# RESEARCH

# BODY REPRESENTATIONS OF PEOPLE WITH HIV/AIDS: BETWEEN VISIBILITY AND SECRECY

REPRESENTAÇÕES DE CORPO DE PESSOAS COM HIV/AIDS: ENTRE A VISIBILIDADE E O SEGREDO REPRESENTACIONES DEL CUERPO DE PERSONAS CON VIH/SIDA: ENTRE LA VISIBILIDAD Y EL SECRETO

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# **ABSTRACT**

Major advances have been made in public policies for the treatment of AIDS; however, from the point of view of PLWHA, there were few changes in relation to the stigma attached to the disease. Physical changes due to the use of multi antiretroviral drugs (ARV) make the disease visible and, in consequence, change people's social relations and the experience of corporeity. The present study aims at understanding how those body changes are perceived and experienced by PLWHA. Data was collected through in-depth open-ended interviews that were afterwards transcribed and analyzed using the structural analysis of narratives. The representations identified were divided in two categories: 1) body being treated and visibility of the disease; 2) secrecy and prejudice in the experience of corporeity. Both are supported by representations concerning *Visibility* and *Secrecy*, which constituted the theoretical categories of this study. Secrecy is central to the interviewee's experience of corporeity. Health education in secondary prevention through the promotion of actions based on building a positive body image can improve PLWHA quality of life, as well as their social and affective interactions.

Keywords: Body Image; Acquired Immunodeficiency Syndrome; Prejudice; Delivery of Health Care; Nursing Care.

#### **RESUMO**

Muitos avanços ocorreram no campo das políticas públicas e do tratamento da AIDS, porém, do ponto de vista das PVHAs, poucas mudanças foram percebidas em relação ao estigma da doença, que pode, por meio das transformações corporais devidas ao uso da TARV, torná-la visível, modificando suas relações sociais e a vivência da corporeidade. Compreender como as mudanças corporais são percebidas e vividas pela PVHA, do ponto de vista da pessoa infectada, é o objetivo deste estudo de caso. A coleta dos dados foi realizada por meio de entrevista aberta em profundidade que, depois de transcrita, foi analisada, utilizando-se o método de análise estrutural da narrativa. As representações identificadas e organizadas resultaram em duas categorias: a) corpo em tratamento e visibilidade da doença; b) segredo e preconceito na vivência da corporeidade. Ambas se sustentam pelas representações relativas à visibilidade e segredo, que se constituiu na categoria teórica deste estudo. O segredo é central na vivência da corporeidade da entrevistada. A educação para a saúde na prevenção secundária nos serviços de saúde, com a realização de ações fundamentadas na construção de uma imagem corporal valorada das PVHAs, pode trazer qualidade e suporte de vida plena a essas pessoas, com a melhoria da qualidade de suas interações sociais e afetivas.

Palavras-chave: Imagem Corporal; Síndrome de Imunodeficiência Adquirida; Preconceito; Assistência à Saúde; Cuidados de Enfermagem.

#### RESUMEN

Últimamente ha habido muchos avances en el campo de las políticas públicas y del tratamiento del sida. Sin embargo, desde el punto de vista de las personas que viven con sida, se han constatado pocos cambios en relación al estigma de la enfermedad que puede, por medio de transformaciones corporales debido al uso de la TARV, hacerla visible, modificando sus relaciones sociales y la vivencia de la corporeidad. El objetivo de este estudio de caso es entender cómo las personas que viven con sida sienten y manifiestan dichos cambios corporales, desde el punto de vista de la persona infectada. La recogida de datos se llevó a cabo por medio de entrevistas abiertas en profundidad que, después de transcritas, fueron analizadas, utilizando el método de análisis estructural de la narrativa. Las representaciones identificadas y organizadas resultaron en dos categorías: a) cuerpo en tratamiento y visibilidad de la enfermedad; b) secreto y prejuicios en la vivencia de la corporeidad. Las dos categorías se basan en las representaciones relativas a la visibilidad y al secreto, que se constituye en la categoría teórica de este estudio. El secreto es central en la vivencia de la corporeidad de la entrevistada. La educación para la salud en prevención secundaria en los servicios de salud, mediante acciones que ayuden a construir una imagen corporal valorizada de las personas que viven con sida, puede brindarles calidad de vida y respaldo para una vida plena, mejorando sus interacciones sociales y afectivas.

Palabras clave: Imagen Corporal; Síndrome de Inmunodeficiencia Adquirida; Prejuicio; Prestación de Atención de Salud; Atención de Enfermería.

