REVRENE
NORTHEAST NETWORK NURSING JOURNAL
ISSN ON LINE 2175-6783

Original Article

SOCIAL REPRESENTATIONS OF SEXUALITY DEVELOPED BY WOMEN IN THE CONTEXT OF AIDS

REPRESENTAÇÕES SOCIAIS SOBRE SEXUALIDADE DE MULHERES NO CONTEXTO DA AIDS

REPRESENTACIONES SOCIALES ACERCA DE LA SEXUALIDAD DE MUJERES EN EL CONTEXTO DE LA SIDA

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This study aimed to understand the social representations of sexuality, developed by women aged 50 and older with or without HIV/AIDS. This was a research with qualitative approach, based on Social Representations Theory, carried out in Fortaleza-CE, Brazil, with 44 women, 22 diagnosed with and 22 diagnosed without HIV/AIDS. We used the techniques of semi-structured interview and non-systematic observation. Data were submitted to content analysis and two main categories were verified: concepts on HIV/AIDS and experiences of sexuality. The results showed that for the women living with the disease there was a mix of anxiety, stigma, socioeconomic difficulties, disruption of emotional bonds, guilt and fear. Among women diagnosed without, a low perception of the risk of acquiring the infection and the fear of discovering the seropositivity, come from the misinformation on the disease. Studies on the issues of HIV/AIDS infection in women aged 50 and older should be widely encouraged, in order to support the development of actions and prevention programs addressed to this population.
Descriptors: Acquired Immunodeficiency Syndrome; Sexuality; Women.

Este estudo objetivou apreender as representações sociais sobre sexualidade, elaboradas por mulheres com 50 anos ou mais portadoras do HIV/Aids ou não. Pesquisa com abordagem qualitativa, fundamentada na Teoria das Representações Sociais, desenvolvida em Fortaleza, CE, Brasil, com 44 mulheres, 22 com diagnóstico e 22 sem o diagnóstico. Foram utilizadas as técnicas de entrevista semiestruturada e observação assistemática. Os dados foram submetidos à análise de conteúdo que apresentou duas categorias principais: concepções sobre o HIV/aids e vivências da sexualidade. Os resultados revelaram que para as mulheres com o diagnóstico, o convívio com a doença era permeado de angústia, estigmas, dificuldades socioeconômicas, rompimento dos vínculos afetivos, culpa e medo. Entre as mulheres sem diagnóstico, a baixa percepção de risco da aquisição da infecção e o medo de descobrir a soropositividade decorrem da desinformação sobre a doença. Estudos sobre as questões de infecção pelo HIV/Aids em mulheres maiores de 50 anos devem ser amplamente incentivados, visando a subsidiar o desenvolvimento de ações e programas de prevenção voltados para esta população.
Descritores: Síndrome de Imunodeficiência Adquirida; Sexualidade; Mulheres.

El objetivo fue comprender las representaciones sociales sobre sexualidad, desarrolladas por mujeres con 50 años o más con VIH/SIDA o no. Investigación con enfoque cualitativo, basada en la Teoría de las Representaciones Sociales, desarrollada en Fortaleza-CE, Brasil, con 44 mujeres, 22 con diagnóstico y 22 sin. Se utilizaron las técnicas de entrevistas semiestructuradas y observación asistemática. Los datos fueron sometidos a análisis de contenido que presentó dos categorías principales: concepciones sobre el VIH/SIDA y experiencias de la sexualidad. Los resultados señalaron que para las mujeres con diagnóstico, el convivio con la enfermedad era lleno de ansiedad, estigmas, dificultades socioeconómicas, interrupción de vínculos afectivos, culpa y miedo. Entre las mujeres sin diagnóstico, baja percepción de la adquisición de la infección y temor de descubrir la seropositividad, debido a la desinformación sobre la enfermedad. Estudios sobre las cuestiones relativas al VIH/SIDA en mujeres con 50 años deben ser ampliamente incentivadas, para apoyar el desarrollo de acciones y programas de prevención dirigidas a esta población.
Descriptores: Serodiagnóstico del SIDA; Sexualidad; Mujeres.

[*] Extracted from the Dissertation "Representations and vulnerabilities of women aged 50 and older in the context of AIDS", presented to the Academic Master's Degree in Clinical Health Care, State University of Ceará – UECE, 2010.

