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.
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 patriarchal 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 generality 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
the semi-structured interview (moment 2). The sample size for the interviews was determined by the technique of theoretical saturation or redundancy of information. A total of seven women in group 1 participated in this study by age group; fifteen in group 2; thirteen in group 3 and four in group 4.

**Data collection**

The interview, as a technique privileges the reality of what is experienced, and the indirect access to the other person’s experience or its interpretation. It was applied from September to November 2018, performed by the researcher in offices and/or rooms available at SCS. After the initial moment of the researcher’s presentation, the Informed Consent Form (ICF) was read and signed. In order to preserve anonymity, participants were identified with the letter “P”, followed by the chronological sequence of participation in the interview and their age.

The semi-structured interview had four questions, proposed to each participant in the following order: “Could you talk about your sexuality before you knew you had HIV infection?”,”After the diagnosis, what changed in your relationship with your partner?”,”Could you talk a little about your relationship with your partner?”, “Would you like to add something more about your feelings towards you and your sexuality after being diagnosed with HIV?”. These questions sought to contemplate the subjective dimension from the representations of women living with HIV.

**Data analysis**

In the qualitative analysis, through the categorization of textual elements, it was decided to keep the literal transcription of the data. After listening and confronting with writing, the corpus was elaborated with the interviews that went through the process of stemming and semantic approximation, and allowed to feed the database of the Iramuteq software. The software enables different types of lexicographic analyzes, in addition to organizing the vocabulary distribution in an understandable way and its graphic representation.

The processed corpus enabled the graphic composition of five Word Clouds. One cloud is representative of the total number of participants, the other four ones represent each of the studied age groups. For the textual analysis, the statements from the interviewees and the identification of central ideas that complemented the terms that had the highest frequencies in the Word Clouds and allowed a better understanding of the findings were organized. Spellings and parts of speeches were analyzed and interpreted according to the understanding of women on the topic through the TSR.

**Ethical aspects**

The study was submitted to the Research Ethics Committee of the Universidade Federal da Bahia, through Plataforma Brasil, being approved under protocol 2.776.570, on July 16, 2018, following the recommendations of Resolution no. 466/12, of the National Health Council. All participants signed the Informed Consent Form (ICF).

**RESULTS**

The social and disease-related characteristics allowed the formation of generational groups and their description in close association with age groups, education level, time of diagnosis, economic status, marital status and partner, whether people living with the virus or not. Thus, women who made up groups 2 and 3 represented 71.7% of the participants. Group 1 was characterized by an mean age of 27 years old, had high school education and a diagnosis time of approximately 3 years; group 2, with an mean age of 37 years old, high school education and a diagnosis of around 7 years; group 3, with an mean age of 53 years old, 6th to 9th school years/high school education, diagnosis time around 9 years; group 4, with an mean age of 67 years old, 1st to 5th school years and mean diagnosis time of 17 years.

Approximately half of the women who made up groups 1, 2 and 3 had a partner; in these groups, a total of eight partners were also HIV positive. The four participants in group 4 informed that they did not live with their partners. Women belonging to the two younger age groups (Groups 1 and 2) were self-supporting economically by working or receiving illness aid, as well as the older adults, through retirement and/or benefits.

From the content of the interviews, the Iramuteq software generated the graph (Figure 1) that presents the result in a Word Cloud, formed with words with a frequency equal to or greater than 50, enabling the identification of the SR of the belonging group.

**Figure 1** – Word Cloud of all participants, provided by the Iramuteq software – Feira de Santana, BA, Brazil, 2019.

In Figure 1, the term ‘people’ stands out for its high frequency (301) and organizes the SR of women about sexuality after the diagnosis of HIV. It refers to the self-denomination ‘people’ or ‘me’, revealing the place of participation as protagonists and/or subjects of their own lives, as they aggregates the others, with greater frequency: partner (277), children (249), person (253) that refer to the idea of a socially constructed family, of nuclear composition, where heteronormativity is the central element in women’s life. The prominent position occupied by the word ‘virus’ (275) probably occurred due to its close association with the term...
‘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.

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.

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.
In the subgroups of participants in groups 2 and 3 (adults and middle age), the terms ‘partner’ and ‘people’ organize the two SR. The terms: ‘person’, ‘partner’ and ‘children’ refer to the idea of family bonding and commitment. However, ‘virus’, ‘stay’ and ‘want’ relate to more specific aspects of the sexuality dynamics. The statements below contextualize the SR and reveal stories guided by situations with a strong emotional burden as they express regret, suffering, fear of vertical transmission and jealousy of the partner.

