



Universidade de Brasília

Repositório Institucional da Universidade de Brasília

repositorio.unb.br



Este artigo está licenciado sob uma licença Creative Commons Atribuição-NãoComercial 4.0 Internacional.

Você tem direito de:

Compartilhar — copiar e redistribuir o material em qualquer suporte ou formato.

Adaptar — remixar, transformar, e criar a partir do material.

De acordo com os termos seguintes:

Atribuição — Você deve dar o **crédito apropriado**, prover um link para a licença e **indicar se mudanças foram feitas**. Você deve fazê-lo em qualquer circunstância razoável, mas de maneira alguma que sugira ao licenciante a apoiar você ou o seu uso

Não Comercial — Você não pode usar o material para **fins comerciais**.

Sem restrições adicionais — Você não pode aplicar termos jurídicos ou **medidas de caráter tecnológico** que restrinjam legalmente outros de fazerem algo que a licença permita.



This article is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License.

You are free to:

Share — copy and redistribute the material in any medium or format.

Adapt — remix, transform, and build upon the material.

Under the following terms:

Attribution — You must give **appropriate credit**, provide a link to the license, and **indicate if changes were made**. You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use.

NonCommercial — You may not use the material for **commercial purposes**.

No additional restrictions — You may not apply legal terms or technological measures that legally restrict others from doing anything the license permits.

Esta licença está disponível em: <https://creativecommons.org/licenses/by-nc/4.0/>

Ethics and deconstruction of prejudice: disease and pollution in the social imaginary about HIV/Aids

Erli Helena Gonçalves
Lourdes Maria Bandeira
Volnei Garrafa

Abstract

This article presents the outcomes of a survey in which 15 HIV/Aids carriers were heard and who received psychosocial support after discovering serum positive. The technique used for data interpretation was speech analysis through which the findings are: i) there was not recording of prejudice for been infected with the virus; ii) they felt as polluted and polluting agents; iii) if this record was abstracted by the carriers themselves or it derived from external reading pervaded by it; and iv) if this record was differentiated in women and men's perception. Discussion focused in gender issues, in socialization processes, governing moralities and moral struggles, included in the sickness process and analyzed in light of bioethical theoretical referential of intervention. The study allowed to conclude that prejudice regarding the disease still persists, highlighting the difficulty for these patients to achieve a dignified life.

Key words: Bioethics. HIV. Acquired immunodeficiency syndrome. Behavior. Prejudice. Sexuality.

Gender identity.

CEPFR Approval No. 006181

In our society the phenomenon of the disease is closely related to notions of asepsis and impurity. By the perception of *healthy* society, being sick means to take the place of the gap, according to the symbolic patterns that organize this same society. It would amount, then, to the subject not belonging to society, not being included in social life.

Throughout history and in different cultures, the figurative sense of diseases has persistently adding moral judgments to the states associated with the illness, ranging from more positive senses to those that are negative and persecutory¹. Sontag points out that *the so-called incurable diseases would be, in social imagination, taken as*

*morally contagious*². The contact with these people would have, in the understanding of Douglas, the property to pollute the soul, and later the bodies of others not yet affected. This is because denudation of the forbidden and of what is hidden has occurred and that they would be paying the price for such a transgression¹.

For Berlinguer³, society transforms the social, cultural and behavioral phenomena into assessments, directing these judgments to social exclusion or moral disapproval. Health and sickness are part of the same dynamic and contradictory process – the vital process – and should not be viewed in isolation; its separate and fragmented analysis



Erli Helena Gonçalves

Graduated in History and Social Studies by the União Pioneira de Integração Social (Upis), an expert in Bioethics at the Universidade de Brasília (UNB), an expert on Government Management Latin America and Caribbean Policy and Integration from Universidade Latino Americana e do Caribe (Ulaac), a specialist in Political Sciences from the University Center of Brasília (UniCeub), Master's and PhD degrees in Health Sciences at UnB, scholarship holder in further education course at the University of Portugal. Associate researcher of the Study Group and Multilateral Cooperation Actions in Education and Health (Geamces) from UnB, director of graduate School of Management Sciences (Facig/SP and a scientific consultant/researcher at the Education Department of the Federal District, Brasília, Brazil

would be a mistake, since it would isolate the moral-social process underlying the studied disease⁴.

The categorization of the disease also is linked historically to the power relationship³, and there exist scales in this conceptualization. Surely, such a classification is derived from the gaze of the dominant perspective. Leal and Duarte⁵ discuss the difficulties, suffering and pain intertwined in the process of illness and how such planning will make the individual more or less vulnerable. The anomaly, therefore, would always be taken as dangerous¹.

In Sontag's approach, the epidemics *have a devastating effect on character (...)* Any important disease the cause of which is unclear and to which treatment is ineffective tends to be overloaded with meaning⁶. The infected individual would carry the stigma of polluted and/or polluting individual, since he would have crossed the imaginary line of the dominant moral rules¹. Goffman says that there are different kinds of stigma: *abominations of the body (physical deformities), individual character's faults (homosexuality, unemployment, suicide attempts) (...) and, finally, race, tribal (transmitted through lineage)*⁷. Intolerance would be residing exactly in the classification fabric in which the patient is fit, in which the identity of this individual would be conferred by the prevailing morality and values assigned to his condition.

For the purposes of this study, we defined *morality* as behaviors or habits that affect (curtail and determine) how people should act. Morality, then, would be the way through which the individual faces (evaluates) the world and how he is visualized by other social agents, given that each community is governed by a certain conduct, as amended (or not) over time. In the social imaginary, therefore, the subject affected by disease is always someone morally evaluated, either in a positive way, rarer, or negative, more frequent.

