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The phenomenology of body image in men living with HIV

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Abstract

Research into how people living with HIV or AIDS (PLWHA) experience and make sense of feared or actual body changes, such as lipodystrophy, is limited. The present study conducted in-depth interviews with gay men living with HIV. Interpretative phenomenological analysis (IPA) yielded themes across five domains. The ambiguity of early-stage lipodystrophy was a cause of distress. There was a drive to detect changes early, leading to anxiety, uncertainty and negative feelings about the body as well as possible misperception of change. In later stages, lipodystrophy was felt to be highly distinctive. Participants struggled to live with a shape that transgressed a body ideal. Feelings of loss of control were evident in both the increased ineffectiveness of strategies to maintain a desirable appearance and in the tendency for such changes to act as a visible marker of status. Conflicting feelings emerged in ideas of thinness and of health, with loss of fat seen as desirable in certain contexts.

The study builds on previous research suggesting that the high value of appearance, particularly within gay communities, may lead to extreme compensatory behaviours. HIV places increased risk on a group highly vulnerable to body dissatisfaction and eating disorders. The study concludes with a cognitive-behavioural model of body image for PLWHA, and suggestions for intervention. Further research is needed to validate the model and investigate whether the findings are generalisable. However, body image concerns should be acknowledged when addressing HIV-related health.

Keywords: HIV, body image, lipodystrophy, gay men

Introduction

Highly-active antiretroviral treatment (HAART) in the 1990s led to a dramatic decrease in mortality for Western PLWHA. These advances, however, have come at a cost, and side effects such as fat redistribution (lipodystrophy) and wasting (lipoatrophy) are prevalent. Such changes have been found to have detrimental psychosocial consequences. Gay men remain the group at greatest risk of HIV in the West, accounting for over 75% of new UK infections (Health Protection Agency, 2005).

Few studies have examined the impact of HIV on body image. Wagner and Rabkin (1999) found that the relationship between psychological wellbeing and nutritional status was mediated by perception and experience of body changes. Those who perceived greater weight loss showed poorer wellbeing. Tate and George (2001) found that perceived emaciation due to wasting was associated with avoidance of social activities and decrease in self-confidence. Gay men are at particular risk of negative body image (Conner et al., 2004; Siever, 1994; Silberstien, Mishkind, Striegel-Moore, Timko, & Rodin, 1989).

Lipodystrophy affects around half of HAART receivers (Milinkovic & Martinez, 2005; Tien & Grunfield, 2004), impacting on their quality of life, reducing perceived health and relationship confidence, and decreasing interest in and enjoyment of sex (Blanch et al 2004; Dukers, Stolte, Albrecht, Coutinho, and de Qit, 2001). It is associated with diminished self-esteem and depression (Collins, Wagner, & Walmsley, 2000), fear of stigmatisation, problems with dressing and social isolation (Blanch et al., 2007).

Self-perceived lipodystrophy is a significant predictor of poor body image (Huang et al., 2006; Santos et al., 2005), distress and nonadherence (Ammassari et al, 2002). Martinez, Kemper, Diamond, and Wagner (2005) found that a subjective measure of body image perception was more effective in predicting psychological well being and medication adherence than laboratory markers of disease progression.

Qualitative approaches may best capture the complex interactions between HIV, sexuality and body image. Qualitative research has attempted to capture complex lived experiences in other areas (e.g. Johnson, Burrows & Williamson, 2004; Osborn & Smith, 2006; Preston, Marshall, & Bucks, 2007) and has recently been applied to HIV (Beusterien, Davis, Flood, Howard, & Jordan, 2008; Persson, 2005; Power, Tate, McGill, & Taylor, 2003). This study explores the experience of body image in HIV+ gay men. It investigates how gay men identify and experience HIV- and HAART-related body changes, what meanings are applied to such changes and how they cope with them. Participants were interviewed in depth and Interpretative Phenomenological Analysis (IPA) was used to identify themes. Increased understanding of how body image of gay men affects the meaning attributed to HIV and HAART amongst health professionals may lead to better management and support for this population.