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INTRODUCTION

In the 1980s, issues related to the Healthcare model in Brazil marked important changes guided by the pursuit of fairness in the health access and in the construction of the Unified Health System (SUS), leading to advances in the reorganization of this sector. During this period, the health injuries caused by the human immunodeficiency virus (HIV) epidemic have caused great impact on society, which led it to be considered an important public health problem [1]. Despite the search for effective diagnosis and therapy, in order to minimize morbidity and mortality caused by the disease, the number of people with HIV and the resulting death toll reached alarming proportions.

The prevalence of AIDS cases is concentrated in the age group between 25 and 49 years. However, there is an increase in the number of reported cases of people over 50 years, which represents the second highest incidence of AIDS by age in Brazil [2]. Among the 53,189 notifications in this population, 34,864 were male and 18,325 were female [3]. The first AIDS case in the country among people over 50 years was reported in 1982 in the Southeast, and the first case in Ceará happened in 1989, with a male person through sexual transmission [4-5]. The incidence rate for men in this age group increased from 5.8 to 9.4, and among women it increased from 1.7 to 5.1 per 100,000 inhabitants [6].

Although the majority of AIDS cases are found in the age group from 25 to 49 years, we verify over the time series a proportional increase of AIDS cases in individuals aged 50 years and older, going from 7% in 1996 to 13% in 2006. The incidence rate in this population has doubled between 1996 and 2006, going from 7.5 to 15.7 cases per 100,000 inhabitants. The increase was identified in all regions, especially in the Northeast, which had an increase from 2.8 in 1996 to 7.6 in 2006 [4].

Regarding women older than 50 years, we must consider that besides the "aging" of the pandemic, there is a clear feminization trend of HIV/AIDS, with significant decrease of the male/female ratio.

The social vulnerability of women to HIV/AIDS could be explained by the interrelationship of different type of factors, which includes three dimensions: the individual, due to the limited access to information on prevention and means to achieve them, such as condoms and educational reports; the social, resulting from the access to public services, such as education and health, able to reduce the individual vulnerability; and, finally, the political, determined by the design and implementation of health policies to fight HIV, articulated to public policies of female population protection [7].

Living with seropositivity comes with favorable conditions for mental suffering or illness, and understanding the confrontation with issues related to AIDS among women is complex, because it carries the stereotype of a shameful disease, strongly associated with connotations of moral and social devaluation [8].

It is known that the results of scientific research have provided advances in transmitting information about HIV/AIDS, optimizing and intensifying the patients' survival. However, we have been reflecting on stigmas, behaviors and fears caused by the disease. And such reflections have raised the following questions: how do women aged 50 and older, living with HIV/AIDS, understand their illness? How do they experience their sexuality? And how do women in this age group understand the issue?

We believe that answering these questions will enable greater knowledge about the vulnerabilities that women aged 50 and older living with HIV/AIDS are exposed to, the necessary knowledge to design public health policies and strategies that contribute to their better quality of life.

Given the above and in order to contribute to more effective health practices targeted at women aged

50 years and older with or without HIV/AIDS, this research aimed to understand the social representations of sexuality developed by this social group.

METHOD

This is an exploratory descriptive research with multimethod approach, based on the Social Representation Theory (SRT), carried out in Fortaleza-CE, Brazil, in an outpatient clinic to patients living with HIV/AIDS, of an AIDS reference hospital in the state of Ceará, and in a social group of elderly at an Urban Social Centre (USC).

We believe that the human being is a symbolic animal within a social environment, capable of guiding the representation that defines the field of communication, of culture, with their beliefs and values, guiding their conducts. The SRT was chosen as theoretical framework for this study, for it considers the possibility that represents how individuals and groups act in the face of HIV/AIDS and its prevention, enabling an individual and collective apprehension of the phenomenon.

44 women followed-up in the services mentioned participated in the research, interviewed from September to November 2009. Of these, 22 were diagnosed with HIV/AIDS (Group A) and 22 were not diagnosed with HIV/AIDS (Group B), we identified the speeches assigning the letter A to represent women diagnosed with and B for women diagnosed without and the number that represents the order of the interviews.