Lourdes Maria Bandeira
Ph.D., social scientist at the Federal University of Rio Grande do Sul (UFRGS), MA in Sociology from the University of Brasilia (UnB), PhD in Anthropology at the Université René Descartes, Paris V, and post-doctorate in the field of Conflict Sociology from École des Hautes Études en Sciences Sociales (Ehess). Professor at the Department of Sociology at UnB and Secretary of Planning and Management of the Secretariat of Policies for Women/Presidency of the Republic, Brasilia, Brazil



Volnei Garrafa
Ph.D., Ph.D., dentist at the Catholic University of Rio Grande do Sul (PUCRS), a specialist in Oral Oncology at the University of São Paulo (USP), Doctor of Science from the Universidade Estadual Paulista (Unesp), postdoctoral fellow in Bioethics at the University La Sapienza, Rome, Italy, Professor, Department of Collective Health, Faculty of Health Sciences, UnB, member of the International Bioethics Committee of UNESCO and coordinator of the UNESCO Chair in Bioethics at University of Brasília, Brasília, Brazil

Intervention bioethics and reading inequalities

The more widespread bioethics in the scientific cosmos, known as principlist bioethics, is based on four supposedly universal principles: autonomy, beneficence, non-maleficence and justice. However, this theory has proved insufficient for the reading and interpretation of social macro-problems recorded in poor and developing countries ^{8,9}, as is the case of the HIV/AIDS pandemics, considering, particularly, most African countries.

Although the initial proposal of this vision entailed no hierarchy among the four principles ¹⁰, in practice what started to occur was that the mainly Anglo-Saxon moral basis of the theory influenced the perception of the prevalence of certain principles over others, with overestimation of autonomy as compared to others. This hierarchy has affected mainly the principle of justice, which becomes almost a mere appendage of the others ' that are perceived easierly and used in interpersonal relationships. Thus, although essential, the idea of justice has a secondary importance in the field of bioethics, directing the decisions, actions and reflection on practices in the health field preferably for the personal and individual fields, to the detriment of the social and collective approach ¹¹.

With the objective of prioritizing the ethical study of collective issues persistently detected in the peripheral countries, a few years ago in Latin America emerged an anti-hegemonic conceptual proposal to principlism. This new epistemological current, of bioethics intervention, aims to deconstruct the hegemonic discourse of traditional bioethics, and put in context moral dilemmas according to the individual and collective moral precepts from the context where the studied problems are occurring ⁹.

The epistemology of intervention bioethics emerges from the thought that all paradigms must be challenged, or, at least, adapted, added or changed, which may lead to the collapse of hegemonic bioethics model ¹¹. Based on Foucault's ideas ¹², it proposes the unevenness of the traditional discourse of bioethics, in order that it may become a theoretical and methodological tool capable to reduce social inequality, prejudice, discrimination, and vulnerability that afflicts the peripheral nations. It advocates, too, that it is ethically legitimate to intervene, not only analyze and describe the moral conflicts seen in the daily lives of disadvantaged nations and people. Such intervention, of course, must be guided by autochthonous moral principles, that reflect the cultural and moral development of those societies, in line with the idea of self-determination of people.

Finally, in concrete terms, the intervention bioethics proposes an alliance of poor countries and developing countries in order to construct a bioethics politically committed with the needed, and also to recognize the social responsibility of the State in order to promote and foster individuals, groups and vulnerable populations' liberation, emancipation and empowerment ^{8,9} – mandatory conditions to change the unequal reality found in the less advantaged nations.

On such foundations, the aim of bioethical intervention is to create devices so that different morality does

not become a discriminatory factor, gender asymmetry is not taken as natural, and diversity is suffocated under the hegemonic perspective, spread on a massive scale. Different ways of conscious individual or public action are incorporated to its context, seeking to anticipate or prevent biased situations (as it happens with patients with chronic diseases - AIDS, mental illness, physical disability), narrowing the dialogue between the theoretical line of ethical thought and social issues, gender, race/ethnicity and others in order to promote facilitating policies regarding the reduction of asymmetries.

As it happened with the social movements, gender issues, in the context of bioethics, first emerged in developed countries with the theoretical modality called critique bioethics of feminist inspiration. Sherwin ¹³, a scholar of this line of argument, argues that sexist oppression is wrong even when *taken for granted* by the community, stressing that it would be essential to find a theoretical cultural basis for the moral critique of these various acceptances. Wolf ^{14,15} also questions the assumptions of the principlalist theory, notably the precept of autonomy, while Tong ¹⁶ advocates a global bioethics that takes into account the cultural diversity of the planet. Several voices surfaced in Brazil and in different countries, not only in bioethics but also in other fields of study, seeking a thought committed to the pursuit of social and gender justice ¹⁷.

Intervention bioethics, in particular, has sought to promote a dialogue with

gender scholars through contextualized ethical reflections and able to contribute to building stronger rights directed at understanding the dynamics of social relations of inequality and power. It seeks to work the complexity of these issues in order to understand *the relationships and boundaries between sex (biology) and gender (culture)* ¹⁸. They fall within the referential presided by the concept of biological sex (man and woman) diverse disciplines that would support themselves in a natural determinism. In other words, rules are imposed to women and men and from both are demanded differentiated attitude¹⁹. It is essential then to permeate the symbolic constructions engendered in the body by means of social construction.

The body carries the scars of the dominant morality. In this respect, the deviant body pays a high tribute for the deviation, or for not been inserted into the dominant moral status. Intervention bioethics has demonstrated a particular concern about the morals that pervade the HIV/AIDS epidemics. Its speech points out that individuals must be recognized along with their peculiar vulnerabilities and that the State must exercise a protective role and even intervene in a concrete way when needed. It is indispensable to incorporate and systematize the discussion of moral confrontations related to the disease and the protective action of the state, enabling its effective interference in the sense of trying to separate the disease from its stereotypes ¹⁹.

