



Women of different generations living with HIV: social representations about sexuality*

Mulheres de diferentes gerações que vivem com HIV: representações sociais sobre sexualidade
Mujeres de diferentes generaciones que viven con VIH: representaciones sociales sobre la sexualidad

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ABSTRACT

Objective: To analyze the social representations of women diagnosed with HIV about their sexuality considering generational characteristics. **Method:** Qualitative study, carried out with women who participated through interviews. The constituted corpus was processed by the Iramuteq software. The analysis was based on the Theory of Social Representations. **Results:** A total of 39 women participated in the study, aged between 18-76 years old and most of them had high school education, evoked the terms 'people' (301), 'partner' (277), 'children' (249), 'virus' (275) and 'want' (216). The younger ones accept to reveal and/or 'tell' about their condition to their partner(s) and family members, an aspect that is not revealed in the statements of women of other ages. For women aged 45 and over, children occupy a prominent place and for the older adults, the centrality of representation referred to self-censorship and maintaining the victim/guilty game. **Conclusion:** This study made it possible to identify processes of anchoring sexualities in terms of what 'cannot be revealed' beyond the family context. It should be noted that the elements 'sex', 'intercourse' conceived by common sense as a synonym for sexuality, regardless of generation, had low frequency.

DESCRIPTORS

Sexuality; HIV; Women; Population Groups; Nursing Care.

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INTRODUCTION

Sexuality is a dimension of human being related to internal and subjective structures, its experience meets a social construction and cultural contexts. In Foucault's perspective, it has been controlled since the 19th century by the sexuality device that regulates and normatizes bodies in a detailed way, as it controls populations and establishes truths from multiple discourses about sex and its pleasures⁽¹⁾.

Sexuality involves rituals, fantasies, symbols, representations and languages that are closely linked to the loving and erotic capacity to take care of themselves, the other and society. For its experience, conducts that limit the freedom to enjoy it in our world are defined⁽²⁾. Thus, women are directly affected by interdictions to sexuality through various body, sexual and reproductive rules that negatively impact their rights⁽³⁾.

The social discourses that produce genders, polarities and differences bear the marks of the patriarchy's political and power relations. Currently, although reluctant, they determine the meaning of sexuality, sexual practices and sex without respecting the differences. Thus, the expansion of the concept of women's health with the incorporation of reproductive rights in the 80s and 90s of the last century, in Brazil, establishes dialogues with heteronormative sexuality and allows the construction of political discussion fields beyond the traditional readings of health and legality⁽⁴⁾.

Nowadays, the Acquired Immunodeficiency Syndrome (AIDS) is closely linked to the experience of sexuality and the transgression of its rules. The idea of risk groups was an operational vector for the processes named heterosexualization, interiorization, impoverishment and feminization, demarcating the increase in the occurrence of new cases during the epidemic⁽⁵⁾. Topics such as vulnerabilities to the Human Immunodeficiency Virus (HIV) and its forms of prevention have contributed to problematizing the diversity of the population attended in public health services, including the difficulties of access involved in this process⁽⁶⁾.

Women living with HIV are particularly stigmatized. The positive diagnosis for the virus imposes several changes, mainly with regard to leisure, the experience of sexuality, work and relationships, in addition to the repercussions on physical and mental health⁽⁷⁾. Thus, when comparing the specificities of the AIDS epidemic, the generation category makes it possible to assess the vulnerabilities of groups that are located in centers that need greater protection.

The concept of generation has undergone different interpretations since its appearance in the field of human and social sciences in the second half of the 19th century. In this study, the generation will be understood in terms of the individual trajectories and their lifestyles, in social contexts from heterogeneous living conditions⁽⁸⁾. Thus, it should be noted that the generation category is considered the least explored, when associated with health demands and needs. However, in line with the understanding of gender and sexuality studies, which are located in the interdisciplinary field, the generational dynamics is relevant for participating in a broader social and cultural order⁽⁹⁾.