Method

Sample

Ten participants were recruited from an HIV Clinic in London. All were HIV positive and self-identified as gay. All were receiving HAART except one, who was shortly due to begin treatment. Seven were British and three were from Southern Europe. All spoke English fluently. The mean age was 49 (range 23-61). Time since HIV diagnosis ranged from two to 22 years. Six had received a diagnosis of lipodystrophy, two reported body changes as a result of the medication and one felt that there had been no changes. The participant not receiving HAART reported body changes due to HIV.

IPA (Smith, 1996) was employed for analysis. IPA aims to use participants' accounts to explore how participants make sense of their lived experiences (Smith, Jarman, & Osborn, 1999). IPA acknowledges that the insider perspective cannot be recognised directly as access is "both dependent on, and complicated by the researcher's own conceptions" (Smith et al., 1999).

A semi-structured interview schedule was developed covering: the participant's experience of body changes due to HIV, understanding of and the meaning made of lipodystrophy, the process of recognising body change, self-perception of body changes versus diagnosis and the interaction between sexuality and body image. Interviews were conducted by the first author (JK), lasted 60-90 minutes and were recorded and transcribed.

Recurrent themes across transcripts were identified and related themes were grouped together. Themes felt to be similar were collapsed into superordinate themes. A master list of themes and a narrative portrayal of themes was produced. To check the credibility of themes, the third author (LS) acted as auditor. After the final list of themes was produced, the auditor randomly chose three quotes for each theme and checked to see that they were good exemplars of the theme.

Results

Table 1 shows the master list of themes and sub-themes.

Insert Table 1 about here

Theme 1: Uncertainty and fear around body change

A major theme was the struggle to determine whether HIV/HAART-related bodily change was occurring. Many participants were concerned about lipodystrophy and much uncertainty appeared to surround signs of the syndrome and diagnosis. This contributed to fear about a process that was perceived as out of their control. Lack of a clear clinical definition led to confusion. Tension arose from the struggle to have concerns about body changes validated.

Limited interventions for lipodystrophy produced a drive to identify body changes early. Fear increased focus on the body and regular self-checking. Increased vigilance and anxiety meant body changes could be exaggerated or misperceived. A need for clear confirmation led participants to search for external evidence, such as interpreting others' stares. Some reported frustration that others did not recognise the lipodystrophy that they felt was highly visible.

Theme 2: Discordant ideas of thinness and health

Participants showed a general drive towards avoiding excess body fat (see Theme 4). A slim, muscular body was associated with "looking after oneself". In the context of HIV, ideas of thinness and health became confused. A longstanding drive towards a 'healthy' slimness clashed with the sudden HIV-related weight-loss. Weight loss became an indicator of serious illness. Participants reported witnessing AIDS-related wasting.

A diagnosis of HIV could lead to confused ideas of a desired body shape. With HIV, appearance became a less reliable indicator of health and there was a reliance on medical measures to inform the individual whether they were well or not. For many, there was discordance between medical measures (i.e. viral load or CD4 count) and appearance or subjective feelings of health. Prior to HAART, external appearance of PLWHA was closely associated with disease progression. In the context of HAART, participants struggled to accept that an 'ill' appearance could indicate the medication's efficacy and good health.

Theme 3: The body of lipodystrophy

Lipodystrophy involves body changes that are not uniformly distributed. Participants struggled to make sense of this unusual appearance. Participants differed as to which effect of lipodystrophy was more feared. Interviewees whose desired body image tended to be larger being more accepting of lipohypertrophy.

Attempts to reduce lipodystrophy using exercise tended to be unsatisfactory or even counterproductive, leading to frustration and reduced motivation. For some, however, exercise remained an important part of retaining a sense of control.