One may state that people who find themselves in situations of fragility experience, at some point, destitution before himself and the other. Hence the relevance of discussing the issue by using some assumptions or theoretical frameworks offered by the intervention bioethics, searching for the deconstruction of the prejudice surrounding HIV/AIDS. The following are nine of these ethical frameworks:

Otherness: it is only possible to work out the difference if there is recognition of each other in his entire plurality, i.e., to recognize the other (individually and collectively) in all his diversity;

Responsibility: the imperative condition of involvement and commitment that the individual should have with himself, with others and with the assets that surround him, such as the public good, the planet, food (production and distribution) and population affected with diseases (epidemics);

Solidarity: it is a transforming moral value, in which would be intertwined socioeconomic and political actions aimed at creating new lens for human demands;

Protection: is linked closely to State action to promote policies to protect the vulnerable, to offer them morally acceptable living conditions;

Caution: the utility to anticipate situations would have as primary

function to routinely play the role of sentinel, in order to grasp crisis, prejudice, discrimination surrounding different issues and work them with the intent to discard this process even before its installation;

Prudence: a fundamental mechanism channeled toward refocusing the re-description of the moral ideas of the socialized individual with the concept of universal morality;

Tolerance: doesn't mean a state of docility, but instead would be the tool of indignation pervaded by a transforming role, in order to stimulate the construction of moral mechanisms capable of respecting differences and to alienate the injustice, promoting, thus, a maternal disposition towards others;

Commitment: the act or effect of creating bond, stand ready to mobilize oneself for others, promoting individual and collective cooperation. It would be the political and social complicity of fighting for public policies more tailored to the needs of different segments (women, ethnic minorities, blacks; patients affected by epidemics);

Justice: it is intrinsically linked to people's quality of life, trying to reduce social inequalities. It refers to the promotion of increased human capacity, even in the sense of its recognition as a form of

ethical judgment of the society towards its peers, in addition to urging the empowerment of the individual. Empowerment was defined for this research, as the ability of individuals to make choices free from political, economic, social ties, that is, make use of their freedom without the mechanisms of coercion; for this to occur accurately, they should be educated for this purpose.

It is also necessary to work the institutions (church, family, state) and not only the person individually, enabling the individual to recognize their vulnerability, increasing their self-awareness, self knowledge and self-motivation in order to seek better conditions for expansion of their real needs, which include education, housing, decision-making power, access to health and social services, freedom of expression.

Method

The study was carried out at the Com-Vivência Project, developed at the University Hospital of Brasília (HUB), which in 2005 cared for 250 people with HIV/AIDS, without restrictions of gender, age or religion. Out of those, 15 individuals were heard from the universe of people with HIV/AIDS, cared for by the project, without statistic responsibility.

The main objective of the research was to define and point out the possible degree of recognition of the discrimination of subjects with positive serology in the light of intervention bioethics in order to evaluate their

perception in this regard, even though they received psychosocial assistance. The secondary objective was to stimulate reflection on the subject, in order, thereafter, to use these data for the construction of intervention responses that enable patients to have an improved quality of life.

The research was designed in the qualitative dimension, using techniques of observation and collection of narratives (or statements) of HIV/AIDS carriers^{20,21}. Although the study has focused on the testimony of patients assisted by the Com-Vivência Project, it does not seek to measure the effectiveness aspects of care. It was, rather, to observe HIV-positive individuals that, despite receiving psychosocial support, feel vulnerable and discriminated against. The study also sought to ascertain whether after the moment at which the individual became aware of the condition of carrier of HIV/AIDS he felt contaminated/polluted, and if such notice has not changed his way of relating. And, finally, it permeated the feeling of guilt for being a carrier of HIV/AIDS and whether this reading was different for women and men.

After the Ethics Committee of the Faculty of Health Sciences, University of Brasilia (CEP/UnB) approved the research project by contact was made with the hospital's general management, coordination and operators of the *Com-Vivencia* Project, for a better understanding of the institution and institutional design. It was agreed that, first, the issue would be

with the carriers; only with their consent actual contact would be then permitted, as described by Seidl and Silva²².

Thus, the choice of study participants happened voluntarily and after the signing of an informed consent formulary (IC). HIV/AIDS carriers were contacted who went in to receive condoms from the program, make an appointment for psychological consultation or were in consultation at the clinic. A total of 15 respondents was divided into two groups: eight males and seven females, intentionally, in order to make gender study possible. In this article were used fictitious names to preserve the identity of respondents.

The criterion for inclusion of subjects used in the research was that of selection by type of route of contamination. Those carriers who had contracted the disease through sexual practices, use of injectable drugs and those who became infected through vertical transmission were able to participate. Moreover, the choice of participants was open to men and women aged from 18 years and older, regardless of color, religion or sexual orientation.

Results and discussion

The study subjects had their lives changed from the moment they found to be carriers of the HIV/AIDS virus, even without the manifestation of the disease. All the interviewees, at some point in the narrative, demonstrated that upon

hearing about the positive serology came to feel "polluted" and/or polluters of the environment or of the other, according to the concept of Douglas¹. After all, the disease, according to Berlinguer, means *constantly losing physical power or human dignity rather than physical pain, a fact that translates into oppression by the healthy, emphasizing social inequality*²³. This record was implicit in the statements when they relate the disease to social or biological death. Upon learning of the contamination Otavio felt: *"without feet, lost the ground (...) helpless, completely. A big empty feeling and strong fear of death (...) it was the approach of death, loneliness."* The notion of *pollution*, for these patients, accompanies them. From the moment they found themselves infected, due to the internal and external evaluative lenses driven by their own readings, they learned the notion that they were different from other people.