# INTRODUCTION

Major advances have been made in public policies geared towards the treatment of AIDS; however, from the point of view of people with HIV/AIDS few changes have happened regarding the stigma attached to the disease.<sup>1</sup>

Early on the syndrome was associated with sexuality, specific social groups and moral values; it meant imminent death and gave rise to prejudice against those infected with the virus. Fear of prejudice brought changes to the life and, specifically, to the social relations of these people, reducing their quality of life.<sup>2</sup>

The initial invisibly of the infection becomes visible to the infected person through signs and symptoms and the effects of the treatment. At its beginning, the disease had no treatment or cure; visibility was characterized by unintentional weight loss in its acute phase and a quick death.<sup>1</sup>

From 1998, free antiretroviral (ARV) therapy in Brazil turned AIDS into a chronic disease. The programme provided treatment and a better quality of life for those infected; scientific advances offered hope for a cure. Still, its chronicity brought challenges to PLWHA, such as perceived body changes that can hinder the treatment.

Lipodystrophy, characterized by impaired glucose metabolism, insulin resistance and dyslipidaemia, as well as an abnormal distribution of body fat (visually noticeable by thinning of arms and legs and fat accumulation in the dorsal and central regions) is one of these changes.<sup>3</sup> The visibility of the lipodystrophy is considered by PLWHA as a sign of infection in their body, an indicator of the disease that has an impact on their psychosocial well-being; it is a source of personal and family conflicts and, in some cases, affects negatively the adherence to treatment.<sup>3</sup>

Body image, socially constructed by the individuals, involves different types of relationships and interactions established in family and work contexts, as well as in personal relationships and it constitutes their corporeity.<sup>4</sup> According to Le Breton, this image is the representation individuals make of their own body that can be perceived roughly from their social and cultural context and is individualized by their personal history; it describes their worldview, defines and supports their identity, known as corporeity. It asserts itself as the truth about oneself and is revealed in social interactions: the body is considered an inseparable element in any relationship with oneself, with other bodies and the objects of one's world.<sup>4</sup>

PLWHA build strategies for being in the world like a game of hide and show, to make explicit or to keep silent about the infection, the falling ill and the physical changes caused by the process. PLWHA hide their body to keep the secret about the infection as a way of self-denial, avoiding any prejudice regarding their condition. People with AIDS live with the stigma of the disease and the fear of being discredited both for the physical awareness of the disease and the moral judgements that surround it.<sup>6</sup>

How do individuals live with such visible marks in the body that may reveal their condition at any time? This case study aims at understanding how body changes are perceived and experienced by PLWHA. Researchers consider the narrative as the basis for identifying the social construction of health and disease, especially AIDS, including the reorganization of life strategies, from the perspective of the infected person.

#### **METHODOLOGY**

Qualitative case study that emphasizes an in-depth understanding of an event, fact or social experience through the individual experience of the study subjects and the interpretation of the meaning they assign to it. The study assumes that individuals reconstruct representations of a given object in their everyday life and in established relationships. Such representations are their perspective on the object experienced and are sensed by the individuals in its complexity, uniqueness and contradictions and represent an explanation, justification and understanding of their context, through their narratives.<sup>8</sup>

This study is part of the research "Representations of the body of people with HIV/AIDS: the construction of corporeity" carried out at a public local referral service for the control and treatment of AIDS in Belo Horizonte. The research was carried out with 14 people aged over 18 years, who agreed to participate after signing the Term of Informed Consent. Data was collected through in-depth open-ended interviews recorded in audio; the guiding question was: I would like you to tell me how you perceive your own body before and after the HIV infection.

Glimpses on their love, sexual, and family life, as well as social interactions allowed researchers to go deeper in the narrative process, to bring out the body of representations and experience of PLWHA corporeity. The study subjects filled in an identification form with personal data (sex, age, marital status, family context and income), as well as data about diagnosis and ARV therapy to support the narrative analysis of their context that could contribute to a better interpretation of all body representations. Medical records provided extra information on the clinical treatment and confirmed the diagnosis of lipodystrophy. The research was approved by the Ethics Committee of the Municipality of Belo Horizonte and the Federal University of Minas Gerais (protocols No. 0555.0.203.410-10 and No. 0555.0.203.000-10, respectively). Resolution 196/96, applicable at the time of data collection, was observed. The participants were identified by a code, ensuring thereby their anonymity. The participant of the present study is identified by letter M.

Data analysis was based on Demazière and Dubar's<sup>9</sup> structural analysis of narratives. Its principle is that everything in a person's discourse has a meaning that is constructed on the relationship with the interviewer, the comings and goings of the narrative, the disjunctions and conjunctions of objects. Such discourse reflects facts,

judgments and explanations and reveals relationships with people and institutions that are part of the person's context, showing world views and revealing representations of the objects in question.