As inclusion criteria for the subjects in Group A we considered: female, aged 50 and older, diagnosed with HIV/AIDS for at least one year and being assisted in the specialized HIV/AIDS outpatient clinic in the reference institution. Regarding the subjects in Group B, we included females, aged 50 and older, diagnosed without HIV/AIDS and participating in the elderly social group of the USC. We excluded from the study women with health changes that made impossible the communication.

For data production we used the techniques of semi-structured interview and non-systematic observation. The semi-structured interview was organized in two parts, the first with socio-demographic data and the second with guiding questions relating to the topic. We used the non-systematic observation to complement the analysis of the interviews.

The interviews were submitted to the thematic content analysis technique, for providing a better way to investigate and analyze the messages obtained, because, due to its advantages, it enables the apprehension of subjective ideas of interviewees, related to beliefs, values and opinions in their everyday actions [9].

These data were organized according to the following steps: pre-analysis, material exploration, processing the results, inference and interpretation. The use of this technique consists in explaining and systematizing the content of the messages and their expressions [9].

As mentioned, the sample consisted of 44 interviews, and we selected the paragraph as context unit and the sentence as record unit.

We emphasize that the study was approved by the Research Ethics Committee of the hospital where the study took place, under protocol No. 018/2009. The individuals were informed about the research topic and objectives, and they also signed an informed consent form, as required by Resolution No. 196/96 of the National Health Council/Ministry of Health[10].

RESULTS AND DISCUSSION

Characterization of the subjects

Women in group A, i.e. with HIV/AIDS, were in the age group from 50 to 64 years, with an average age of 54 years. Of these women, 10 had eight or more years of study, seven with four to seven years of study, two with one to three years of study and three of them admitted not having studied.

As for the monthly family income, 12 women said they lived with a monthly income of one to three minimum wages, eight with up to one minimum wage, one with four to six minimum wages and one with more than seven minimum wages. Of these, ten supported the home with another relative, eight alone and four were financially dependent on their children.

With regard to marital status, nine women were widow, four single, four divorced, three married and two were informally separated, i.e. without regular legal situation.

We aimed to know the family situation of the participants and found that only five of them were living alone, whereas 17 were living with relatives (partners, children, grandchildren, nephews, siblings).

With regard to religion, 15 women reported being Catholic, five Protestant and two reported other religion. As for HIV/AIDS infection, 12 women were seropositive, while 10 women had already developed AIDS.

Among women in group B, diagnosed without HIV/AIDS, the age ranged between 53 and 80 years, with an average of 67 years. Like in the other group, 10 women reported eight or more years of education, whereas eight had one to three years of study, three had four to seven years, and only one reported not having studied. In this group, eleven women reported living with a monthly family income of one to three minimum wages. Five women reported family income below one minimum wage, four lived with four to six minimum wages, and only two with more than seven minimum wages. Unlike in the group of women diagnosed with HIV/AIDS, 14 women supported the home alone, while three had help from other family members and five were financially dependent on their children.

With regard to marital status, six women were widow, five single, four were in stable union, three were married and four were not living with their companions, being three separated and one divorced. The question about the family situation revealed that only two women were living alone, whereas the others were living with relatives (partners, children, grandchildren, siblings, nephews, sons and daughters-in-law). Regarding religion, 17 women were Catholic and five Protestant.

Data obtained through the guiding questions listed in the semi-structured interviews were submitted to content analysis technique, potentially subjective data.

Eight categories of analysis emerged from the analysis of interviews, with their respective subcategories: 1) Concepts on HIV/AIDS (technical-professional; sociocultural; religious; and clinical symptomatology); 2) Perceptions on HIV/AIDS (self and hetero-perception); 3) Self-perception (self and hetero-perception); 4) Causes of HIV/AIDS (scientific; sociocultural; and transmissible); 5) Perceptions on sexuality (self and hetero-perception); 6) Experiences of sexuality (sociocultural influence; sex in old age; and sex with HIV/AIDS); 7) Psycho-affective perceptions (fear of death; prejudice and discrimination; death and HIV/AIDS; support and/or helplessness situations); 8) Beyond HIV/AIDS (socioeconomic conditions; family everyday life and drugs; and family experiences).

Of these, we chose to present two categories considered of great relevance to the topic: Concepts on HIV/AIDS and Experiences of sexuality, since these categories better define the social representation of women on AIDS and on sexuality in this context.