The most relevant issues that need to be answered about the epidemic are related to subjective and inter-subjective meanings that do not appear in a naturalistic framework. For intervention bioethics, this is equivalent to thinking about the need to discuss, in the context of the disease, the moral values of caution and prudence, with the objective of protecting the carrier from self-judgment and community's value judgments²⁴. The subjectivity of the subject and the notion of embodiment that is produced in him at a given moment with indelible marks (for

example, when the individual begins to be aware of their infection) are, in view of intervention bioethics, two important points to be considered²⁵, because the *body characteristics bring with them important social meanings*²⁶. Based on these assumptions, it is believed that through the body it is possible to capture, somehow, the degree of vulnerability in which the individual is inserted. Thus, in the case of HIV/AIDS, the infected socially constructs a contaminated body endogenously from their own perception, and also assimilates the external notion of pollution.

When conceiving the idea that their body is venous, the HIV/AIDS patients end up contributing to the rules imposed by the dominant, in which the ruled, on numerous occasions, cannot even register their own domination^{27,28}. Therefore, they agree with the assessment that any illness brings along a moral opinion^{1,2,29}. The disease becomes the cold and dark side of life. The notion of pollution can start in one's own family, as Gilberto reports: *"My wife [who is also HIV positive] had a niece who took her daughter from my wife's lap, saying she was contaminated and would contaminate as well."* Analyzing the evidence from Sherwin's position¹³, one may develop the analysis and realize that, beyond the notion of polluted/polluter individual registered by the family member, we may note how much there are rules and perceptions intertwined in the individual that exist in the community's social fabric, which will catalogue these patients. It is as if there was a representative definition of impurity for the very people with HIV/AIDS.

Another point emphasized by the participants relates to the induced

removal process that the patient suffers institutionally, be it by the health system, in the person of the health professional or by the company in which they work, represented by the manager. From the moment in which the institutions are aware of the disease installed on individual's body, it triggers a stimulatory process for the distancing of that person, using mechanisms, proposals or pressure to cause the retirement of the polluted agent. The person with HIV/AIDS, in this study, records this attitude as a violence committed against his person. Translated, it would be like saying to the individual that he is not part of the portion of subjects able to produce the work force, depriving him of his place of belonging within the working class, which, consequently, causes pain and isolation. For example:

“It was just like, I stayed eight months [working after learning that he was infected], once in a while I felt some fatigue. Then (...) I told my boss, [she] went to the company to tell the other boss. They said: he can leave immediately, he cannot continue to work. This for me was the death of everything. Gosh!!! I'll be leaving. For this reason I leave, I sell everything, everything (...)People despise us a lot, reject us” (Abel);

“You see everyone rushing in the morning, like, I'm late, gonna be late for work and I can't go to work (...)But that desire to be in the market (...)It hurts us so much (...) Then the doctor said boy, let's stop with this?”

Let's retire you once and for all? Okay, then I go into retirement (...)The most negative part is that I can't work (...)Then, I feel that envy. Then one says: ah! If I had your life (...)Hey, don't speak like this, you don't know” (Joaquim).

As for disclosure, to sexual partners, close relatives or friends the patients had diverse positions, prevailing, however, the idea of omission, at least at first. To reveal would be to expose oneself to rejection, a possible break-up, or exclusion from the family or social environment, setting up a process in which others avoid the patient. The people, according to statements, the subjects that are not *polluted*, would evade physical contact, feel disgust due to the infection, and there would be a moral assessment of their contamination. With regard to abandonment and the reaction of the non-contaminated individual, we registered the following statements:

“It hurt me very much. I would hear this speech: you are a good person, I like you very much, but with this virus I will not relate. Then, I felt reduced to a virus” (Gilberto).

“I met someone very young, she became involved with me and I with her, inside my house. And eventually I fell too much in love, I cried, screamed, jumped, shouted for that person. This person was with me twice and I told her and then (...) she left me so (...), you know? So she left me, as someone would abandon an animal” (Abel).

"Then I didn't say anything to anyone. I [crying] with that locked inside (...) didn't say anything even to my brothers, nobody. I did not dare comment (...) I was afraid (...) because people were disgusted of me, I thought because I am HIV. I was so isolated. They thought I was passing AIDS to them in the cup or something. I walked away from many friends of mine, because I was afraid of going for a drink of water and the person, you see? Wouldn't like (...) that was it" (Vitoria).

The infected subject, *the author of the impurity is subject to general disapproval, first, because he crossed the line, second, because it constitutes a danger to others*³⁰. This line would be the dominant moral demarcation established by society.

As the morals surrounding patients are suffused with guilt and moral judgments, there would be the appearance of disciplinary scars¹⁹. In Sontag's evaluation², institutions impose the blame to the patient for his illness, either moral or psychological, as in the case of cancer, in which responsibility is attributed to the affected, both by the disease, and for his healing. Responsibility and blame are punitive notions rooted in social imagery that need to be deconstructed so that the HIV/AIDS patient does not feel marginalized by being sick.

The exercise of sexuality has always instigated humanity. Foucault³¹ warns that surveillance and disciplinary power are everywhere, silent and subliminally.

Therefore, invasion of privacy becomes legal, resulting in the need of secrecy about how the individual conducted sexual practice, who thus seeks to exercise their sexuality secretly, so as not to be punished by those who adopt the dominant morality, who judge him differently from the exclusionary perspective of their own morality. The author states that heterosexuality is conceived as *natural* and also universal and normal, while other sexual orientations are considered excessive and abnormal, while an obsessive vigilance must be exercised about them.

