Lipodystrophy and prejudice for the new face of AIDS: a dialogue with intervention bioethics

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Abstract

Prejudice and discrimination related to people living with HIV/aids are still present today, and may be increased with the emergence of lipodystrophy and, thus, unwittingly reveal the positive serum individual. It is an article of bibliographic material critical-review and it is based on principles of the intervention bioethics, emphasizing persistent situations. It is believed that the bioethical debate on the values and moralities permeating the stigmatizing issues of aids could help the visibility of the problem with possible positive impact to reduce vulnerabilities that affect people living with HIV/aids suffering of lipodystrophy. It is concluded that the precariousness and inefficiency of the public response to the resolution of the issue could lead to infringement of the right to equity.

Key words: HIV. Aids. Prejudice. Lipodystrophy. Equity in health. Intervention bioethics.

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In Brazil, just as in many other countries, the appearance of the first cases of AIDS was marked by the identification of people who belonged to specific groups. From the beginning, AIDS has been associated with *high-risk groups,* owing to certain social segments – particularly homosexuals, injecting drug users, and sex professionals – which revealed themselves to be more vulnerable to the Human Immunodeficiency Virus (HIV).

Another segment of the population that also showed vulnerability to AIDS, especially in the 80s, were hemophiliacs and the recipients of blood transfusions, taking into consideration that, at that time, adequate quality control did not exist at the blood banks. The confirmed neglect towards issues of blood control at the start of the epidemic resulted in the expansion of post-transfusion AIDS. According to Souza, cited by Nichiata, Shima and Takahashi [1], during that period,

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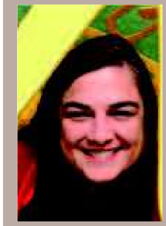

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95% of hemophiliacs were infected through contaminated blood and its derivative forms.

The lack of scientific knowledge on the forms of transmission, allied with the labeling of *gay* men as the preferred targets for the new disease, strengthened the social imaginary idea that AIDS was related to specific risk practices. In the wake of the disease's conception, this reinforced the taboos that permeate modern society: sexuality, pleasure, guilt, and death. In this manner, the idea that AIDS only struck groups composed of *unusual people* solidified itself, which then led to legitimizing the social exclusion of HIV carriers as a punitive act for the supposed transgressions they had practiced [2].

Contrary to this strong association between the new illness with the stigma and prejudice which mold the social imaginary, the disease had a noticeable effect on other segments of the population from the beginning, although the numbers were still unimpressive: men of a heterosexual orientation, as well as women and children who did not fit in with the concept of high-risk groups also contracted the infirmity.

Still in the 80s, the historical-political situation marked by the end of the military dictatorship and the movement for returning democracy to the country stepped to the forefront. Another noteworthy event was the constituent process and, in the field of healthcare, the strengthening of the sanitation movement, and the creation of the Single Health System (SUS). The change in the contributory system which had prevailed until then, to reasoning health care as a universal right – with the State in the role of great provider – was a milestone that cannot be disregarded.

The new health care system incorporated the principles of universality, integrality, and justice to the construction process. It might me argued that this trend is consistent with the issues and concerns inherent to principles of bioethics, considering that a peripheral country such as Brazil, with serious social inequalities, advanced toward the construction of universal public policies which favored the defense of a socially excluded population as opposed to defending the individual rights of a small segment of society.

It is within this scenario, more specifically after 1985, that the first responses in relation to AIDS began to emerge from the social and governmental movements[3]. The first social and political strategies for combating the disease in Brazil were established. This period was also marked by the fight against the prejudice that plagued the AIDS victims and by the creation of the first non-governmental organizations (ONG) of the country, founded with the objective of dealing with questions related to the epidemic.

As there were no efficient alternatives for treatment, the people affected by AIDS received health care only for opportunistic infections, which did not prevent imminent death. Due to the strong discrimination and prejudice which marked the appearance of AIDS, and consequently struck the first victims, it was observed that social death often preceded the physical death [4]. Thus, an illness with unknown etiology and inefficient therapy tended to gain various significances, causing HIV-positive people to live with and face the stigma of discrimination in their day-to-day lives.