Today my daughter took two blood samples and there was no problem, as a couple we have to be more careful, always talking about the virus, because we have suffered a lot during pregnancy so that the child won't get it too (P 04, 59 years old).

I was very jealous of him, of his ex-wife, of the attention that my partner gave to his son, I noticed that it really didn't work because I can’t stand it anymore and I need to take care of my health (P 38, 54 years old).

Older adults (Figure 5) added group 4 and composed the Word Cloud (Figure 5), which was formed by words with a frequency equal to or greater than 10.

Figure 5 – Word Cloud of older adults, provided by the Iramuteq software – Feira de Santana, BA, Brazil, 2019.

For the subgroup of older adults, the term ‘children’ stands out and organizes the SR and made it possible to infer the idea that refers to their direct and affective connection with the figure of their children. Group 4 is the only group in which none of the participants lived with a partner, possibly linked to the condition of widowhood and/or divorce. The terms: ‘stay’, ‘know more’, ‘want’, ‘virus’, ‘live’ and ‘alone’, pointed to the importance of the diagnosis, regarding the need for more information on the repercussions of HIV and the family dependency.

I have a house from Minha casa Minha vida project [government social program], because before I used to live as a favor and lived with my daughter, now I have my own house (P 15, 64 years old).

It’s not because I lost my partner, because we have our desires, as I went through the drama when I found out, I used to think: why do I have to tell my daughter? (P 13, 62 years old).

DISCUSSION

A profile characterized by women with heterosexual relationships, in stable relationships, with only one partner or living alone was designed, pointing to sexual and gender normativity guided by heterosexuality. Corroborating the profile of women living with HIV in Brazil, which is characterized, according to a study, by young women, with low education, who declared that they do not perform any type of activity outside their home(19). For the authors, the study findings identified characteristics related to women’s vulnerability and related them to sexual exposure and asymmetry of gender relations. In a study carried out in Belém, Pará state, health professionals stated that they perceived in their daily lives that most HIV-infected women reported stable, heterosexual relationships with only one partner(7).

Regarding Figure 1, the narratives of the 39 participants indicated antagonism, between guilty and victims, in relation to contagion with the virus. However, somehow it became evident that there is a kind of hierarchy between people and their sexual practices, in which some are more vulnerable than others, such as children and women. This hierarchy is also reflected in the idea of contamination perceived as punishment. It also seems to be based on a representation attributed to the partner as someone free from HIV infection and/or related to the representation of themselves as a person with a “clean body”, that is, invulnerable to the risk of contamination and with only one partner(18). The feeling of invulnerability of women soon turns into vulnerability in the face of HIV contamination, whether as a victim and/or guilty(7).

SR develops due to the way individuals determine knowledge and communication based on social relationships in the world and with life. In this logic, the knowledge that is reframed in daily anchorages contributes to singularize the social changes of the established order(11). The HIV diagnosis reveals issues of women’s sexuality as it breaks with the silence and dynamics of the relationships between the couple by unveiling infidelity, while exposing them to the judgment of those around them. If they do not reveal their condition when diagnosed, they will probably keep them in a certain position of comfort and safety.

Study results(17) have already shown that prejudice and discrimination configure the name of AIDS as an epidemic that produces a deleterious effect - stigmatization - on people. Intra-family prejudice, translated into discrimination, is a way of daily coping with the disease(18). Thus, in view of the stigmatization produced by the epidemic, the importance of equipping people living with seropositive persons stands out, based on the assumption that people with HIV and their families become ill together(19). The family nucleus that marks the word cloud (Figure 1), possibly, revealed the need to hide the diagnosis as a form of protection and/or to minimize the stigmatization suffered by the participants, which can also reach their relatives.

Prejudice is understood as a social construction that has its roots in the symbolic universe of culture and in power relations when it crosses several social levels(20). Thus, it is important to emphasize that prejudice has implications for people’s daily
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(12).

In this study, the main problem faced after the diagnosis was they corroborate with a research carried out with a total of 23 groups with the largest number of participants and ages between 30 and 59 years old. Who, in addition to being infected through sexual intercourse, is not different among other population groups. Depending 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).

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(6). 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 conjugal'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(19).

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(13).

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(8). 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.

REFERENCES

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


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