[Is your sexuality in work and family exposed?] *(laughs) "(...) it is silent, but (...) also not something that has to be kept under lock and key, completely hide (...) people are not dumb huh? They are not. Eh? (...) I prefer it to stay that way. To (not) expose my sexuality nor to my family nor in the workplace" (Otavio).*

The disciplined body³¹ bears scars, social, educational and behavioral markings that sexually categorize this subject and, depending on the way they present themselves, they will be sentenced and reprimanded³². The mark of sexual misconduct will be printed in the body through illness. Guilt and concealment of illness and of sexuality are to the *not polluted* subject a sign of the dominant's justice over the discordant body. The carrier, through pathological manifestations such as herpes, Kaposi's sarcoma, weight loss, hair loss, physical weakness, is being punished within the social imaginary, by his devious

procedure. This is shown in one interviewee's speech; she was infected by her bisexual first husband, who died due to complications of the disease:

"It was a subject that was barely touched between us. He refused to touch it. He was terrified the family would know, especially his family. I think he would not like it, if the family was sure that he was bisexual. I think there was that embarrassment, I felt this (...) everything was veiled. Nothing was ever said, but I'm not stupid. I believe that his family knew he was bisexual [sad smile] (...) this virus is devastating" (Eulalia).

Despite saying that he assumes his sexual practices, one respondent never disclosed in his jobs and even to neighbors and friends his sexual orientation, only to close family members, as evidenced by his statement:

"I felt a victim of fate, for being so correct, I was born in the gospel, used to go to church many years ago (...)I'm gay, I assumed this position, my whole family knows. But there in my heart, I did not accept my condition. Although everyone accepts (...) I did not accept. So I went into therapy (...)This disease is directly related to sex, it is a cultural issue. Religion is one thing we're soaked in. One may even say he's a carrier, but if I say that I am a carrier, people will start to look at you

with bad eyes. When someone says they're taking medicine, assumes that he is homosexual, or assumes the posture of the carrier, ah! everyone looks as if seeing an animal. I see, I perceive that here [in hospital]" (Carlito).

The disease is considered in the public mind as shameful, sordid and full of sin, encouraging in the *polluted subject* a strong reservation to talk about it ². Diseases linked to sexual behavior are reprimanded morally and culturally recorded as a sought for and deserved sickness. In the classification system of the diseases, Douglas ³³ points out that there are mechanisms of repression and guilt: *nature, in rescue to the moral code [sanctions]: this disease is caused by adultery, that by incest.*

"I was starting to own to my sexuality, fear of not living a full love life. The fear to see my sexual orientation discovered within the family, all this (...) guilt, blame, you know, the fact of being HIV positive, living in silence, having to lie, omit, living many years hiding this condition from the partners, for fear of losing them (...) For many years living relationship hidden for fear of being ostracized" (Otavio).

"...fear. Fear of prejudice ... rejection ... gossip ... the speculation that this would cause in the midst [family]. To this day I did not open, I live with this lie. We are ten brothers, they do not know, my mother does not know.

Ah! I think it's needless, my mother is 73 years old and is sick, has health problem (...) to spare her (and spare me), the two things [laughs]. Both. Not accusations, but judgment from brothers and such. I did not tell [sad smile] ... I do not feel like it" (Mariana).

For women it seems to be even harder to deal with the fact of being identified as a person infected by a disease marked by the stigma of deviant sexuality. Because women grow to be afraid, asexual, to not identify their own bodies' needs, it becomes embarrassing to women to associate their identity to that of living with HIV/AIDS³⁴. Given the above, infected women would be associated to wrongdoing, too much sex.

Gender relations observed in the investigation at some point combine, becoming linear even if starting from different positions. When discussing the affective-sexual relation, the speech of the male subject, whose subjectivity is female, is very close to the female report. For both genders, when sex is affectively bonding the use of condoms becomes unnecessary. But often, the possible risk of contamination is considered lower than the stress caused by condom negotiation, because negotiation can mean a breach of trust between the couple^{19,32}.

In the social imaginary sex with bonding is regarded as legitimate, undisputed and coated with sacredness, thus excluding the possible risk of HIV/AIDS³⁵. One may

say that the affective feeling would be taken as an antidote to the virus³⁶. In the survey, homosexual males had the same discourse as heterosexual female in the sense that if they were with a partner with whom he maintained amorous liaisons or marriage tie, they did not use condom before contamination. They believed in the monogamous conduct of the partner, or, if he was to break that covenant, that condoms should be used when they registered the change and not in a relationship ruled by affection. In short, the need for condom use was only considered in cases of relations without formal social or emotional commitment; in addition, AIDS is *the other's disease*, not being possible for the syndrome to install itself into emotional relationships^{37,38}: "*I did not use condoms, I trusted, I thought I lived with the person inside the house, right? I thought she had nothing" (Abel).*

Interviewees consistently reported that they always worked to help their husbands to keep the house, reinforcing the representation that the man was the provider and they only contributed, did not cultivate vices, did not drink and were monogamous. Even demanding recognition of that role of collaborator/mainstay of the home, the women did not mention in their narratives the discussion about condom negotiation. After all, the relationship was built on trust, which forbids them to discuss the matter. The visibility of their social identity, of being a respectable/ worthy female figure, runs

through all of this organized structure in the sense of continuing to maintain the domestic obligations of a married woman.

It is noted that women, even when infected by their partners, have not taken the initiative to break the union. On the other hand, the men who were into a committed homosexual relationship distanced themselves from their partners after having knowledge of the disease. Otherwise, it was possible to locate in the words of women that there was no claim for their associates to be monogamous; they had, in fact, the expectation that if there was a breach of the covenant the mate would take care, that is, he would use a condom. In the narrative of men who practiced homosexuality, there was the thought that there could be no extramarital relationship, since it would be considered breaking the commitment.

It is worth to remember that the heterosexual men infected have not acquired the disease through their wives, but through partners outside of marriage, or even for marrying other carriers after the installation of the virus. This prevented the analysis, in this research, of their behavior if they had been infected by their partners. In this case, what would be the possible demands and attitudes towards them (abandonment/care/blame)? Note that underlying to women's stories there is the record of the fact that the *polluted subject* is the husband and *polluting* his wife would not characterize the suspension of the role of caretaker, whether of the home, children, household duties and her husband.