Concepts on HIV/AIDS

This category refers to the subjects' concepts on HIV/AIDS and includes a mix of concepts acquired over time, developed through cultural influence, experience of signs and symptoms of the subjects themselves, besides religious aspects. It is divided into three subcategories: sociocultural, clinical symptomatology and religious aspects, illustrated in Table 1.

Table 1 - Distribution of frequencies and percentages of the category and subcategories regarding the concepts on HIV/AIDS, according to the groups diagnosed with and without HIV/AIDS. Fortaleza, CE, Brazil, 2011

Subcategory	Women diagnosed with HIV/AIDS	%	Women diagnosed without HIV/AIDS	%	Total	%
Technical-professional	97	32,0	19	21,8	116	30,0
Sociocultural	147	48,5	63	72,4	210	53,8
Clinical symptomatology	25	8,3	2	2,3	27	6,9
Religious	34	11,2	3	3,5	37	9,4
Total	303	100,0	87	100,0	390	100,0

When comparing the social representations between the two groups, we verified that the women involved in this context presented greater knowledge on the theme, which was revealed by the difference between the units of analysis of the two groups: 303 units in the group of women diagnosed with HIV and 87 in the group diagnosed without.

Concepts on HIV/AIDS anchored in technical-professional aspects

Here we identified the several associations related to HIV/AIDS, as the recurrence of the concept that refers to sexual transmissibility, which reflects the media influence and leads to a reflection on the power that it has on people, attributing them a responsibility that goes beyond mere information. *Because I believe that is not transmittable, only through sex* (A1).

The awareness of the existence of two phases of infection comes with an association to the human productive capacity, reminding the importance of work in the individual's life: *it is one thing to be carrying the HIV virus, because you are able to work, you have the energy. You are able to act like a normal person, but AIDS is a complicating factor. AIDS itself means a series of weaknesses, of impairments that make people inoperative sometimes* (A1).

The certainty that there is no cure also emerged clearly, leading women diagnosed with HIV/AIDS to translate this insecurity compensating the lack of cure with the possibility of treatment. In this context, HIV/AIDS takes on the status of chronic degenerative disease: *but they don't say, well, that HIV is a chronic disease; it has treatment, like tuberculosis does* (A5).

The study reports that for the people interviewed, AIDS brought up, in a new and scary way, the ghosts build in the social imagery about sexuality and death, physical disfigurement and weakness, vulnerability and risk seen in the face of the others. Thus, the stigma, the pain of their own illness and the pain in the others' eyes, the fear of rejection, especially in the workplace, and the suffering caused by prejudice and the possibility of being discriminated start to strongly affect the people interviewed. Feelings of anxiety, persecution and doubt may represent sources of stress in their daily lives[11].

Concepts on HIV/AIDS anchored in sociocultural aspects

In this subcategory we highlighted the knowledge built on common sense, with concepts addressed at incurability, at the "immoral" aspect present in the sexual transmissibility of the disease. Allied to this, the association of HIV/AIDS to end times disease takes up the idea of risk groups, a fact that led undiagnosed women to believe in non-vulnerability because they were not sexually active or had only one partner.

The same culture recommended that women should be submissive to their husbands, respecting, serving and accepting them without limits,

unconditionally: *I've never been a woman that denied anything to him. Thank God, the way he came to me, I served him well. And we are married, we have a husband, the husband does not understand us, and whenever he needs, at that time, he wants us to be happy* (B3).

Some differences can be observed when facing the illness or the seropositivity situation, as the individual ages or gets contaminated with HIV or acquires the infection or the disease itself, in the later stage of his life.

On the other hand, there are also registers of situations in which the disease, despite all its connotations of pain, suffering and death, comes with gains and improves the lives of women with HIV/AIDS. *Today I have another life, because after I was contaminated my life improved; I mean it with all my heart, after I was contaminated my life changed for the better* (A2).

It becomes clear that even before the great technological breakthrough of coping with the disease, the accumulated experiences, the antiretroviral advances, which have provided better quality of life and driven people away from the lethal nature of the disease, living with HIV/AIDS still causes great suffering due to stigma, prejudice and discrimination that comes with the disease[12].

The information disseminated by the media, based on the progress of antiretroviral therapy and the consequent improvement in signs and symptoms of the disease for those living with this condition, seems to cause a misunderstanding and underestimate its magnitude, causing lines of unconcern. *I have this problem, but this is not... that does not exist to me. Also, you just need to be careful and there is treatment* (A3).