Based on these observations, studies using the Social Representations approach⁽¹⁰⁻¹¹⁾ (SR) makes it possible to capture the sensitivity of women who live with chronic diseases considering the impact directly on the experience of sexuality. Thus, addressing sexuality from the perspective of women in view of aspects concerning gender and generationality will contribute to respect the singularities, strive to strengthen the link to services, adherence to treatment and recognition as people with rights. The study aimed to analyze social representations of women diagnosed with HIV about their sexuality considering the generational characteristics.

METHOD

TYPE OF STUDY

This is an exploratory study because it allows the researcher to recommend a new interpretive discourse for the phenomenon it describes in the search for systematic interconnections with the context of the object being researched⁽¹²⁾. It is characterized as a study with a qualitative approach and its theoretical-methodological focus is the Theory of Social Representations (TSR), which is understood as a space for everyday production, where common sense is seen as an appropriate force to reinvent and displace the subject⁽¹¹⁾. In this study, it allowed to perceive the space where sexuality is constituted as an SR action.

SCENARIO

The study was carried out in a municipal health unit, the only one in operation as a Specialized Care Service (SCS), in Feira de Santana, Bahia state, the road axis in the North/Northeast of the country, whose female population is 292,643 inhabitants⁽¹³⁾. Nowadays, this service attends around 1200 women living with HIV in the micro-region and covers 28 cities, with a total of 1,184,358 inhabitants in the territory of the Bahia countryside.

POPULATION

Considering that out of the 36.7 million people living with HIV, 34.5 million are adults and 17.8 million are women over 15 years old, the age range allowed to study different stages of life. The participants comprised four groups aggregated by age: 18 to 29 years old (Group 1); 30 to 44 years old (Group 2); 45 to 59 years old (Group 3); 60 and over (Group 4). The inclusion criteria were: being over 18 years old, carrying out follow-up at the SCS selected for the study; knowing about the positive diagnosis for HIV; living with the diagnosis for at least six months and, being on Antiretroviral Treatment (ART). The exclusion criteria were: using medications only as a prophylactic measure regarding vertical HIV transmission or Treatment as Prevention (TasP).

This is an excerpt from a broader research, bringing together 39 out of a total of 191 women who participated in the study. Their insertion, in the main study, occurred in two moments. Initially, 191 women participated in the application of the Free Word Association Technique (FWAT) (moment 1), then 39 women were available to participate in

'disease' that intervenes in the dynamics of family relationships regardless of 'wanting' (216) or will.

AIDS, as the main consequence of HIV infection, was constituted as a cultural phenomenon with a strong moral connotation, carrying negative representations about lifestyle and sexuality, resulting from its association with the idea of a very active sexual life, and/or by the multiplicity of partners. When experiencing the diagnosis, women fear to reveal to their family how they experience their own sexuality. The following statements point to affective, psychic and attitudinal elements such as fear, shame, the need to hide the diagnosis and changes in the relationship with the partner.

He took the test and it was negative, I didn't speak to my partner right away, but with the lectures we have here I learned and told him (P 01, 38 years old).

The relationship with my partner was great, then it wasn't anymore, I even thought about separating because when we're honest and receive a news like this, it seems like the world is falling on our heads, my partner cheated on me a lot, I'm sure it was him who infected me because I never had any other guy, so I'm sure (P 25, 49 years old).

The term 'partner' assumes, from a gender perspective, that their oppression can influence the decision, for example, on the use of protective methods in affective-sexual relationships. Besides, it can influence the reinforcement of hegemonic representations about the "myth" of stable relationships. These aspects enhance and configure themselves as risk situations to which the participants were exposed, with regard to contamination by the virus, as can be seen in the following narratives:

I don't want my sexuality anymore, I'm young, I'm 31 years old, I found out about the virus because my partner and I did it, it's been a year since I had sex, my partner died (P 26, 31 years old).

We won't go around having sex with another one, because we also won't contaminate another person, even using condoms, so we have to stay with our partner (P 25, 49 years old).

Therefore, considering issues related to generation implied a disaggregation of the corpus by age (18-29 years old), made possible by Iramuteq through sub-corpus. Figure 2 shows the Word Cloud formed by the youngest women - group 1, from the frequency equal to or greater than 10.



Figure 2 – Word Cloud of young women, provided by Iramuteq software – Feira de Santana, BA, Brazil, 2019.

