevens J**. About face. *Positive Nation* 2001;**73**:1-3.
- 16 www.hivline.com
- 17 www.thebody.com
- 18 **Glaser B**, Strauss A. *The discovery of grounded theory: strategies for qualitative research*. New York: Aldine, 1967.
- 19 **Vamos M**. Body image and chronic illness: a reconceptualisation. *Int J Psych Med* 1993;**23**:163-78.
- 20 **Chapman L**. Body image and HIV: implications for support and care. *AIDS Care* 1998;**(Suppl 10)**:S179-89.
- 21 **Tate H**, George R. The effect of weight loss on body image in HIV positive gay men. *AIDS Care* 2001;**13**:163-9.
- 22 **Carr A**, for the HIV Lipodystrophy Case Definition Study Group. An objective case definition of HIV lipodystrophy. Program and abstracts of the 9th Conference on Retroviruses and Opportunistic Infections. Seattle, Washington. Abstract 31. 24-28 February 2002.
- 23 **Marelich WD**, Johnston Roberts K, Murphy DA, *et al*. HIV/AIDS patient involvement in antiretroviral treatment decisions. *AIDS Care* 2002;**14**:17-26.



Have your say

eLetters

If you wish to comment on any article published in *Sexually Transmitted Infections* you can send an eLetter by clicking on the 'Submit a response' link at the end of each article. Your response will be posted on *Sexually Transmitted Infections* online within a few days of receipt (subject to editorial screening).

www.stijournal.com