The disproportionate body shape was felt by many to be unattractive, even repulsive. It served to increase the stigma associated with HIV. Many highlighted the marked contrast between the lipodystrophy body and the body ideal. Lipodystrophy also caused fat loss in areas that were more valued for some, such as the buttocks for an 'active' gay participant.

Interviewees reported changes in dietary habits. For some, maintaining a healthy diet clashed with a need to increase calories to counteract weight-loss. Lipodystrophy led to the desire to gain fat in some areas, but lose it in others. Side-effects such as loss of appetite and fasting around medication made it harder to maintain a healthy diet. Some reported disordered eating patterns.

Theme 4: Lipodystrophy and the gay scene

For many, the HAART-related body changes were particularly significant within the urban gay male community. Many felt a pressure to attain a certain ideal body shape, particularly when socializing in gay bars and clubs.

The experience of having lipodystrophy on the 'scene' was uncomfortable for the participants, leading to feelings of exclusion. Interviewees felt that those with lipodystrophy had become a stigmatized subsection amongst HIV+ gay men. In the urban gay community, body image and sexual behaviour appeared to be intractably linked. Appearance was a means of attaining sexual partners, and sexual relations were a way of improving body image. There were mixed feelings as to whether the appearance of lipodystrophy should be normalised and thus more recognisable. Some were reluctant to raise body shape concerns with doctors for fear of appearing vain.

Many participants perceived the body changes as permanent, leading to feelings of loss of control and hopelessness. Some reported using muscle gain to compensate for fat loss. In addition, many participants felt conflicting drives towards thinness and towards muscularity.

Theme 5: The face of lipodystrophy

Facial changes were considered more significant than other body changes. There was an immediacy in recognition of facial lipoatrophy, unlike lipodystrophy elsewhere. Interviewees attempted to avoid looking at their bodies but there were moments when the face would be necessary, such as shaving.

The image of facial lipoatrophy was inextricably linked to HIV, particularly on the gay scene. The loss of control over disclosure of one's status contributed to feelings of powerlessness and sometimes despair. Many participants struggled to articulate what made the appearance of facial lipoatrophy distinctive and what conclusions uninformed others would draw if they saw it. The appearance was linked to premature ageing. Some reported, however, that fat loss could, in rare instances, produce a desirable, sexier look.

There were difficulties adjusting to the changing facial appearance. Some reported seeing their reflection in the mirror and not recognising themselves. The mirror image reflected changes that they were unwilling to acknowledge; their new identity as an individual who was HIV positive, with the accompanying problems of lipodystrophy.

The consequences of body dissatisfaction could be very serious. Some participants engaged in unhealthy behaviours to compensate for perceived body changes, such as excessive exercise, restrictive dieting, and anabolic steroids. For some, body shape was of such importance that discontinuing HAART as a method of suicide was raised as an option should lipodystrophy become severe.

Discussion

The present study explored the phenomenology of body image in gay men living with HIV. Identification of HIV-related body changes was a distressing experience for participants. The men expressed difficulties negotiating an ambiguous process. Uncertainty was inherent in identification of body changes, which contributed to feelings of loss of control and body dissatisfaction. Ultimately the men feared an identifiable and stigmatising body shape that transgressed a body ideal within gay communities. Overall the study lends support to a cognitive-behavioural model of body image (Cash, 2002), with identification of cognitive, affective and behavioural factors.

How are HIV related body changes identified and experienced?

The study indicated that identification of HIV-related body change was a complex and ambiguous process, vulnerable to misinterpretation and possible misdiagnosis. Many participants expressed difficulties ascertaining whether HIV-related body changes were occurring and a frustration in having concerns validated. These difficulties reflect the lack of a clear clinical definition (Kosmiski et al., 2003) leading to potential conflict between clinical diagnosis and self-diagnosis. Furthermore, the subtlety of early signs made it difficult to distinguish between pathological changes and 'normal' changes. This may have led to negative body image and/or misperception of bodily changes. In Figure 1, the cognitive behavioural model developed by Williamson and colleagues (Williamson, Stewart, White, & York-Crowe, 2002) has been tentatively adapted for gay men with HIV on the basis of previous research and the current study. The model outlines possible triggers and maintaining factors for body dissatisfaction (e.g. Adams, Turner, & Bucks, 2005) that arise from the process of identifying possible lipodystrophy.