For the subgroup of younger participants, the term 'people' also organizes SR. The terms with high frequency: 'virus, so, know, stay and tell', refer to the idea of surprise regarding the challenge of living at the beginning of their active sexual life with the 'virus'. This organization reveals a need to 'know more', possibly associated with the need to know preventive measures and to cope with a 'disease' that is still stigmatized. The word 'tell' appears as a "new" element or act of courage that implies anticipating the discovery of the diagnosis as they reveal their condition to the 'partner'.

No one said anything here. If someone knows who your partner is, he will know it too, so I immediately tried to tell him. When you meet someone, just tell him as soon as possible (P 31, 29 years old).

You have several partners and you take medicine, use other methods such as condoms, but I was completely free in bed, during sex. Then, it got totally different, it was very frustrating after the virus (P 28, 26 years old).

For presenting the most frequent terms with great similarity, the clouds were analyzed together (Figures 3 and 4), formed with words with a frequency equal or greater than 10, which aggregate women from groups 2 and 3, each one represented in a specific cloud.



Figure 3 – Word clouds of adults, provided by Iramuteq software – Feira de Santana, BA, Brazil, 2019.

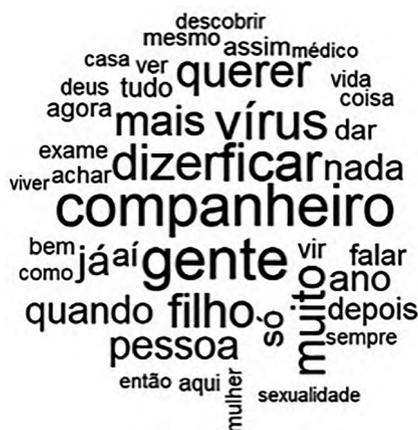


Figure 4 – Middle age Word Cloud, provided by Iramuteq software – Feira de Santana, BA, Brazil, 2019.

experiences, including affective ones. For the first situations of prejudice and rejection often occur within the family. In this regard, a study carried out in São Paulo points out the following main difficulties listed by people living with HIV: prejudice arising from the family and social context; managing their affective and sexual partnerships; managing treatment with a view to maintaining quality of life⁽¹⁸⁾.

In Figure 2, in which only the participation of women in group 1 is analyzed, the terms in greater evidence allow establishing links with situations, where discovering themselves HIV positive demands fidelity in a relationship that affective and sexually can no longer be pleasurable nor satisfactory. In this case, emotions tend to be the focus of greatest concern, in view of the problems that impel the disruption of social life. Thus, AIDS destabilizes and reorders, in an unexpected way, life trajectories and projects, through the experience of living with the disease.

When trying to achieve a satisfactory quality of life, interruptions in their life trajectory are necessary; rupture of interpersonal and occupational relationships, aspects that can lead to social isolation, depression, problems with sexuality and social relationships, which can compromise the mental and physical health of women⁽²¹⁾.

SR are dynamic, refer to the positioning and location of intersubjective awareness, and are mediated mainly by the language used in social spaces. Therefore, they aim to constitute perceptions and behavior on the part of individuals in their interactive processes⁽¹⁰⁾. For the participants in this study, the main problem faced after the diagnosis was prejudice. Considering this, the need to take medication daily and concerns related to the desire of being a mother permeate the periphery of representation.

With regard to adolescents, sexual vulnerability to HIV is based on several factors, for example, the early discovery of sexuality, multiple partners, greater sexual freedom, doubts about prevention, the need for group self-assertion and resistance regarding condom use⁽²²⁾. Some of these factors are consistent with the statements of the participants in this study. Likewise, they corroborate with a research carried out with a total of 23 women, who had a serological diagnosis between 11 and 19 years old. Who, in addition to being infected through sexual contact, also present situations of vulnerability, such as: disbelief or not using condoms, promiscuous partners or injecting drug users and submission to situations of violence⁽²³⁾.