In 1996, due to the editing of a federal law, the guarantee of universal access to antiretroviral medications may be a highlight of the SUS. This measure enabled the availability of treatment, favoring a better quality of life for people infected with HIV and sick with AIDS[5]. The various conquests in the areas of health care, human rights, and specific legislations, contributed greatly to the consolidation of responses to the AIDS related stigma. Nevertheless, situations of discrimination and prejudice still occur, which brings to light the need for furthering discussion on the topic.

The present article deals with a critical revision of bibliographic material, and aims to discuss current issues related to prejudice and discrimination as evidenced within the context of the epidemic. In relation to living with HIV/AIDS, one fact, especially, will be taken under consideration, which emerged in the last few years: Lipodystrophy, whose manifestations may leave the affected people even more vulnerable, due to the risk of having their HIV-positive condition forcefully revealed, which can make them the target of stigmas and prejudice. For reflection on the theme, the analysis will be grounded on the precepts of intervention bioethics, with an emphasis on persistent situations.

The concept which emerges with the advance of the epidemic: vulnerability

Twenty-five years after the birth of the epidemic, perceptible aspects related to the stigma and discrimination of people living with HIV/AIDS are still present, but with different components and, in some cases, more subtle than those which were observed in the first years of the epidemic within the country. The concept that AIDS is associated with high-risk groups gave way to the notion of risky behaviors and contexts. The propagation and transmissibility of HIV beyond the said "specific groups" fostered the emergence of the concept of *vulnerability*, which would then mark out studies and actions for comprehending and battling of the epidemic.

According to Ayres, cited by Seffner [6], vulnerability is related to the contexts – personal, social, and programmatic – which provide the opportunity of becoming infected/ ill in the possible situations of HIV transmission. According to Guilhem and Gonçalves, vulnerability to AIDS is understood as a situation resulting from a conjunction of individual (biological, cognitive, and behavioral), programmatic (prevention programs, education, control, and driving politics), social (related to economic and social questions), and cultural (submission to moral beliefs and standards, hierarchies, power relations, topics of gender) factors which are interdependent and mutually influenced [7].

Despite advances in the concept of vulnerability for the ample and multidimensional comprehension of issues relative to preventing and living with HIV/AIDS, Garrafa and Prado [8] ponder that vulnerability leads to an idea of *fragility, lack of protection, disadvantage* (disadvantaged populations), and even, *neglect* or *abandonment*. These aspects of vulnerability may characterize the condition of HIV positive people, which highlights the need for deepening the analysis in an attempt to reveal what these people are vulnerable to.

From this perspective, the contribution which the concept of vulnerability brings, relates to a wider range of dimensions, reducing individual responsibility and focusing on other aspects – socioeconomic, cultural, and programmatic – which exercise influence over the prevention and care of HIV/AIDS.

Current AIDS tendencies in Brazil: feminization, pauperization, and internalization

From the evidence observed in the epidemiologic analysis, the current pattern for the dissemination of HIV and AIDS points to tendencies that are characterized by *feminization, pauperization*, and *internalization*. The feminization of the epidemic stems from the growing incidence of AIDS among females in full sexual and reproductive health. According to the Integrated Plan to Combat the Feminization of the AIDS Epidemic and other STDs [9], it was found that in Brazil, of the total number of reported cases, 67.2% (290,917) were males and 32.8% females (142,138). The gender ratio (1980 to June/2006, average per 100,000 inhabitants) has been decreasing, going from 15.1 men per women in 1986, to 1.5 men per women in 2005.

The AIDS epidemic has been affecting people in situations of poverty. Although the level of education alone is not sufficient to indicate the socioeconomic condition of the population affected by the epidemic, this measurement comes the closest to poverty indicators. In this sense, the data shows that 52% of the female cases refer to those women who have no education or who did not complete the first level of elementary school (29% with about three years of study and 19% with four to seven years of study). Another important indicator is the level of education among pregnant women diagnosed with HIV, which confirms the verified tendency toward the pauperization of the epidemic. Of the 31,921 cases of pregnant women who are HIV +, 3% are illiterate, 13% have only three years of education, and 39% have between four and seven years of education. As to internalization, a progressive increase has been observed in the number of Brazilian municipalities with at least one reported case of AIDS, reaching about 80% of the municipalities [9].