INSERT FIGURE 1 ABOUT HERE

The model suggests that a number of proximal and immediate factors contribute to the development of appearance-related self-schema. As found in previous studies (Giles, 1997; Tiggeman, Martins, & Kirkbride, 2007; Yelland & Tiggeman, 2003) high body investment and significant actual-ideal body discrepancies within the gay communities were reported by interviewees. These may contribute to maladaptive appearance-related self-schemas such as overvaluing of shape or weight as a determinant of self-esteem (Cash & Labarge, 1996). Self-schemas and body image can be associated with mood (Cash, 2002) and external stressors can trigger and maintain negative body image. The many significant stressors associated with HIV diagnosis and being an HIV+ gay man are likely to contribute to negative emotion (Hughes, Jelsma, Maclean, Darder, & Tinise, 2004). Many participants reported great anxiety on commencing HAART, often due to fears of side effects including LD.

According to the CB model, body dissatisfaction arises when a trigger clashes with maladaptive, or dysfunctional, appearance-related self-schemas (Cash, 2002). Williamson and colleagues (2002) outline a number of possible stimuli that feed into appearance-related self-schema, and these appear to be manifest for PLWHA who fear the onset of lipodystrophy. These include increased focus on the body, body checking, interpretation of ambiguous stimuli and self-referent tasks. Aspects of living with HIV serve to increase body focus and eating focus, such as regular weight-checks,

fasting around some medication, fluctuations of appetite, and in weight due to secondary infection. Furthermore, the necessity to detect lipodystrophy early may exacerbate body focus. Difficulties distinguishing between 'normal' body changes and lipodystrophy may lead to increased body focus and body checking in an atmosphere of anxiety and uncertainty. The CB model proposes that negative external stressors, individual characteristics, and stimulus may feed into maladaptive appearance-related self-schema.

Appearance-related self-schema process information that is relevant or perceived to be relevant to appearance (Cash, 2002). These schema can lead to cognitive distortions or biases in how information is processed. These cognitive biases serve to maintain maladaptive schema and, in turn, body dissatisfaction. Various cognitive biases have been identified (Williamson et al., 2002) and a number of these were experienced by the interviewees (e.g. attentional biases, selective attention, and catastrophic thinking). Further research is required to test the different elements of the model amongst gay men with HIV.

How do participants make sense of HIV-related body changes?

The present study also explored the meanings associated with HIV-related body changes. A central theme related to discordant ideas of thinness. Many interviewees struggled to differentiate between 'desirable' and 'undesirable' thinness. A 'thin ideal' has been found to be a key component of eating disorders and has been associated with ideas of health and self-control (e.g. Cafri, Yamamiya, Brannick, & Thomson, 2005; Rand & Wright, 2001). A drive towards thinness has been recognised in gay male populations and associated with disordered eating and compensatory behaviours (Silberstein et al., 1989; Yelland & Tiggeman, 2003). In the present study, ideas of thinness became more complicated in the context of HIV. The body shape changes caused by HIV/HAART were particularly significant for gay men. Loss of sexual attractiveness was as much a source of distress as loss of control over HIV disclosure.

Facial lipoatrophy was the most recognisable physical manifestation of lipodystrophy. It led to fears about loss of control over HIV disclosure within the gay community and a sense that facial lipoatrophy appeared 'unhealthy' in a more vague sense to those outside the gay community. This raises questions as to whether attempts should be made to raise awareness of lipodystrophy. Facial lipoatrophy was also associated with a prematurely aged appearance leading to difficulties distinguishing between normal ageing and possible signs of lipodystrophy.