In the imaginary of these interviewees, they should continue to conform to this role. For Gilligan³⁹, this category is part of the representative pertaining of women. Thus, the study authorizes us to note that there is a double stand when it comes to heterosexual and homosexual relationships (men who have sex with men). It is worth noting that in the sample there was no woman who had sex with another.

One may say then that it is possible to register a differentiated lens between women and men with regard to affective-sexual/relationship expectations - which can be explained by gender modeling, which refers to the socialization of individuals. Another important fact is that all the interviewees and males with female subjectivity evidenced to have trouble talking with their partners about sex, love and emotional needs. One interviewee even mentioned in a faltering voice that in his sexual practices there was no kissing. "*And [the sexual partner] said: this is how it should be. There was never kissing" (Abel)*. Asked about the reason, the carrier said that the partner, on their first encounter, even without knowing about his HIV status, it was soon determined that the practice should occur without kissing; although embarrassed, the narrator did not question. The relationship had already lasted six years. In turn, men who related to women have made it understood that they wouldn't use condoms, or did not discuss sex with their partners, because they thought that this issue was not essential. The important part was the development of techniques of the sexual game.

It was observed also how the social life of the virus carrier was structured. All interact socially within their own groups that develop therapies for HIV/AIDS and are creating new circle of friends with the same uniqueness: that of having HIV/AIDS. Both males and females pointed out as a positive factor of contamination the fact that they met others affected by the syndrome and established affective and social relationships. The social and affective relations, however, are *truncated*, what was then called in this study of *ghettos of survival*.

The immersion in the category of *an individual who stands outside the accepted structures and enters into a marginal region is at the mercy of a power capable of eliminating or making him a man*⁴⁰. In this sense, carriers seek to protect themselves by relating with other carriers, regardless of sexual orientation. This sociability among *polluted subjects* would be, perhaps, a way to justify its embodiment marked by the dominant morality, built within the exclusive behavioral rules, which catalogues socializing with people with HIV/AIDS as dangerous and deviant.

As for prejudice, it was realized that although interviewees did not realize the fact that they themselves create, at times, the vilification of their own image, the notion of polluted and polluting individual is internalized into any environment they enter.

However, the investigated claim that the *pure* subjects are the ones who will judge them. Ismenia, in her testimony, stared at the ceiling as if trying to find something firm and flat in order to showcase her process of rejection, since she lives separated from her son and now has no job. Making an analogy with the thought of Eisenbruch (*apud* Helman)⁴¹, the interviewee would be experiencing *cultural grief* - that would be a pain for the loss of connection points that drove her who she was and how she should run her life. Thus, the imbalance permeates their existence, forcing the subject to find mechanisms to survive in order not to perish in the symbolic death. Translated, it would be a way to survive rather than perish socially: *"Imagine if you write here [points to forehead] AIDS, I'll be stoned (...)Imagine this HIV disease that is contagious (...)This cross is very heavy. I think there is still much prejudice in the matter of accepting the disease, which is sex-linked (...)It is an embarrassment for those who are carriers"* (Carlos).

In the statement above is observed a profound reflection on prejudice, which allows simultaneous capture of the appreciation of feelings such as pain, exclusion, violence and guilt to which the respondent is submitted, and the importance for society to urgently discuss the redirection of imaginary and social roles. The various instances on which the daily violence is structured tend to legitimize themselves, becoming a new interaction pattern⁴². To combat such legitimate violence is one of the challenges to scholars of intervention bioethics.

Final considerations

Evaluations effected by respondents show that the ethical reference points defended by intervention bioethics like otherness, tolerance, responsibility and protection, should be thoroughly debated in preventive activities planned in relation to HIV/AIDS, in the process of patient care, in educational campaigns to the general population, directing the discussion to the realm of the moralities inserted in the syndrome and also scrutinize the social imaginary that surrounds the contaminated subject. In this case, the value of otherness is precisely the subject recognizing his diversity and seeking to realize that it is not necessary to be *pure* to accept and be accepted.

For that to happen, moral values and the morals that facilitate and/or impede the social understanding of the disease need to be disseminated in schools, the media, the family, in government decisions, in order to provoke a reassessment by the existing social organization, changing or debating the categorization that surrounds the HIV/AIDS patient, a categorization that can be used as a tool of inclusion or exclusion within the dominant community. To discuss these issues in light of bioethics at all possible institutions would certainly be a means of trying to protect the subjects from the condemning evaluations of others and of himself.

The processes of identity and exclusion are a social construction in which the destitute can or cannot digest the

concept consciously or unconsciously, adopting a posture of self-protection as to register or not the recognition process, with a single purpose: to preserve himself. The categorization is a value that surrounds more sharply those who feel vulnerable. Thus, intervention bioethics defends that HIV/AIDS patients need to be protected not only by organized society, but mainly by the state, with a view to public policies that allow, in fact, the empowerment of individuals together and not only at the individual level.

Further explaining this position, one appropriates the idea that by working the individual, of course, you can not produce significant changes in the social classification of the collective, because one person can not change the value judgments given to the disease. However, it is believed that if people are worked within institutions such modification may be one of the ways to protect the patient, discussing the subjectivities involved in the process of being a *polluted/polluter subject*.

Gender issues are exposed when one realizes that marriage is based on trust: the women in the study did not expect their husbands could fail to protect them. It is part of their social representation that their husbands would not bring them any harm – in this case a disease. The women anchored themselves in three possible reasons for not using the condom they were monogamous; their husbands protected them, if they had relations outside of marriage, it was the husband's responsibility to protect themselves.

In its social representation the disease is seen as able to install itself in those who are transgressors, which would distance them from a possible contamination. However sex, for some men in this study, was considered a physiological need that should be practiced, even aware that the sexual act was not being performed safely.