The researcher's interpretation begins with a reconstruction from the individual's line of reasoning that leads to the construction of theoretical categories unveiled through the reported situations, as suggested by the *grounded theory*.<sup>10,11</sup> Therefore, priority should be given to field data, in this case, language that reveals the formulation and categorization performed by the respondent, which defines the researcher's analytical stance. It differs therefore from illustrative or conservative approaches present in other types of research<sup>12</sup>

A first level of analysis identifies sequences (S) through discourse aggregators that show reported stories and facts (F). Each sequence has a second level of actions identifying players (P) according to their significance to the respondent.

A third level of analysis reveals that within each sequence there is a "level of narration" where the individual presents his arguments to convince the interlocutor: explanations of facts, world views and justifications (J). This case study uses narrative analysis which allows for the investigation of a complex social phenomenon within the context of "real" life.<sup>7</sup>

# **RESULTS AND DISCUSSION**

The study subject is a female patient (M., aged 51) treated at a public health care unit and recruited randomly during her monthly follow-up. After the final analysis of the interviews, researchers considered that, among the interviewees, the selected patient represented the "ideal type", according to

Demazière and Dubar's° structural analysis of narratives. The interview transcription enabled the sequencing of the narrative (Table 1), the identification of situations and facts (F), their players (P), and justifications (J) for her actions and ways of thinking in the face of the situations described.

The above analysis synthesized the interviewee narrative, which allowed the unveiling of her representations, systematized in Figures 1, 2 and 3.

The representations identified by the structural analysis of narratives resulted in two categories: a) body being treated and visibility of the disease; b) secrecy and prejudice in their living of corporeity, which provided an understanding of their daily experience of fear, changing social interactions and the experience of corporeity. These categories are based on the representations of *visibility* and *secrecy*, theoretical categories of this study.

# BODY BEING TREATED AND VISIBILITY OF THE DISEASE

Since the diagnosis of HIV infection, M. began antiretroviral therapy (ARVT) and physical changes were noticed almost immediately. Fear of being exposed by the visibility of the disease began to "terrify her":

[...] many differences since I started the treatment. Muscles and arms started to sink; the leg was the worst! Arms and legs were getting thinner; the midriff fatter. [...] I felt total despair [...] I am afraid of prejudice, I am afraid people will notice my thinness... they may guess what I have. I feel hopeless! (M.).

Table 1 - "Deconstruction" by sequences of M.'s interview on corporeity and HIV/AIDS infection with facts, players and justifications

Facts (F)	Players (P)	Justifications (J)
F1- 51 years old; hates her body now.	P1- Narrator	J1- Liked her body before the diagnosis of infection and treatment J2- She was "plump" but thought herself "beautiful" J3- Now considers her body deformed and ugly, because she has thin legs and is "too slim"
F2- Secrecy about the disease	P2- Mother/Family P3- Co-workers	J4- Fear of prejudice J5- Protection against distress that knowledge about the disease can cause
F3- Lipodystrophy	P1- Narrator	J6- Visibility of the disease
F4- Social and family withdrawal	P3- Co-workers P2- Mother/Family	J7- Fear of being exposed J8- "Pain" when characterized as thinner than before
F5- Gym attendance	P1- Narrator	J9- Justifies alleged thinness
F6- No sexual partners since husband's death	P4- Husband died 15 years ago	J10- Sadness over infidelity and transmission of HIV infection
F7- Sadness over the disease	P1- Narrator	J11- Lipodystrophy and body changes
F8- Source of infection	P4 – Husband	J12- Husband only sexual partner
F9- ARV	P5 Children/Granddaughter	J13- Gave her the hope to see them grow
F10- Disclosure of diagnosis	P6- Sister /confidant	J14- Needed someone to unburden herself

Source: M.'s interview, female, 51 year old, HIV- positive – case study.

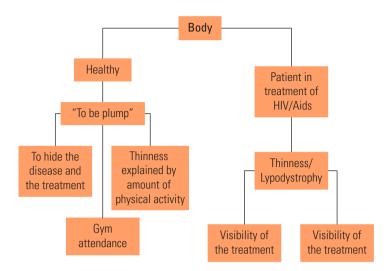


Figure 1 - Body representations of PLWHA in ARV treatment.

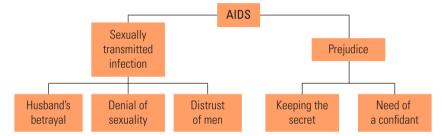


Figure 2 - Representation of AIDS in PLWHA in ARV treatment.