Considering that, in our study, Figures 3 and 4 depict the groups with the largest number of participants and ages between 30 and 59 years old, the terms 'partner', 'people', 'person', 'children', 'virus', 'stay' and 'want', as well as the excerpts of statements refer to aspects related to stories of regret, suffering, fear and jealousy of the partner. In this sequence, the result of a research with women, point out that the HIV diagnosis is followed by losses, feelings of humiliation and awakens anguish arising from psychological suffering. The admissible way of dealing with the current condition implies having to distant from loved ones and restrict interpersonal relationships. However, the subjective aspects associated with the need for self-care and the performance of the maternal role prevail⁽¹⁵⁾.

A study, which pointed out women's narratives focused on the exposure of sexuality and the loss of trust in their partners, resumes, somehow, a discourse associated with the idea of romantic love, fidelity, respect and complicity that were historically constructed in the West⁽⁴⁾. In another study, carried out in the United States, Australia and Europe, it was revealed that people with high-risk heterosexual activity, due to not realizing that they are at high risk of contracting HIV, ended up contributing to the late diagnosis of HIV associated with heterosexual transmission⁽²⁴⁾. With regard to the feeling of distrust/jealousy in relation to sexual partners, the participants in this study related the figure of men to a tone of accusation for their current condition - that is, the disease onset.

The aspect related to jealousy and the centrality of the partner is based on the characteristic of groups 2 and 3, in which most participants live with a partner. These aspects, which allow one to believe that the contextualization of this discourse, through the maintenance/loss of a space of supposed protection/care, may mask sexist relationships in which the male domain makes it difficult to interpret conjugality's and protection against HIV⁽²⁵⁾. The SR of these groups point to a generational specificity in which 'me/people' intertwines with 'partner' as a sign of unity/marriage, where contamination occurs and at the same time remains as a necessary support for coping with HIV.

A study carried out in the state of Paraíba with people who had a late or very late diagnosis of HIV infection, revealed that the risk denial was supported by a position of distance from HIV and by the frequent practice of unprotected sex, mainly due to the feeling of trust established in the relationships with only one partner or official conjugality, in which the attitude of trust was anchored in the ideas that the other does not cheat on the partner⁽¹⁶⁾.

The group formed by the older adults pointed out terms: 'stay, know more, want, virus, live and alone', indicating greater dependence on family members (Figure 5). Being sexually active for a longer time, they are also exposed to Sexually Transmitted Infections and the form of infection, by sexual intercourse, is not different among other population groups. The epidemiological characteristics of elderly adults living with HIV are concentrated in the age group 60-64 years old⁽²⁶⁾.

The aspects that cross the speeches of the older adults interviewed refer to the binomial children/HIV and reveal a painful difficulty in making their sexuality visible in a nuance of denial and self-censorship. Not even the understanding of sexuality closely related to the construction of sexual and loving relationships, with new conformations in the practice of sexuality, and to the interference factors - chronological age and altered health condition - were present in SR. The difficulties pointed out by people living with HIV and their quality of life presented personifications that are anchored in prejudice and stigma, as a common branch and in a network of contacts, which family members seem to have the most negative impact⁽¹⁸⁾.

With regard to the dimension of the representational field under analysis, of the groups studied on aspects concerning sexuality, SR is pictured from the axis 'women/virus/partner'. Thus, the narratives presented aspects related to gender that run through all generations, where family is placed at the

forefront and signal women's need to disengage themselves from the idea of a sexual life with multiple partners.

The possibility of personalizing HIV is intrinsically linked with ways of moralizing sexuality, or even with ignorance, where accusatory nature is still attributed to living in these conditions⁽⁴⁾. Thus, it opposes the study on the media that pointed to the mobilization of specific speeches, metaphors and visual resources, as promoters of a better understanding on how HIV can be acquired and prevented. This conception may contribute to the deconstruction of hegemonic representations by pointing to the manifestation of new representations about sexuality⁽²⁷⁾.

However, one should consider the subjective understanding of sexuality based on affectivity and love relationships, which includes feelings, affection, caresses and conjugal dialogue⁽²⁸⁾. For the participants of this study, the meaning of sexuality was associated with the figure of women/mother and demarcated the understanding of sex for procreation purposes by pointing out the social place of women, at the same time that it is related to the sexual practice, the sexual act and the biomedicalization of life and sexualities.