To discuss this issue in the institutions and government agencies working with AIDS will certainly be a fundamental step in the process of deconstructing prejudice. It must be emphasized in the context of inattentive educational measures, beyond gender issues and power relations embedded in them, the fundamental importance of this discussion for the insertion of the carrier in the society that excludes him³².

It is believed that people's quality of life is a fundamental factor for them to obtain true freedom. In this line of reasoning, empowered individuals mean social, political and economic progress for the nation, strengthening the role and responsibility of the state to promote public policies that promote the empowerment of and effectively protect people⁴³. It could be argued that a person with just their basic needs met has a more integral construction as a

human being and citizen, becoming capable of making choices.

Parker⁴⁴ also warns that it is necessary to increase understanding and awareness of the individual to *individual vulnerability and social vulnerability*. To reach this stage of registration, however, it would be imperative to start the debate at school not only in Brazil but also in all the peripheral countries of the world, to try to deconstruct prejudice. So it is defended, in the epistemological foundation of intervention bioethics, a different view to the HIV/AIDS patients, and especially a unique lens for infected women.

Accordingly, Gonçalves and Varandas³² point to the dangers of moral evaluations built around the disease, including the gender differences that, through the look of a thoughtless society said to be *healthy*, may be distorted. We support the need to work moral values in the included society. When excluding the infected individual from society, the society has become more diseased than one who suffers the disease. The retirement imposed to the patient is morally reprehensible in bioethical discourse. Working moral standards mechanisms for the institutions is undoubtedly one of the ways to deconstruct the prejudice that surrounds the carrier.

The authors acknowledge CAPES/MEC for research funding.

Resumen

Ética y desconstrucción del prejuicio: dolencia y polución en el imaginario social sobre el VIH/Sida

Este artículo presenta resultados de pesquisa en la cual fueron oídos 15 portadores del VIH/Sida que recibieron apoyo psicosocial tras descubrir que eran seropositivos. La técnica para la interpretación de los datos fue el análisis de discurso, por medio de la cual se averiguó en los comentarios: i) si había registro de prejuicio por estar contaminados con el virus; ii) si se sentían agentes de polución y polucionantes; iii) si ese registro era abstraído por los propios portadores o si advenía de una lectura externa ultrapasada por el mismo; y iv) si ese apuntamiento era diferenciado en la percepción de mujeres y de hombres. La discusión tuvo como foco las cuestiones de género, los procesos de socialización, las moralidades dominantes y los enfrentamientos morales, imbricadas en el proceso de enfermar y examinadas a la luz de los referenciales teóricos de la bioética de intervención. El estudio permitió concluir que el prejuicio en relación a la dolencia persiste, acentuando la dificultad para que esos pacientes alcancen una vida digna.

Palabras-clave: Bioética. VIH. Síndrome de inmunodeficiencia adquirida. Conducta (imaginario social). Prejuicio. Sexualidad. Identidad de género.

Resumo

Ética e desconstrução do preconceito: doença e poluição no imaginário social sobre o HIV/Aids

Este artigo apresenta resultados de pesquisa na qual foram ouvidos 15 portadores do HIV/Aids que receberam apoio psicossocial após descobrirem ser soropositivos. A técnica para a interpretação dos dados foi a análise de discurso, por meio da qual se averiguou nas falas: i) se havia registro de preconceito por serem contaminados com o vírus; ii) se sentiam-se agentes poluídos e poluidores; iii) se esse registro era abstraído pelos próprios portadores ou se advinha de uma leitura externa perpassada pelo mesmo; e iv) se esse apontamento era diferenciado na percepção de mulheres e de homens. A discussão teve como foco as questões de gênero, os processos de socialização, as moralidades dominantes e os enfrentamentos morais, imbricadas no processo de adoecimento e examinadas à luz dos referenciais teóricos da bioética de intervenção. O estudo permitiu concluir que o preconceito em relação à doença persiste, acentuando a dificuldade desses pacientes em alcançar uma vida digna.

Palavras-chave: Bioética. HIV. Síndrome de imunodeficiência adquirida. Comportamento (imaginário social). Preconceito. Sexualidade. Identidade de gênero.

References

1. Douglas M. Pureza e perigo. Lisboa: Edições 70; 1991.
2. Sontag S. A doença como metáfora. Rio de Janeiro: Edições Graal; 1984. p.10.
3. Berlinguer G. A doença. São Paulo: Hucitec; 1988.
4. Garrafa V. O processo saúde-doença. *Humanidades*. 1990;7(1):68-75.
5. Duarte LFD, Leal OF, organizadores. Doença, sofrimento, perturbações: perspectivas etnográficas. Rio de Janeiro: Fiocruz; 1998.
6. Sontag S. Op.cit. p. 76.
7. Goffman E. Estigma: notas sobre a manipulação da identidade deteriorada. 4ª ed. Rio de Janeiro: LTC;1988. p.14.
8. Garrafa V. De uma bioética de princípios a uma bioética interventiva. *Bioética*. 2005;1(2):112-32.
9. Garrafa V, Porto D. Intervention bioethics: a proposal for peripheral countries in a context of power and injustice. *Bioethics*. 2003;17(5-6):399-416.
10. Beauchamp TL, Childress JF. Princípios de ética biomédica. São Paulo: Loyola; 2002.
11. Garrafa V, Kottow M, Saada A, organizadores. Bases conceituais da bioética: enfoque latino-americano. São Paulo: Gaia; 2006.
12. Foucault M. A ordem do discurso. 7ª ed. São Paulo: Loyola; 2001.
13. Sherwin S. No longer patient: feminist ethics of care. Philadelphia: Temple University Press; 1992.
14. Wolf S. Erasing difference: race, ethnicity and gender in bioethics. In: Douchin A, Purdy L, coordinators. Recent embodying feminist bioethics advances. New York: Rowman & Littlefield; 1999. p. 65-81.
15. Wolf S, coordinator. Feminism & bioethics: beyond reproduction. Oxford: Oxford University Press; 1996. Chapter Introduction: gender and feminism in bioethics; p. 3-33.
16. Tong R, Anderson G, Santos A, coordinators. Globaling feminist bioethics: crosscultural perspectives. Boulder: Westview Press; 2001. Chapter Is a global bioethics possible as well as desirable? A millennial feminist response; p. 25-36.
17. Oliveira F. Feminismo, raça/etnia, pobreza e bioética: a busca da justiça de gênero, antirracista e de classe. In: Garrafa V, Pessini L, organizadores. Bioética: poder e injustiça. São Paulo: Loyola; 2003. p.345-63.
18. Bandeira LM. Relações de gênero, corpo e sexualidade. In: Galvão L, Diaz J, organizadores. Saúde sexual e reprodutiva no Brasil: dilemas e desafios. São Paulo: Hucitec, Population Council; 1999. p.181-2.
19. Gonçalves EH. Da gramática dos sonhos e da realidade: uma leitura bioética das campanhas educativas governamentais de prevenção ao HIV/Aids e sua aplicabilidade às mulheres casadas [dissertação]. Brasília: Universidade de Brasília, Faculdade de Ciências da Saúde; 2002.

20. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. São Paulo: Hucitec, Abrasco; 1999.
21. Ferreira MM, coordenador. Entrevista: abordagem e usos da história oral. Rio de Janeiro: FGV; 1994. 172 p.
22. Seidl EME, Silva MA. Integrando assistência, pesquisa e ensino da atenção a pessoas vivendo com HIV/Aids: a experiência do Projeto Com-Vivência. In: Primeiro Congresso Brasileiro de Extensão Universitária; 2002; João Pessoa. João Pessoa: EDUEPB; 2003. v. 1 p.296-7.
23. Berlinguer G. Op.cit. p.38.
24. Parker R. Na contramão da Aids: sexualidade, intervenção, política. Rio de Janeiro: Abia; 2000. 141 p.
25. Porto D, Garrafa V. Bioética de intervenção: considerações sobre a economia de mercado. Bioética. 2005;13(1):111-23.
26. Sherwin S. Op.cit. p.341.
27. Bourdieu P. A dominação masculina. Lisboa: Gradiva; 2002.
28. Kottow M. Participación informada en clínica e investigación biomédica: las múltiples facetas de la decisión y el consentimiento informados. Santiago de Chile: Unesco; 2007.
29. Berlinguer G. Bioethics, power and injustice. In: Garrafa V, Pessini L, organizadores. Bioética: poder e injustiça. São Paulo: Loyola; 2003. p. 45-58.
30. Douglas M. Op.cit. p.163.
31. Foucault M. Vigiar e punir. 25ª ed. Petropolis: Vozes; 2002.
32. Gonçalves EH, Varandas R. O papel da mídia na prevenção do HIV/Aids e a representação da mulher no contexto da epidemia. Ciênc Saúde Coletiva. 2005;10(1):229-36.
33. Douglas M. Op.cit. p.15.
34. Berer M, Ray S. Mulheres e HIV/Aids. São Paulo: Brasiliense; 1997.
35. Gonçalves EH, Guilhem D. Leitura bioética das campanhas educativas governamentais de prevenção ao HIV/Aids e sua aplicabilidade às mulheres casadas. In: Siqueira JE, Prota L, Zaccaro L, organizadores. Bioética: estudo e reflexões 4. Londrina: Cefil; 2003. p.75-108.
36. Guilhem D. Escravos do risco: bioética, mulheres e Aids [tese]. Brasília: Universidade de Brasília, Faculdade de Ciências da Saúde; 2000.
37. Parker R. A construção da solidariedade: aids, sexualidade e política no Brasil. Rio de Janeiro: Abia, IMS-UERJ, Relume-Dumará; 1994. Capítulo A aids no Brasil: a construção de uma epidemia; p.39-48. (Série História Social da Aids, vol. 3)
38. Knauth DR. Subjetividade feminina e soropositividade. In: Barbosa RM, Parker R, organização. Sexualidades pelo avesso: direitos, identidades e poder. Rio de Janeiro: IMS/Uerj; 1999. p.121-36.
39. Gilligan C. Uma voz diferente. Rio de Janeiro: Rosa dos Ventos; 1982.
40. Douglas M. Op.cit. p.118.
41. Helman CG. Cultura, saúde e doença. 4ª ed. Porto Alegre: Artmed; 2003. p.277.

42. Suárez M, Bandeira IM. A politização da violência contra a mulher e o fortalecimento da cidadania. In: Bruschini C, Unnbehaum SG, organizadoras. Gênero, democracia e sociedade brasileira. São Paulo: FCC, Ed.34; 2002. p.295-320.
43. Garrafa V. O Brasil deve buscar respostas bioéticas próprias. *Radis*. 2004 ago;(24):32-3.
44. Parker R. Na contramão da aids: sexualidade, intervenção, política. Rio de Janeiro: Abia; 2000. Capítulo Mudança de paradigmas na intervenção e pesquisa de HIV/Aids: comportamento, cultura e política; p. 65-78.

Received: 2.17.10

Approved: 1.14.11

Final approval: 3.16.11

Contacts

Erlí Helena Gonçalves - *erlli6@hotmail.com*

Lourdes Maria Bandeira - *lourdesmbandeira@yahoo.com.br*

Volnei Garrafa - *volnei@unb.br*

Erlí Helena Gonçalves - AOS 8, bl. B, aptº 406, Octogonal, CEP 706660-082. Brasília/DF, Brasil.

Authors participation in the study

Each of the authors worked in every preparation stage of the article, which derives from Erlí Helena's PhD dissertation, with Volnei Garrafa as advisor and Lourdes Bandeira as co-advisor.