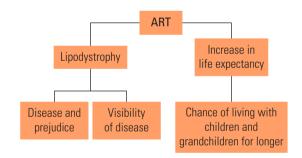


Figure 3 - Representation of ART of PLWHA in ARV treatment.

The subject's values and body patterns changed throughout her life. Obese in adolescence, being considered skinny (a compliment in other circumstances), became a source of sadness after diagnosis:

[...] before getting the virus or using the drugs, when someone said: how thin you are! I thought it wonderful! Nowadays when they call me skinny, I feel it is the end of the world [...]. If someone tells me "you are too thin", I feel like dying! (M.).

ARV treatment and infection changed her body, which became a showcase for the disease that she tried to hide fearing

prejudice. Blashill's study<sup>13</sup> reveals that quality of life of PLWHA is hindered by lipodystrophy and that they are twice as likely to experience fear of being recognized as HIV-positive because of their physical appearance.

Lipodystrophy is central to psychosocial issues related to the side effects of ARV treatments. Characteristic physical changes of HIV infection and its implications on people's lives were associated to fear of prejudice<sup>13</sup> and to changes in the individual's social interactions<sup>14</sup>: they prefer not to socialize for fear of being exposed. The new figure is not accepted because it breeds prejudice usually coming from the infected individuals themselves: "I reject my body, I find myself horrible!" (M. after ARV treatment)

PLWHA associate lipodystrophy to a negative body image that changes their social interactions and leads to social and family isolation. Feelings about body shape changes influenced M.'s way to dress given her embarrassment about her body and about what it may reveal and caused withdrawal and sadness.

I don't wear skirts anymore; only trousers; even in the gym I don't wear shorts. When I am due to a health check I have to wear shorts and for me this is the end of the world, I think everyone is looking at me; I think my legs are too

thin. [...] I feel sad! Sometimes people say I look sad; but I am living like that; I do not only look sad, I am sad... I think fear made me withdraw, and then it became sorrow (M.)

The negative self-image and a body representation that can reveal the disease brought in the need to slow down and even reverse changes caused by lipodystrophy through physical exercise. The physiological and psychological benefits of physical activity to PLWHA are already known.<sup>15</sup> In this context, however, it is associated not only to a better health and improved quality of life, but to the possibility of hiding or justifying physical changes that may be noticed by others. Being overweight is, for M., to disguise the existence of the disease, even to herself: "I liked to weight 59 kg. After I began ARV therapy I was happy with 61 kg, but it's been years since I weighted 61, I get so sad" (M.)

ARV treatment is represented by M. as a necessary evil lived paradoxically: she shows sadness but feels delighted with the prospect of living longer and enjoying family life.

The downside of side effects is that it hurts a lot: your body changes, your face changes and sadness, fear of people finding out come together. [...] I saw my children grow up, study; my son getting married, I have a granddaughter, so that's good; I'm sure I wouldn't be here if I hadn't taken the drug (M.).

Lipodystrophy meant a decrease in social interaction, social isolation and difficulties in treatment adherence, common in this type of therapy.<sup>3,16</sup>

# SECRECY AND PREJUDICE IN THE EXPERIENCE OF CORPOREITY

Secrecy about her condition and social life restriction demonstrate M.'s fear to be rejected and questioned as a professional, mother and person, because the patient's body ends up being judged as harmful, unwanted and unappreciated.<sup>6</sup> Social withdrawal is a way of keeping the secret; the need to share her suffering meant that M. needed a confidant which took two years to make an entrance.

[...] When I received the results [the positive HIV test] I became desperate! I told no one for almost two years; when I realised I couldn't stand it anymore, I told my sister [...] only she knows. When I want to talk to someone, I call her [M.].

Social withdrawal caused by fear of being identified as HIV-positive and consequent discrimination were revealed in Renesto's study<sup>17</sup> of infected women that even without lipodystrophy diagnosis, feared being stigmatized.

The Greek word *stigma* indicates the moral status of those individuals with a physical mark that identifies them as different from others.<sup>7</sup> Avoiding being stigmatized, discriminated against or socially degraded is always present in the lives of people with HIV/AIDS, a contagious disease associated with certain behaviour and groups against whom prejudiced attitudes prevail<sup>16</sup>, as demonstrated below:

[...] I was in hospital for 11 days and the doctor told me I was going to be tested [for HIV diagnosis]. I was not worried, because I had no partners, had not had a blood transfusion, I wasn't a drug user; I thought I was not in the so-called risk group, right? Now I think such no risk groups do not exist anymore (M.).