The epidemiological tendencies show that the distribution of AIDS in Brazil is not democratic, building on the indicators from recent years. One might affirm that people of a dark or mixed race, in a condition of poverty, and with fewer years of study, are more vulnerable, given that they are provided fewer resources to protect themselves against HIV infection. Here fits the question: if these people contracted HIV because they were not given access to the means by which they could protect themselves from the illness, would they not also be more vulnerable to AIDS, due to the difficulties which impede their benefiting from access to universal healthcare in their treatment, with issues in adhering to this treatment, and with no condition of dealing with the eventual adverse affects resulting from a chronic disease, such as Lipodystrophy?

AIDS as a chronic disease

AIDS initially presents as a disease which is full of symbols, meanings, and imprecise and fallacious images which stimulated attitudes of panic, negation, intolerance, and discrimination toward the affected people [10-13]. The appearance of AIDS updates the theme of disease as a collective catastrophe, which frightens people. Berlinguer [11] comments that, throughout the history of humanity, some infirmities disappear and others appear and those diseases have a history associated with human activities and with their environments. The author also mentions that during *ages illnesses were seen as a danger, and that various motivations coexist among them,* (...) *the search for the 'target-individual', in other words, the 'scapegoat' on whom to drop the woes of the community, and thereby gain release.* This text allows us to draw a parallel between the emergence of the AIDS pandemic as a global threat of rapid dissemination which marks the end of the XX century.

Today, the policy of universal access to treatment is a major point; this is one of the differentials of the Brazilian response. This reality constitutes a global marker on the possibilities for combating the epidemic and puts Brazil at the forefront of the international scenario. With the availability of antiretroviral therapy, there is a confirmed downward trend in the number of hospitalizations and deaths from AIDS in the country. This achievement propels changes in a reality characterized by the offer technologies for battling AIDS, which makes it possible for people who live with HIV/AIDS to gain the right to a life. Nevertheless, even today, the experience of living with AIDS imposes the need for actions that deconstruct the stigmas and myths associated with the illness, so as to guarantee the full application of this universal right.

Prejudice and discrimination of HIV/AIDS

To work through the issues relative to stigma and discrimination, we chose to relate major theoretical contributions and dialogue with the inherent reality of HIV/AIDS. In this sense, one might quote Goffman's classic text [14] upon signaling that *society provides the means of categorizing people and the total of attributes regarded as common and natural,* and that it utilizes attributes that have a depreciative significance *to disqualify people.* It does not consider a person in their totality, but visualizes only a single attribute, *reducing them to a ruined and belittled figure.* (…) *Such a characteristic is a stigma, especially when the discrediting effect is very great.* Thus, the term stigma will be applied to the text *in reference to a profoundly depreciative attribute.* (…) *A stigma is then, in reality, a special kind of relationship between attribute and stereotype.*

Bandeira and Batista [15], in an essay on prejudice, point out that, in general, there exists a negative attribute of discredit in society. Studies mention this phenomenon, tying it to discrimination and exclusion. Prejudice, in the semantic sense, corresponds to the *emission of a premature judgment, unsuited to the thing in question.* According to the authors, prejudice manifests *as a producer and reproducer of controlled situations, contempt, it always implies a social relationship. It appears as a way to relate to one another, different, out of a denial or devaluation of the other's identity and the overvaluing or affirmation of one's own identity* [16]*.*

In relation to AIDS, a strong depreciation of the infected people is observed, who are held responsible for their own infection. Added to this, HIV is a transmissible disease, strengthening the social imaginary idea which places yet another responsibility on the carrier; this may contribute to the perception of these people as being a threat to society. Allied to these issues, and even taking under consideration the contribution of current technologies in combating the epidemic, the possibility of a cure does not exist, at least not in the short term. Therefore, the impact from the AIDS-related stigma imposes the need of giving care and protection to the affected population group.

Berlinguer [17] establishes a correspondence with the fear people have of illnesses, in other words, *fear arouses irrational behavior and acts of discrimination.* Actions born from the prejudice against people with HIV and AIDS provoked the experience of *singular emotions, permeated by suffering, within a context full of meanings, among them: fear of abandonment, of being judged and of revealing one's social identity, guilt for falling ill, impotence, escape, covertness, omission, exclusion, and suicide, originated and constructed from the real interaction with a social paradigm that reinforces habits and expectations* *and which is profoundly engrained in a prejudiced society* [18].