How do gay men living with HIV cope with perceived HIV-related body changes?

Participants had adopted several strategies to regain a sense of control. Exercise and dietary changes were commonly used to try to alter appearance. These strategies tended to have limited effectiveness, however, leading to frustration and potentially unhealthy changes in eating behaviour.

The study identified certain strategies used to reduce recognition by others and themselves of body changes (e.g. growing a beard, using clothes to camouflage appearance). According to the CB model, these behaviours arise from cognitive biases that serve to maintain negative body image (Cash, 2002).

Limitations

The present study used a qualitative methodology, and is hence subject to limitations that apply to qualitative research in general (Elliott, Fischer, & Rennie, 1999). For instance, controlled studies would be necessary to provide evidence of trigger factors, causality and interactions. IPA focuses on the lived experiences of the individual, which allowed the present study to explore in depth a novel area of research and attempt to capture experiences previously unrecognised. The themes that emerged are specific to the individuals and the context. However, the identification of recurrent themes across transcripts allowed for limited generalisation to others in similar contexts.

Implications

It is hypothesized that cognitive-behavioural interventions may be useful in reducing distress that may arise from perceived HIV-related body changes. Such interventions could focus on cognitive biases, identifying and challenging selective attentional and memory biases (e.g. excessive attentional focus on specific areas or reinterpretation of feedback received from others). CBT may use cognitive strategies to challenge perceived deficits with one's own appearance. Possible 'safety behaviours' (Salkovskis, 1985), such as avoidance and camouflage behaviours (Veale et al., 1996), were identified in participants' strategies to cover one's face or avoid bright lights in bars. These may be challenged using behavioural exposure to social situations and self-exposure (Veale et al., 1996). In addition, for those with more severe symptoms of LD, CBT has been found to be effective at reducing anxiety and depression for those with body disfigurement (Rumsey & Harcourt, 2004).

Conclusions

Prospective and actual body changes that result from HIV and HAART are a significant preoccupation for PLWHA. Onset of lipodystrophy is a major concern and a high degree of uncertainty surrounds identifying HIV-related changes. Although many positive coping strategies emerged from the study, the high value of appearance, within gay communities may lead to extreme strategies to maintain appearance. Increased awareness of the situation is needed and there is a need to acknowledge body image concerns when addressing HIV-related health. The reluctance of men living with HIV to raise appearance concerns increases the need for normalisation and access to support. High body investment and history of negative body image may be linked to adjustment difficulties and treatment adherence. The proposed cognitive-behavioural model provides suggestions for intervention. Further studies are needed to validate the model and investigate its generalisability.

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Table 1: Master list of superordinate and subordinate themes.

SUPERORDINATE THEMES	SUB-THEMES	Data Extract
1. Uncertainty and the process of identifying body change	1. Uncertainty over diagnosis of LD 2. Fear and habitual body checking 3. Ambiguity and sudden change 4. A need to detect early 5. Distorted perspective of body changes 6. Search for objective evidence of body changes	<i>"...I gave [the diagnosis of LD to myself quite a long time before anyone else would accept it"</i> <i>"...it was always on my mind"</i> <i>"It was something I noticed before they did"</i> <i>"I told myself not to let it dominate what I did... but at the same time I didn't want it to get out of hand..."</i> <i>"I think I was amplifying [the side-effects]...making them bigger in my mind"</i> <i>"... my watch was more loose..."</i>

	<p>7. Reliance on and misinterpretation of feedback from others</p> <p>8. Rumination on body shape and reminders</p> <p>9. Loss of control and passivity</p>	<p><i>"...it's beneficial to have subjective viewpoints..."</i></p> <p><i>"My problem is that I'm conscious of it all the time"</i></p> <p><i>"...we are live experiments... when it goes wrong, it's difficult"</i></p>
<p>2. Discordant ideas of thinness and health</p>	<p>1. A drive towards slimness</p> <p>2. Wasting and the image of AIDS</p> <p>3. Conflicting feelings towards weight gain</p> <p>4. The diseased body and confused ideas of health</p>	<p><i>"[Thin is] to be accepted... to be attractive..."</i></p> <p><i>"He died away as a skeleton... like the air going out of a flat tyre"</i></p> <p><i>"But at the same time possibly people might think 'That's a nice, slim looking body'..."</i></p> <p><i>"I felt a lot better when I was dying than I do now..."</i></p>