Concepts on HIV/AIDS anchored in clinical symptomatology

This subcategory revealed that among women diagnosed without HIV, the speeches demonstrate the knowledge learned from other's experience, which pointed the weight loss as a modifying factor of the physical appearance, besides classifying the disease as worse than any other. *We're just "bones". As I have seen the people on television, like this, pale, with AIDS, with other diseases... but AIDS is worse, it destroys you all at once* (B2).

AIDS is represented as a disease that mistreats you, causing suffering and death. Also, living with this disease creates anxiety, stigma, socioeconomic difficulties, disruption of affectional bonds, guilt and fear.

People who present HIV/AIDS infection realize themselves often vulnerable to feelings of guilt, self-hatred and rejection. We found among the women in the study that they blamed themselves for the contamination. Among the different "blames", these women believe that their previous behaviors may have contributed to their contamination, for example, because of promiscuity and non-use of condoms[13].

Concepts on HIV/AIDS anchored in religious aspects

In this subcategory, the women diagnosed with HIV reported the relationship with the divine, assigning to God the responsibility of forgiving them, since they considered the disease as a punishment for their sexual behavior; furthermore, they assigned to God the power of healing, the strength and conditions to continue life. *I don't know if God wanted it, but I didn't care for myself, I didn't open my eye. Do you think that I was the only one who made love? I have sinned. No one has sex. I did and got the virus! It is not like that!* (A3).

It is worth mentioning the importance of religious belief among professionals and patients, in which the critical moment represented by the disease brings patients closer to believe in something beyond their lives. The confidence of trusting God arises from the possibility of having overcome previous difficult times experienced. Certainly, this kind of feeling is very important for people living with diseases that can lead to death at any time [14].

Experiences of sexuality

This category presents the units of analysis, in which women participating in the study expressed their experiences as sexual beings, exposing the cultural

influences surrounding issues of gender, age and HIV/AIDS itself. It is divided into three subcategories, according to table 2: sociocultural influences, sex in old age and sex with HIV/AIDS.

Table 2 - Distribution of frequencies and percentages of the category and subcategories of experiences of sexuality, according to the groups diagnosed with and without HIV/AIDS. Fortaleza, CE, Brazil, 2011

Subcategory	Women diagnosed with HIV/AIDS	%	Women diagnosed without HIV/AIDS	%	Total	%
Sociocultural influences	42	15,1	50	25,3	92	19,3
Sex in old age	86	31,0	146	73,7	232	48,8
Sex with HIV/aids	150	53,9	2	1,0	152	31,9
Total	278	100,0	198	100,0	476	100,0

Experiences of sexuality anchored in sociocultural influences

The thematic units identified indicated the gender issues to which the women were submitted. The culture that treated sex as something dirty and immoral, created only to promote the perpetuation of the species, caused great difficulties for future relationships. *So, I come from a culture where sexuality was nasty, it was disgusting... I don't know what they wanted to teach us with this, because it caused serious damages to the relationship* (B1).

These women lived their sexuality at a time when it was not accepted that women had more than one partner and it was imposed on them to trust unconditionally in their husband or partner. We also verified the difficulty in negotiating the condom use. *But I didn't have the courage to ask him to use condom* (B4).

Women diagnosed with HIV revealed no longer wish for sexual intercourse, due to the difficulty in explaining the need for condom use, without revealing their seropositive status. *Because if I do this with him... I'll always use condoms. One day he's going to ask why I keep demanding condom. Then, of course he will suspect something. So, I'd rather not have anyone else in my life* (A1).

A study carried out with women reveals that, regarding the use of contraceptive methods, the participants reported difficulty in negotiating with the partner to use condoms during sexual intercourse and reported inconsistent use of it. Others reported abstinence or reduction of sex intercourses as contraceptive method, which may sign the presence of difficulties in sexual experiences after the diagnosis of seropositivity[15].

Experiences of sexuality anchored in sex in old age

Sexuality was remembered by many women in the study as something that happened and that it's over. Many referred to this as a disappointing aspect of their lives. *I was disappointed a lot too. Oh, before I lived in the illusion that it was the best thing* (A5).

We consider the relevance of this subcategory because we believe that sexuality affects significantly the quality of life of human beings, considering that it is usually related to situations of personal well-being, regardless of age.