In order to ascertain the full extent of prejudice and stigma from the perspective of concrete subjects who are the targets for the violation of their fundamental rights, various narratives were selected, based on the research conducted by Almeida and Labronici – who interviewed five people between 25 and 34 years of age, two women and three men – on the experience of living with AIDS. For example: *"It's difficult to admit that I have AIDS, because it puts me in a place where people will look at me differently* (…) *it's like I'm an alien, and because I have AIDS I'm not myself anymore, like I feel differently, think differently, and behave differently. They will no longer remember what I did that was good, and my qualities, though they will put me on a cross and stone me as a disqualified, worthless, person"* (collaborator 3); *"I never admit I had the virus* (…) *The people here in the neighborhood are very cruel, they are a bunch of gossips, who spend their time talking about other people's lives. I don't want those mean people talking about my life"* (collaborator 2). These testimonies expose the feelings of HIV-positive people, and illustrate the fear of prejudice which circles this condition, as well as its consequence over the identity and life history of people living with HIV/AIDS (PLWHA).

Aspects and current contexts of the epidemic: Lipodystrophy

As was said, the progress achieved in treatment poses new challenges, taking under consideration improvements in the quality of life for people infected by HIV and taken ill with AIDS. The availability of highly potent antiretroviral therapy through SUS for all people that need it caused a noticeable impact on the reality of the epidemic in Brazil, with a decrease in mortalities, a decrease in hospitalizations, and progressive change in the way society and health-care professionals relate to the patients [19].

Nevertheless, the maintenance of situations that are persistently characterized by expressions of stigma and discrimination towards the affected people are still observed. After fifteen years of highly potent antiretroviral therapy, the advent of HIV Lipodystrophy Syndrome indicates that the collateral effects, progressive and accumulated, have provoked reactions and changes which trigger events that strengthen and stimulate situations of stigma and discrimination. Some scholars suggest that antiretroviral therapy, regardless of its benefits and advantages, brought the occurrence of side effects.

One of these effects is Lipodystrophy, a syndrome characterized by the abnormal redistribution of body fat, which can manifest as loss (Lipoatrophy) or gain (Lipohypertrophy) in the body's fat. Lipodystrophy Syndrome may be accompanied by alterations in the metabolizing of glucose, insulin resistance, and dyslipidemia. Dyslipidemia is characterized by an elevation in the levels of lipids in the blood (cholesterol and triglycerides), contributing to a greater risk of cardiovascular problems.

Currently there is no consensus for the treatment of the syndrome, whose cause remains unknown [20-22]. As the prevalence of Lipodystrophy Syndrome is still controversial – studies show the percentages vary from 25% to 60% – it is difficult to define the number of HIV-positive people who are affected.

Lipodystrophy implies a reduction in peripheral fat, with the loss of subcutaneous tissue in the face, arms, legs, and buttocks. The accumulation of fat, called Lipohypertrophy, is evidenced by the appearance of dorsocervical fat, the expansion of the circumference of the neck, and an increase in the volume of the breasts and abdominal region. Lipodystrophy has contributed to giving AIDS *a face* again, enabling the body/disease association as a mechanism for identifying people within the social setting who have HIV/AIDS, just as is was when the epidemic began. Consequently, such a possibility favors the manifestation of prejudiced and stigmatizing reactions and attitudes.

Data from the research conducted by Machado, Raggio, Carvalho, and Garrafa [23] on Lipodystrophy in HIV-positive people, indicated a widespread concern with the return of prejudice. After interviews with 30 HIV-positive people affected by the syndrome, the authors observed that more than 50% of the participants said they were worried that Lipodystrophy would make it possible for others to discover their HIV-positive condition. It is then possible to affirm that the non-public visibility of the problem may be the only protection these people have against prejudice and stigma – which might resurface if HIV-positive status (through physical characteristics) should become easily identifiable by the population. Therefore, there is a great possibility of a resurgence of the stigma through the recognition of Lipodystrophy Syndrome and its association with HIV seropositivity.