<p>3. The body of lipodystrophy</p>	<ol style="list-style-type: none"> 1. A disproportionate shape 2. Frustrated efforts to reduce disproportion 3. Transgression of a body ideal 4. Increased dietary focus 	<p><i>"No-one I know has this distinct body shape... this disproportion..."</i></p> <p><i>"I can't put any weight on the bottom half... it's all on the top"</i></p> <p><i>"You look like a stick with a paunch"</i></p> <p><i>"... the binging goes on because I realize I'm so hungry..."</i></p>
<p>4. Lipodystrophy on the gay scene</p>	<ol style="list-style-type: none"> 1. Gay males and high body investment 2. Shunned from the gay scene 3. The body and sexual behaviour 	<p><i>"You must look good in order to get by"</i></p> <p><i>"...when I looked horrendous I couldn't possibly face people laughing at me"</i></p> <p><i>"...trying to socialise again, body image seems to be very very important... again"</i></p>

	<p>4. Body competition with partner and others</p> <p>5. High value of muscularity</p> <p>6. HIV and a loss of muscularity</p> <p>7. No universal body ideal on gay scene</p> <p>8. An internal source of body image</p> <p>9. Vanity of body image concerns</p>	<p><i>"I'm constantly comparing myself to everyone... even when I'm at the gym..."</i></p> <p><i>"It's more agreeable to look at a statue that is well-carved than a block of meat..."</i></p> <p><i>"I worked hard to look in really good shape... that's just about evaporated"</i></p> <p><i>"...these new bear clubs are specifically for guys that are rather big"</i></p> <p><i>"It's a stain in your brain... more the way you feel about yourself"</i></p> <p><i>"I always feel a bit loath to go on about it... I think [my doctor] thinks I'm a little bit vain"</i></p>
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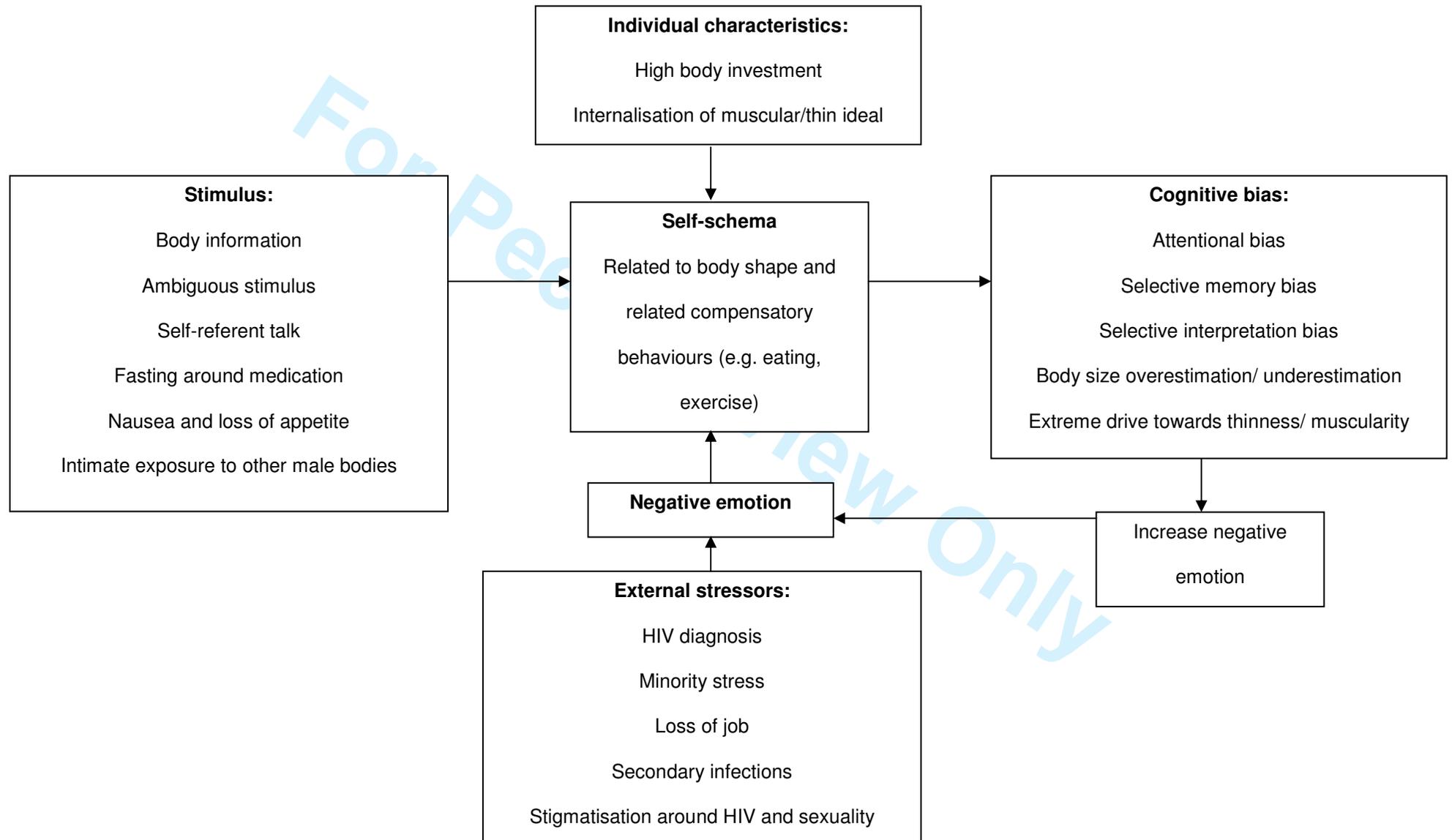