Some women diagnosed with HIV/AIDS mentioned the experience with other partners and the will of continuing an active sex life, describing the pleasure they felt in being able to remain active. *When I met this person, who is with me already for four years, a lot has changed. So, just in reminding that I have someone to hug, to kiss, to caress, this is a very nice strengthening, it's a pleasure* (A6).

The sexual experience of someone in old age is far from being understood and accepted by society as something healthy and natural. Prejudice and lack of information reinforce the stereotype of the absence of sex in this period of life, resulting in attitudes and behaviors that may increase the vulnerability of the elderly facing AIDS issues[15].

The same was not noticeable among women diagnosed without HIV, which when reporting their sexual experiences always referred to their husbands. *Today it is worthless for me. I've given up long ago. I belong only to God and that's it. And I don't even miss it, thanks to God. My husband and I have always gotten along very well* (B5).

With regard to women, we concluded that their femininity is being built through their experiences and the experiences with their sexual partners. Sexuality, however, evokes body proximity, and once it is not experienced, it becomes incomprehensible and not incorporated in subjectivity. Maintaining the sexual activity of women depends on several factors, such as physical, psychological, existence of partner and the sociocultural context[16].

Experiences of sexuality anchored in sex with HIV/AIDS

This subcategory included the units of analysis that described situations and behaviors reported by women on the experience of sexuality when living with HIV/AIDS.

Most women diagnosed with the infection reported not having sex life after knowing of the HIV/AIDS infection, some pointed to be painful and sacrificing, therefore representing an obstacle to experience new relationships. *It's something that stuck me, that affected me. It is painful for me, is a sacrifice and I think I'm being pretty bad to myself. Maybe I could be more affectionate, more caring, which I'm not, and sometimes I wonder what if I didn't have HIV, would it be any different?* (A7).

The fear of infecting someone, together with the difficulty of using condoms and negotiating its use, are also factors that influence the decision of these women in no longer having sex. *I guess I would never have the courage to have sex with someone, so I think that sexuality doesn't exist for me, even if using condom, I would not dare to have sex with anyone, I think about him* (A11).

The speeches represent life histories whose romantic relationships have been frustrated by the disappointment associated with the contamination by a disease that carries the stigma of death and suffering. *And we were so in love that I didn't even remembered that there was AIDS. And suddenly I was frustrated. I got married because I wanted to, because I liked him... but then came the disappointment* (A15).

HIV prevention programs should also take into account psychological, socio-economic and cultural factors that affect the vulnerability of this age group, before and after infection. And for a wider reach of their actions, the programs should be developed in places frequented by this group (day centers, recreation centers, ballrooms, bingos, etc.) and use a specific language to them[17].

FINAL CONSIDERATIONS

The social representations understood in this study allowed the identification of subjective aspects of women aged 50 and older in the context of HIV/AIDS, especially in understanding a biopsychosocial being surrounded by historical, social and cultural aspects.

With regard to sexuality, they conceived pain and sacrifice as social representations. Aspects of these women's life that deserve to be faced openly and without prejudice, encouraging an effective and efficient care, listening to fears and anxieties, and understanding that the social structure relegates them to a second plan, causing suffering and unprotected and unsatisfactory sexual practices.

It is important to emphasize that the ability to maintain an active sex life among people in old age, recognizing them as individuals able to maintain a full life in all aspects, must be associated with initiatives of prevention and assistance for Sexually Transmitted Diseases.

Moreover, we highlight the vulnerability of these women, since gender inequality allows an increasingly exposure to the risk of acquiring new infections and reinfections with resistant HIV strains, as well as maintaining the virus transmission chain.

Assessing the entire context in which the actions related to the topic are developed, we infer that there is

need to include the elderly, once the media only uses young people in prevention campaigns, so that the elderly realize themselves vulnerable to the risk of contracting HIV, bringing them closer to this reality.

Thus, studies involving issues such as HIV/AIDS infection in people aged 50 and older should be widely encouraged, in order to support the development of preventive actions and programs, justified by several reasons, among them changes in sexual behaviors that were not preceded by incentives for prevention, in a population that does not realize themselves vulnerable, particularly women that are historically and culturally in disadvantage when it comes to gender issues.

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Received: Apr. 19th 2012
Accepted: June. 6th 2012