In another study on the subject, Seidl and Machado[24] interviewed 21 HIV-positive people with Lipodystrophy and verified, based on the testimonies of the participants, that the discovery and experience of living with Lipodystrophy may affect psychological well-being, occasioning reduced self-esteem, a negative perception of physical appearance, and the avoidance of social contact. According to the authors, the fear of forced exposure was mentioned as an important source of worry and stress for most of the respondents. They related that the visibility of the signs of Lipodystrophy, especially on their faces, could jeopardize the confidentiality of their HIV-positive status, leaving people who live with HIV/AIDS exposed to the discovery of their diagnoses by third parties, and vulnerable to their probable consequences: prejudice and discrimination. From this perspective, some participants mentioned that Lipodystrophy is the new face of AIDS.

One aspect which was not the objective of this work, but of great relevance, concerns the non-esthetic components of Lipodystrophy, the ones which are not visible and, therefore, have no social impact. These are metabolic disturbances such as the impaired metabolizing of glucose, insulin resistance, and dyslipidemia, which also leaves the health of these people more vulnerable [21].

The results of these surveys demonstrate how the advent of Lipodystrophy is bringing relevant concerns to people living with HIV/AIDS, which may adversely affect their quality of life. Specifically in the case of Brazilians, how can public policies toward HIV/AIDS offer an efficient and equitable response to this theme which characterizes the current situation of the epidemic? And in what measure does intervention bioethics constitute a valuable tool against these challenges?

Prejudice and discrimination of HIV/AIDS: a dialogue with intervention bioethics

Porto [25] emphasizes that the studies conducted in the area of healthcare through intervention bioethics aim to contribute to the promotion of social equality. To formulate such a conception, the author believes that *Bioethics should call attention to those morals that have generated increasing injustice and inequality* (...) *it should also point out the power relations that sustain these morals and mold the inequality, especially when considering the influence of the market in shaping the symbolic structure of morals and of the resulting behaviors.* In the production and reproduction of power relations, stigma and discrimination are concepts that are historically and intrinsically tied to the AIDS epidemic.

Returning to the year 1987, the initial period for theoretical construction on the epidemic, the studies of Mann, quoted by Parker and Aggleton [26], described three distinct phases that could be expressed as three different, but concomitant, epidemics. The first is the infection by HIV, an asymptomatic period which develops over many years. The second is comprised of AIDS itself: it is characterized by a syndrome of opportunistic diseases due to the actions of the virus on the human immune system. The third phase, potentially the most explosive, was described an epidemic of social, cultural, economic, and political responses to AIDS – reactions that were characterized, especially, by exceptionally high levels of stigma, discrimination and, at times, collective denial. It is noted that stigma and discrimination are recurring themes, and are always present in the debate on the social dimension of AIDS.

As an example, nearly thirty years after the first case of the illness, research conducted with healthcare professionals in São Paulo [27] who look after people with HIV/AIDS on a day to day basis, analyzed the meaning these professionals attributed to their experience in contact with these patients. Among the principal themes that surfaced during data analysis what stood out was the *persistence of discriminatory behavior related to feelings of insecurity and the fear of contagion among the service professionals and general hospitals*.

Garrafa and Porto [28] assert that *Bioethics should preferably be concerned with persistent situations, in other words, with those problems that continue to occur and that should no longer be repeated at this stage of the XXI century.*

In the case of AIDS, the occurrence of stigma and discrimination characterizes persistent situations that power the mystification of the disease, as has happened in the past with tuberculosis and syphilis, which aroused society's aversion.

The dramatic confirmation of discriminatory and inhuman conduct present in the daily lives of people living with HIV is a reason to mobilize intervention bioethics as it calls attention to moralities, and unveils the power relations that give support to said moralities, thus revealing the attitudes of prejudice and intolerance. It is believed that the bioethical debate on the values that permeate the stigmatizing issues of AIDS could assist with the visibility of the problem, with an eventual, positive repercussion toward a reduction in the vulnerability which affects people living with HIV/AIDS.

One point which continues unanswered today, and which requires the precepts of bioethics for a dialogue, refers to the scenario imposed by AIDS, especially the conflict generated by the right to life – the access to antiretroviral therapy – and its consequences, especially the bodily marks provoked by Lipodystrophy. In Brazil, the achievement of universal access to antiretroviral medications brings to light the need for tools, such as those which intervention bioethics offers, to deal with the unpleasant effects that feed stigma and compromise the self-image of people affected by Lipodystrophy.