<p>5. The face of lipodystrophy</p>	<ol style="list-style-type: none"> 1. Prominence of the face 2. Lipodystrophy as a marker 3. Articulating the appearance of facial lipoatrophy 4. Facial lipoatrophy and premature ageing 5. Facial attraction 6. Lipodystrophy as a fashionable look 7. A changing identity 	<p><i>"My main concern was the face..."</i></p> <p><i>"It's like a badge of office... It's wearing a biohazard tattoo... to declare their status"</i></p> <p><i>"people know there's something wrong... it's not a sign of health"</i></p> <p><i>"It's premature elderly..."</i></p> <p><i>"The face is the first thing you notice in a person"</i></p> <p><i>"...there were some benefits... I had this chiseled jaw... it was sexier..."</i></p> <p><i>"when people say 'look in the mirror and a stranger looks back" and it really was"</i></p>
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	<p>8. A mirror of the mind</p> <p>9. New fill and reduced visibility of LD</p> <p>10. Difficulty getting support from others</p> <p>11. Taking risks to alter appearance and high value of appearance</p> <p>12. A positive outlook</p>	<p><i>"I got this fierce, stern look... I looked really mean"</i></p> <p><i>"It stops you looking gaunt but... it changed my look altogether"</i></p> <p><i>"I didn't really have any friends in the same boat"</i></p> <p><i>"... if things get to much for me I ultimately have the option of opting out"</i></p> <p><i>"It made me realize how human I am and... at the end of the day I'm not that worse than anyone else"</i></p>
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Figure 1: A proposed cognitive-behavioural model of negative body image as it applies to PLWHA (adapted from Williamson et al.'s (2002)

information processing model of eating disorders)



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