According to M. she got the infection through her husband, given that he was her sole sexual partner. After being diagnosed as HIV seropositive, she denied her sexuality renouncing to live an important dimension of her corporeity. When talking about her current desire for sex, her explanation referred to one of the illicit types of secret present in the interactions: her husband's betrayal. M.'s sorrow justifies her rejection of sexual relations: "No. It was such a shock! I loathe it! If my late husband was alive I'd kill him! I bear an intense grudge against him [...]" (M.).

Another study examined the impact of the disease on the active sexual life of adult infected women. However – unlike the present research which links the origin of the infection to sexual intercourse with a regular partner – it is justified by the stigma attached to the disease, the concern with body image and the refusal to disclose the condition. For M. secrecy about the infection means rejection of the previous married life: to expose her condition is to reveal a negative and shameful relationship with her husband.

Keeping her condition a secret is also, in M.'s representation, a way of sparing her family, because knowledge of her situation would be painful to them: "When I saw her distress [her sister's] I thought, 'and if I told my mother and my father? No need to tell them now" (M.).

Surkan's<sup>19</sup> study reveals that HIV/AIDS-related stigma affects infected individuals and their families alike. The secret, kept as protection, is revealed only when support is considered necessary. "[...] I do not hide my condition from the doctors; as soon as I see them I warn them: my family does not know and I do not want them to" (M.).

What is said and unsaid of the representations mediate the visible and the invisible as to protect the secret.<sup>20</sup> Keeping the infection a secret is legitimatized as safeguard against social prejudice, allowing such people to socialize with friends and family, even if only occasionally. The keeping of secrecy, interpreted in this case study as central to the experience of cor-

poreity, was not a determining aspect in other studies in which people with HIV, who revealed their condition to family and friends, were more adherent to treatment, did not regret having revealed it and could also benefit of an extended network of social support.<sup>21,22</sup>

The theoretical categories that emerged from the representations focused on the study subject are *visibility* and *secrecy. Visibility* is presented as the stigma of the disease, even if it is associated with the "possibility of recognition", that could turn the individual into a discredited person<sup>17</sup> which bears signs that could alienate people if they are identified as an infected body, i.e. the body undergoes a value judgment that defines it as harmful and socially devalued. In this sense, secrecy is a form of protection legitimized by the person's intimate zone.<sup>20</sup>

M. expresses her arguments through representations of what she thinks about herself and what she thinks people think about her body, after those physical changes brought about by ARV treatment.

The body is the result of social and cultural influences, as well as the individual's personal history, which can determine experienced interactions. It is, therefore, an image seen by the eyes of others; representation individuals make of what they think others think of them.

The physical changes perceived by PLWHA give a social meaning to the disease, because they reveal the ambivalence of visibility not only as stigma and prejudice, but also as an undesirable or unlovable body. Health services actions to relieve body changes and the creation of spaces for the expression of fear of possible physical changes, supervised by health professionals, can reduce anxiety and distress: visibility of the disease, even if only imagined, makes sense for people with HIV/AIDS.

The secret is the unfolding of the dichotomy between the disease's visibility and invisibility, which includes its denial for many infected people that, according to Taylor<sup>23</sup>, is a way of keeping the secret from oneself. In M.'s case, keeping the secret preserves her autonomy as a social subject, even if to keep it means to deny important aspects of her corporeity.

# **CONCLUSION**

The use of structural analysis of narratives aimed at unveiling the representations of health/disease and HIV/AIDS treatment was relevant to the present case study. It enabled an indepth interpretation that encompassed several psychosocial aspects of the experience of the research subject.

Results demonstrate that the living of corporeity is changeable because the experienced relations change significantly in the social and family context as well as in sexual interactions. Results showed that the body is the object that identifies people and, as such, is a showcase of their experiences.

Physical changes experienced and perceived were directly related to lipodystrophy. The latter represents the physical visibility of the disease that, when seen by others, can present the individual as a lessened being, subject to stigma and discrimination and therefore socially discredited.

The secret then becomes central to the living of the subject's corporeity; mediated by the conflict to preserve his identity or disclose himself as a sick person, transmitter and accountable for a promiscuous sexual behaviour. Thus, it can be said that even representing the body as showcase of his condition, it is the word that defines the disclosure.

Actions that aim at the building of a valued body image of PLWHA are central to reconstruct a culture where corporeity is lived and expressed. Health education in secondary prevention, focusing on representations and carried out by trained professionals can improve quality of life and the quality of social and affective interactions of people with HIV/AIDS.

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