In this sense, the concept of healthcare in its wider dimension, which supports the ideals of humanization and the construction of SUS, is in conflict with the slowness and difficulty of public policy in presenting efficient answers to this situation. The appearance of the new face of AIDS and the historical experience of civilian deaths once lived by people who were HIV-positive, did not make it possible, until the present moment, to provide universal access to new procedures and technology in order to minimize the impacts arising from antiretroviral treatment. Despite all the incontestable advances of the national response, the incorporating of reparative procedures to minimize the adverse effects of Lipodystrophy [29] is still a great challenge for Brazilian politics, notwithstanding the editing of Joint Ordinance No. 1/2009 of the Ministry of Health (DOU 23/1/2009, section 1) [30], which aimed to regulate the matter. The document, among other points, established norms for the reparative treatment of Lipodystrophy, which includes surgical procedures for Lipohypertrophy in the region of the abdomen, breasts, dorsocervical, and submandibular; in the case of Lipoatrophy in the gluteus and perianal region, reparative surgical techniques are also indicated. In the reparative treatment of facial Lipoatrophy, a filling with polymethylmethacrylate (PMMA) is recommended. The document provides guidance on the qualification, accreditation, of health units, and composition of teams, defining the criteria for the indication of these modes treatment.

Despite the legal contribution, it should be stated that the majority of Brazilian municipalities have not yet implemented these recommendations from the Ministry of Health. In regard to the treatment of facial Lipoatrophy – even though it is ambulatory, less technically complex, and less expensive – there is still a delay in the execution of this procedure.

It is worth noting that intervention bioethics has respect for the rule of equity as a precept, in other words, *special attention to the unequal.* Garrafa points out that *equity means the disposition to equally recognize the rights of each based on their differences* [31]. Creating public policies based on equity makes possible the understanding that *only when facing this paradigm, associated with the theme of responsibility (individual and public) and justice, that we can assert the value of the right to healthcare.*

Still quoting Garrafa, equity is *the recognition of different needs, also of different people, to achieve equal rights, is the way of practiced and applied ethics in facing the realization of universal human rights, among them the right to life. Equity is the category that resolves a fair share of the distortions in the distribution of healthcare by increasing the life possibilities of major portions of the population* [32].

It is necessary, then, to focus on the condition of vulnerability due to the adversities branching from seropositivity, aiming to better the quality of life for people who live with HIV/AIDS. It is therefore expected that a *bioethical reflection will detect and condemn all things that mistreat predisposed or vulnerable people* [33].

In the literary revision, it was verified that prejudice and discrimination are phenomenon that resist and persist in the wake of the epidemic, matching the faces it acquires through resources available for new treatment. It is important to examine the statements of Herbert de Souza from a decade ago: *I believe we may transform the tragedy of AIDS from an infirmity and illness, to a challenge, to a possibility for recovering in our society, in ourselves, in each of us, and in all of us, the meaning of life and of dignity. And, with this meaning of life and dignity, we will be able to fight, to build a democratic society, a just and fraternal society* [34].

The words of Betinho establish a dialogue with intervention bioethics, whose realm of practice is in the search for strategies to debate moral dilemmas. In this case, it may contribute to a reduction in the negative impact of stigma and discrimination. In this sense, it calls attention to – based on the reference of intervention bioethics – the strengthening of a policy directed towards human rights, with emphasis on challenging the prejudice directed toward PLWHA, it is the condition *sine qua non* to successfully deal with the challenges that are still present in the current context of the epidemic. Brazil - which has already achieved global recognition for its public policy on HIV/AIDS, most notably the universal access to antiretroviral medications - may still contribute to the structuring of new milestones in defending the dignity of PLWHA and, consequently, ease the path to reaching that ideal which moves us to build a more just and unified society.

Lastly, it is fundamental to clarify that, in these reflections, there is no intent to disregard the enormous scientific and technological advances relative to the treatment of HIV/AIDS and the benefits to the universal access to antiretroviral therapy, a milestone in Brazilian policies. The intention is to broaden the discussion on the impacts of the adverse effects of antiretroviral treatment - Lipodystrophy - which may cause an upsurge of stigmas and prejudice. It should be noted, that to guarantee the right to equity, it is necessary to give access to technical procedures, backed scientifically, to HIV-positive people who demand reparative procedures, as well as ample campaigns directed toward eliminating the prejudice and discrimination against patients; especially women, the poor, and those who live in rural areas in general. Otherwise, Brazilian public policy would be injuring this right by failing to promote healthcare in an integral and qualified manner for the people affected by Lipodystrophy, with demands of a medical and psychosocial order.