CONCLUSION

In the statements of the women who participated in this study, it was possible to identify the processes of anchoring

the common knowledge of sexualities on the part of social 'actresses' in everyday life. The woman merges with the 'partner/children' and marks her social place/role in the social sphere. The generational issues, observed in the disaggregation of the corpus, showed convergences for being central in terms that refer to the family and 'new' demands arising from the condition of living with the 'virus'. The terms 'sex, sexual intercourse, couple, pleasure', among others, which, in common sense, are considered synonyms for the term 'sexuality', had low frequency.

Younger women agreed to disclose and/or 'tell' about their condition to their partner(s) and family members. This aspect was not revealed in the statements of women of other ages. For women aged 45 and over, the children occupied a prominent place and for older adults, they played a central role in the representation by referring to self-censorship and maintaining the victim/guilty game. The SR made it possible to reflect, in an attempt to demonstrate what is behind and what motivates the discursive action on the sexuality of women living with HIV. Likewise, how this motivation became shared knowledge, based on a denied sexuality that needs to remain secret.

The findings of this study became relevant to the area of health, especially nursing, by directing the team focus to issues related to the dynamics of sexuality in the planning and implementation of health care for this social group.

RESUMO

Objetivo: Analisar as representações sociais de mulheres com diagnóstico de HIV sobre sua sexualidade, considerando características geracionais. **Método:** Pesquisa qualitativa, com mulheres que participaram por meio de entrevista. O corpus constituído foi processado pelo software Iramuteq. A análise ancorou-se na Teoria das Representações Sociais. **Resultados:** Participaram 39 mulheres, com idade entre 18-76 anos e em sua maioria com ensino médio, que evocaram os termos 'gente' (301), 'companheiro' (277), 'filho' (249), 'vírus' (275) e 'querer' (216). As mais jovens aceitam revelar e/ou 'contar' sobre a sua condição para seu(s) parceiro(s) e familiares, aspecto que não se revela nas falas de mulheres com outras idades. Para as mulheres com 45 e mais anos, o/a filho/a ocupa lugar de destaque, e para as idosas a centralidade da representação remetia à autocensura e à manutenção do jogo vítimas/culpadas. **Conclusão:** Este estudo possibilitou a identificação de processos de ancoragem das sexualidades em termos do que 'não pode ser revelado' para além do âmbito familiar. Nesse sentido, os elementos 'sexo' e 'relação-sexual', concebidos pelo senso comum como sinônimo de sexualidade, independentemente da geração, apresentaram baixa frequência.

DESCRITORES

Sexualidade; HIV; Grupos Populacionais; Mulheres; Cuidados de Enfermagem.

RESUMEN

Objetivo: Analizar las representaciones sociales sobre sexualidad de mujeres con diagnóstico de VIH, teniendo en cuenta las características generacionales. **Método:** Se trata de una investigación cualitativa entre mujeres que participaron por medio de entrevistas. El corpus constituido se procesó con el software Iramuteq. El análisis se basó en la Teoría de las Representaciones Sociales. **Resultados:** Participaron 39 mujeres de 18 a 76 años, en su mayoría con el secundario completo, que evocaron los términos "personas" (301), "pareja" (277), "hijo" (249), "virus" (275) y "querer" (216). Las más jóvenes aceptaron revelar y/o "contar" su condición a su(s) pareja(s) y familiares, aspecto que no se reveló en las declaraciones de mujeres de otras edades. Para las mujeres de 45 años o más, el hijo/a ocupa un lugar prominente, y para las mayores, la centralidad de la representación se remite a la autocensura y al mantenimiento del juego víctima/culpable. **Conclusión:** Este estudio permitió identificar los procesos de anclaje de la sexualidad en términos de lo que "no puede revelarse" más allá de la esfera familiar. En este sentido, los elementos "sexo" y "relación sexual", concebidos por el sentido común como sinónimo de sexualidad independiente de la generación, presentaron una frecuencia baja.

DESCRIPTORES

Sexualidade; VIH; Mujeres; Grupos de Población; Atención de Enfermería.

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