Final considerations

The article presents initial reflections on Lipodystrophy and prejudice against HIV/AIDS, using the contribution of intervention bioethics to break down the subject. With no intention of providing neither ready-made, nor finished answers, it emphasizes the esthetic and visible dimension of Lipodystrophy due to the alterations resulting from this syndrome becoming the new physical expression of seropositivity, marking these people with the persistence of stigma and discrimination.

Two years after the publication of the last ministerial decree on the subject, it was found that there is a need for a critical analysis of the implementation of this strategy and its effects on the quality of life for PLWHA who are affected by Lipodystrophy. In this sense, a greater social movement – as with historic achievements in the enforcing rights and the structuring of government response to facing the epidemic in the past – could, in the same manner, contribute to technical-scientific, political, and social advances, making possible greater integrity in the care and, consequently, the eventual reduction of the stigma within the context of seropositivity.

It is important to underline that the treatment of Lipodystrophy should not limit itself simply to medical-surgical approaches. Investment in technology of a preventative character, with the practice of physical exercise, adequate nutritional diet, and changes in life-style, allied to a better relationship between healthcare professionals and patients would favor the solving of actions within the field of Lipodystrophy.

Facing these challenges, and considering the complexity that the subject requires, dealing with AIDS demands inter-sector actions, the organization and qualification of a web of services for HIV/AIDS, the constitution of interdisciplinary teams, and the incorporating of new specialties and technologies in the SUS scenario, as well as an ample and unrestricted consideration of prejudice, discrimination, and stigma. The precariousness and the inefficiency of the public response to solving this issue could result in an infraction of equity, through blatant disrespect for the civil rights set down in the Brazilian constitution.

Resumo

Lipodistrofia e preconceito na nova cara da aids: diálogo com a bioética de intervenção

O preconceito e a discriminação relacionados às pessoas vivendo com HIV/aids, ainda presentes nos dias atuais, tendem a ser acentuados com o advento da lipodistrofia, que pode revelar involuntariamente a condição de soropositividade. Trata-se de artigo de revisão crítica de material bibliográfico, com análise embasada em preceitos da bioética de intervenção, enfatizando as situações persistentes. Acredita-se que o debate bioético sobre os valores e as moralidades que permeiam as questões estigmatizantes da aids poderia auxiliar na visibilidade do problema, repercutindo positivamente na redução das vulnerabilidades que atingem as pessoas soropositivas portadoras de lipodistrofia. Conclui-se que a precariedade e a ineficácia da resposta pública para a resolubilidade da questão poderão redundar em infração ao direito à equidade.

Palavras-chave: HIV. Síndrome de imunodeficiência adquirida. Preconceito. Lipodistrofia. Equidade em saúde. Bioética de intervenção.

Resumen

Lipodistrofia y prejuicio en la nueva cara del sida: diálogo con la bioética de intervención

El prejuicio y la discriminación relacionados a las personas que viven con VIH/Sida, aún presentes en los días actuales, tienden a acentuarse con la aparición de la lipodistrofia que puede revelar involuntariamente la condición de seropositivos. Se trata de un artículo de revisión crítica de material bibliográfico, con análisis basado en preceptos de la bioética de intervención, enfatizando las situaciones persistentes. Se cree que el debate bioético acerca de los valores y de las moralidades que involucran las cuestiones estigmatizadoras del sida podría auxiliar en la visibilidad del problema, impactando positivamente en la reducción de las vulnerabilidades que afectan a las personas seropositivas portadoras de lipodistrofia. Se concluye que la precariedad y la ineficacia de la respuesta pública para la posibilidad de resolución de la cuestión podrán redundar en infracción al derecho a la equidad.

Palabras-clave: HIV. Sida. Prejuicio. Lipodistrofia. Equidad en salud. Bioética de intervención.

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Authors’ participation in article

Maria das Neves, Ana Paula Prado, and Paula Mendes designed the study, carried out literature review, and writing of article. Eliane Seidl was advisor for the paper and contributed in writing and final review of text.